Care of the Dying Adult
Consultation on draft guideline - Stakeholder comments table
29/07/2015—9/09/2015

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Age UK	Full	General	General	There remains a huge amount of sensitivity around the topic of end of life care, as shown by the media reporting when this draft guidance was first published. We believe there should be clearer references to, and promotion of, high quality patient-facing information on this guidance and end of life care generally. Age UK has recently published a booklet on planning at the end of life (Before you go, Age UK, 2015) which could be promoted alongside this guidance. The Dying Matters Coalition and the National Council for Palliative Care also have a range of publications which could help people to understand the role of healthcare professionals and the decision-making process during the dying process. The guidance should recommend making such materials available, and NICE should highlight them as part of dissemination of this guidance.	Thank you for your comment. We believe that we have provided clear guidance to users of this guideline regarding information sharing and effective communication in the last days of life which is the scope of this work. NICE guidelines do not promote publications but we will make the NICE implementation team aware of the availability of the publications you refer to.
Age UK	Full	General	General	We are concerned the guideline is making generic recommendations across a highly disparate number of settings. Though the clinical factors may be the same, there are very different practical barriers to delivering effective end of life care in hospital, a care home, and a person's own home, for example. Availability of nursing support, particularly out of hours in the community is frequently cited as a factor in poor end of life care as is availability of pain relief. Poor skills in some care home staff, often the result of low wages and high staff turnover, means there may be an unreasonable expectation that certain	Thank you for your comment. The Committee feels that all of its recommendations should be relevant to the care of people in the last days of life regardless of setting. We do note that there is variability in relation to service provision however, service delivery, including skills mix and service organization, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and these topics may covered by that work. Please note that more detail about the development of this guideline can be found at the following link:

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				tasks can be carried out. We therefore believe there should also be recommendations aimed at commissioners and providers. These should include guidance on appropriate skills mix and staff numbers as well as the amount and type of commissioned services relevant to a local area, particularly where there are large concentrations of older people or care and nursing homes. Guaranteeing seven day palliative care services, regardless of setting, would be essential and is recommended by a number of recent reports (see for example, House of Common Health Select Committee (2015), PHSO Dying without Dignity (2015), National care of the dying audit for hospitals, England (2014).	http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Age UK	Full	General	General	The guidance has an underlying assumption that the skills and training to carry out the recommendations exist in the range of settings described. The lack of education and training is cited not only in the reports mentioned above, but also in the Neuberger Review, the Francis Report (2013) and many others, in relation to poor standards of care at the end of life. This is equally the case with care of older people, a group for whom end of life care is most relevant as it represents 90% of all deaths. A significant skills gap also exists in recognising the transition from, for example, severe frailty to dying (see for example, Gardiner, C., et al, Barriers to providing palliative care for older people in acute hospitals, Age and Ageing, 2011). Indeed, there may be a long period	Thank you for your comment. Service Delivery, including education and training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and these topics may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799

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				where someone is living with multiple conditions and frailty for whom a sudden change can lead very quickly to entering the dying phase. This is even more challenging to recognise when their needs are non-specific, i.e. relating to general declining health rather than the symptoms of a condition, and an event like a fall is just as likely to precipitate dying as a stroke (an event this guidance appears to exclude under "major trauma"). Skills and training relating to end of life care and older people in general are still very poor and the recommendations to providers and commissioners (see above) must include having sufficient professionals with appropriate levels of training and ensuring that care of the dying is fully incorporated into the operations and pathways of any setting.	
Age UK	Full	General	General	The guidance does not sufficiently capture the need to record information, both clinical and relating to patient/family wishes, and to do so clearly and accurately. Handover of information about dying patients was cited in the Neuberger review as a factor in poor care, meaning a change of work shift could undermine the quality of care someone is receiving. The guidelines should place specific emphasis on accurately capturing and recording patient wishes, the outcomes of clinical assessment and any changes observed during reviews in a way that can be handed over to staff at the end of a shift or to out of hours staff. They should also include how	Thank you for your comment. We believe that we have made a number of recommendations in the areas you raise, (see recommendations1.2.6 and 1.3.6).

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				this information should be communicated to family and carers if changes occur while they are not there – there is a general assumption in the guidance that there will always be a family member or carer available to discuss the care needs of a dying patient, which is unrealistic. Furthermore, the Neuberger review specifically highlighted the distress caused by family members arriving in a setting to learn that someone had been placed on an end of life pathway.	
Age UK	Full	12	1	This recommendation suggests reviewing patients at least every 24 hours. Though this may be appropriate with regards to a full review, the *National care of the dying audit for hospitals, England,* RCP, 2014, recommends that a person's pain and symptoms be reviewed every four hours. This should be referenced here.	Thank you for your comment. The recommendation states 'at least every 24 hours' and does not preclude more frequent monitoring. Please also note that the reference you state is for hospitals and this guideline also covers community settings, where monitoring every 4 hours may be challenging.
Age UK	1. Full	2.	3.	4. After "information", add: "involving a multi-professional team". We believe the current guidance risks giving the impression that a single professional can undertake this assessment.	Thank you for your comment. We consider that this recommendation is for whoever is delivering care and that information from the multiprofessional team is captured under recommendation 1.1.3. This is discussed in the 'Linking evidence to recommendations' section.
Age UK	Full	11	18	Additional bullet point: "Ensure this information is accurately recorded and can be easily found and understood by other professionals involved in their care".	Thank you for your comment. We have amended the recommendation to read "gather and document information on..."

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Age UK	Full	12	7	At the end of this line, we recommend including: "For some older people, it may be appropriate to initiate comprehensive geriatric assessment or other similar evidence based intervention".	Thank you for your comment. Further detail is provided in the full guideline 'Linking evidence to recommendations' section to note that further advice may be sought from geriatricians.
Age UK	Full	13	11	At the end of this line, we recommend including: "Any support and information they may need to engage in shared decision-making should be made available, including emotional and psychological support".	Thank you for your comment. After careful consideration, the committee did not choose to add your suggested text. We have already provided a cross reference to the NICE guideline on patient experience in adult NHS services where recommendations already exist to support your suggestion (please see section 1.5 of that guidance).
Age UK	Full	13	19	After "encouraging", add: "and supporting".	Thank you for your comment. After careful consideration, the committee have chosen not to make the amendment that you have suggested.
Age UK	Full	13	40	After "care team", add: "ensuring this can be easily communicated to professionals who may be involved in care at a future point and to out of hours teams".	Thank you for your comment. Additional text has been added to the full guideline 'Linking evidence to recommendations' section to state to emphasise communication with all members of the multiprofessional care team, including those that may be working on different shifts throughout the day or week (please see 7.6).

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Age UK	Full	12	24	At the end of the line, we recommend including: "Staff should be confident to carry out these discussions sensitively and training should be made available for those that are not".	Thank you for your comment. Service Delivery, including training, is outside the remit of the guideline. NICE is currently developing guidance on palliative care service delivery and this topic may be included in that guideline. More details can be found at the following link: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799. The recommendations ask that healthcare professionals ensure that the shared decision making can be supported by experienced staff at all times. Further, the multiprofessional team is asked to respectfully consider the needs, goals and wishes of the dying person and encouraged to maintain an individualised approach during the delivery of end of life care.
Age UK	Full	12	28	Additional bullet point: "while recognising that all staff should have basic competence in end of life discussions".	Thank you for your comment. The Committee considers end of life discussions to be a very sensitive issue and have drafted a recommendation to ensure that shared decision-making can be supported by experienced staff at all times and that further specialist advice can be sought by the multiprofessional team if required.
Age UK	Full	General	General	There is no guidance around the nature of consent and application of the Mental Capacity Act. We believe this should be included as a headline recommendation, potentially after recommendation 10 (page 13) with sign-posting to relevant guidance included in the full document.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the

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					relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009
Age UK	Full	14	6	The Neuberger Review was clear that with regards to hydration and comfort, the "default course of action should be that patients be supported with hydration and nutrition unless there is a strong reason not to do so". The *Priorities of Care for the Dying Person* (2014) also recommends "If a dying person makes an informed choice to eat or drink, even if they are deemed to be at risk of aspiration, this must be respected". We do not believe the current wording on this point makes this sufficiently clear. After "are able to" on this line we recommend including: "recognising the default action should be that a person is helped to drink".	Thank you for your comment. The Committee agree that drinking should be supported and is preferable to clinically assisted hydration as reflected by the order of the recommendations. The wording of recommendation 1.4.8 has been amended to state "Consider a therapeutic trial of clinically assisted hydration if the person has distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium and if oral hydration is inadequate." Nutrition is beyond the remit and scope of this guideline.

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Age UK	Full	14	31	Additional bullet point: "This conversation must be handled sensitively, fully recognising this could be a particularly distressing moment for the individual, their family and carers".	Thank you for your comment. After careful consideration the Committee felt that this level of detail was not required.
Age UK	Full	15	7	Additional bullet point: "if there is any uncertainty, consider seeking advice from palliative care specialists".	Thank you for your comment. We have carefully considered the recommendation and feel that no change is required.
Andrew Mooney	Full	General		I welcome the publication of this document. As a practising Renal Physician I recognise that my specialty is one which regrettably carries a high mortality, and therefore guidance on the management of end of life is welcomed. I strongly agree with the authors in the second paragraph in the Introduction (page 23, lines 10-21) that the Liverpool Care Pathway was a valuable contribution to patient care, but any failings were more due to implementation of the care pathway than of the care pathway itself. With this in mind, I furthermore strongly welcome the emphasis throughout the guidance on the importance of communication between the caring team and the patient and those close to them, plus the regular review of the appropriateness of the care plan. Despite broadly welcoming the document I do have a few specific comments relating to its use by our	Guidance regarding withdrawal of life saving treatment. Thank you for your comment. The Committee has drafted a recommendation encouraging clinicians: when it is recognised that a person may be entering the last days of life, to review their current medication and, after discussion and agreement with the dying person and those important to them, stop any previously prescribed medicines that are not providing symptomatic benefit. Guidance around prescribing in organ failure (caveat needed in the prescribing tables) Thank you for your comment. The preamble in the prescribing section, includes a list of principles used by the Committee when drafting this guidance. This list of principles includes the following: Specialist advice should be sought if there are uncertainties about how to prescribe for individual patients (for example renal impairment, concerns about lack of response when titrating medications). We believe this addresses your concern.

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				specialty. These are listed below 1) Guidance regarding withdrawal of life-sustaining treatment Firstly, a great deal of the document is concerned with managing new end of life symptoms with pharmacological and non-pharmacological interventions. In paragraph 54 of the summary (page 17, lines 24-17) mention is made of changing/stopping medications. It is my view that the guidelines would be improved by addition of a section providing guidance regarding the continuation or discontinuation of existing physical life-sustaining treatments. In our specialty a very significant consideration is whether dialysis should be continued or not. I expect other specialties might have similar challenges (eg motor neurone disease treatment and assisted ventilation). I believe that many renal physicians will have experienced continuing dialysis for patients whose prognosis is terminal even up to the last few days, where our judgment would have been that continuation would not have been extending life, and might have had very questionable impact on quality of life. Guidance around this might be very helpful for us in future practice.	Improved clarity around timing of end of life care planning and advance care planning Thank you for your comment. The evidence looked at for this review covered a time frame of hours/days, thus accounting for the range of symptoms listed in the draft recommendation. Regardless of the timing of prognosis, the Committee felt it important that health care professionals are encouraged to explore the possibility that an Advance Care Plan may exist, in an effort to ensure that the articulated needs and wishes of the dying person are met.

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				2) Guidance around prescribing in organ failure I note a large amount of the guidance relates to using pharmacological treatments to alleviate end of life symptoms, and balancing their use against side effects. Obviously, drug pharmacodynamics are significantly altered in organ failure including renal failure. I believe it might be helpful to acknowledge this as a caveat regarding all prescribing. I know that in my own area we developed a local prescribing pathway for end of life care specifically for renal patients and I suspect many other areas will have done likewise. I would welcome a section in the guidance acknowledging the issue and promoting or supporting such initiatives. 3) Improved clarity around timing of end of life care planning and advance care planning In my view the second section of the guidance regarding assessing for signs and symptoms suggesting a person is entering the last days of life are a little confusing. In my view some of the symptoms cited are associated with death within hours (eg mottled skin) and others associated with death within weeks (eg fatigue). I would welcome some clarification regarding those associated with imminent death and those associated with death soon. I would also welcome advice that those which	

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				could still indicate a prognosis of days to weeks would represent an opportunity to discuss and create an Advance Care Plan, prior to development of symptoms which would suggest an even shorter prognosis. Dr Andrew Mooney, Renal Physician, Leeds Teaching Hospitals, 25 August 2015 for the Renal Association	
Anscombe Bioethics Centre		General	General	Email sent to XXXX Dear XXXX, Please find attached a response from the Department for Christian Responsibility and Citizenship of the Catholic Bishops' Conference of England and Wales to the National Institute for Health and Care Excellence's (NICE) draft guidelines for consultation on care of the dying adult. The response has been prepared at the request of the department by the Anscombe Centre for Bioethics, and I understand that the Centre has formally registered with NICE. We would be grateful if you would regard the Anscombe Centre response along with this letter as a response from the department of the Bishops' Conference. We very much welcome the opportunity to respond to this consultation on such an important subject.	Thank you for your comment. The RCP undertakes an annual audit of end of life care and we would hope that that audit If funded further would measure implementation against our recommendations.

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				You will note that in our submission we draw particular attention among other matters to the difficulty of the diagnosis of dying. The draft guidelines rightly highlight this issue, and we have some thoughts about how the language in the guidance could be strengthened to underline what is often a tentative diagnosis in need of regular review. We also draw attention to the importance of developing high quality professional judgement in conditions of uncertainty, and the recognition that this has a moral character to it: the development of the virtue of prudence or wisdom through experience is a distinct aspect of what is involved in the making of good decisions in this area and we believe this should be made more explicit. Finally, we believe it is important there should be a review of implementation of these guidelines in practice to ensure that if there were to be any significant mis-interpretation it is identified and corrected at an early stage. The Anscombe Bioethics Centre welcomes the opportunity to contribute to the shaping of a guideline that has the potential to improve the care of people who are dying, but which also carries the risk of unintended adverse effects, a possibility exemplified by the failures of implementation of the Liverpool Care Pathway that were highlighted by the	

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				Independent Review.	
Anscombe Bioethics Centre		General	General	The Anscombe Bioethics Centre is a research centre in ethics and its response is thus at the level of ethical principles and not on the basis of particular clinical expertise, (though it has been reviewed by medical members of the board of Governors of the Centre).	Thank you for your comment.
Anscombe Bioethics Centre		General	General	The fundamental starting point of the current submission is the previous Anscombe Bioethics Centre Response to The Independent Review of The Liverpool Care Pathway (LCP), a response endorsed by the board of the Centre, including four Roman Catholic bishops. http://bioethics.org.uk/anscombestatementonlcpandneuberger.pdf This should be read in conjunction with the accompanying statement on the Ethics of Care of the Dying Person. http://www.bioethics.org.uk/images/user/TheEthicsofCareoftheDyingPersonwebsite.pdf Another important reference point of this submission is the guide produced by the Catholic Bishops' Conference of England and Wales on The Spiritual	Thank you for submitting these references for consideration. Unfortunately we were unable to include them within any of our evidence reviews as these did not meet our inclusion criteria.

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				Care of the Dying Person. http://www.bioethics.org.uk/images/user/guide-spiritual-care-dying-person.pdf	
Anscombe Bioethics Centre		General	General	In the Anscombe Centre Response to the Review of the LCP we stated that "The Review noted a remarkable evidence gap in relation to the LCP: 'No research has yet produced evidence by robustly comparing these pathways with other forms of care'. It is also important therefore that, if new 'end of life care plans' linked to 'condition-specific guidance' are introduced, this be done in such a way as to include assessment of their effectiveness in a robust manner (both in comparison to the LCP and analogous pathways, and in comparison to deaths managed without the support of any care plan or pathway)." (Anscombe Bioethics Centre Response to The Independent Review of The LCP, para 51 citing Independent Review page 17). Thought should be given not only to when and how to revise the NICE guideline in the light of future evidence of best practice, but also into recommending research into the impact of the guideline itself, and whether the guideline, in the way that it is phrased and promulgated is actually effective in improving care, and whether it might fail to improve care, or even have an adverse effect on	Thank you for your comment. NICE guidelines are updated in accordance with the NICE guidelines manual which can be found at the following link: http://www.nice.org.uk/article/pmg20/chapter/1%20Introduction%20and%20overview. NICE also provides implementation support on publication of the guideline but is not in a position to commission the research you outline. The RCP undertakes an annual audit of end of life care and we would hope that that audit, if funded further, would measure implementation against our recommendations.

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				care in some aspects. Given the role of NICE such evaluation cannot be done by a controlled trial but low level evidence may at least be gleaned from before-after comparison, audit and qualitative research on its implementation.	
Anscombe Bioethics Centre	Short	1	5	A second notable omission from the list of topics considered by the guideline is any reference to assessment of spiritual or religious needs or to access to spiritual or religious care. Spiritual and religious support is an aspect of care that is not only relevant to dying people, but it is particularly relevant to this context. This reflects the received understanding of the scope of palliative care. For this reason the LCP included an assessment of spiritual need. However, national audits of use of the LCP suggested that this aspect of care was rarely accomplished. Directly relevant to NICE is the evaluation of the benefit of providing spiritual or religious care, for example through chaplaincy services, as an aspect of holistic care of the dying person. There is an insufficient evidence base for those forms of spiritual support that are both beneficial and cost effective and NICE could have helped to identify available evidence and make recommendations for further research.	Thank you for your comment. Spiritual care was beyond the remit and scope of the guideline. The Committee chose to co-opt a spiritual advisor to consider the spiritual needs of the dying person when considered against the topics that were in included in the scope. However, we would also comment that the Committee ensured that as far as possible the dying person's spiritual needs were acknowledged and considered in our 'Linking evidence to recommendations' in the relevant sections of the guideline.

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				In addition to the assessment of the effectiveness of spiritual care, access to religious services, reflective of a person's beliefs and adherence through life, is a human rights issue. This right concerns access, rather than cost-effective care, but it is relevant to the NICE guideline in that, were the guideline not to refer to it, such an omission might have a negative impact on practice generally and might also disproportionately impact on religious minorities.	
Anscombe Bioethics Centre	Short	1	5	The scope of the guide is described as those "who are in the last few days of life". In the light of uncertainty about the recognition of this state (see more below) it would be better to describe it as covering those "who are thought to be in the last few days of life". This will include people who were wrongly thought to be dying and also people who were close to death and might have died but who subsequently recover. Assessment of whether the person may be entering the last days of life is, and ought to be, included in the guideline. The guideline should include and not simply presuppose such an assessment. Those covered by the guideline will therefore include people who may be entering the last few days.	Thank you for your comment. We are content with our definition of the last few days of life. A number of our recommendations acknowledge the difficulty of being certain that this is the case and recognize that people thought to be in the last days of life may stabilize or recover. An assessment is implicit in our recommendation (1.1.4) that people should be monitored for change at least every 24 hours.
Anscombe Bioethics		3	2	One of the causes of concern raised in relation to the LCP was its reliance on recognition of death, with some critics objecting to *any* care based on	Thank you for your comment. The Committee agree that recognising dying is difficult and that clinical judgment is important. We have amended the title to

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Centre				prognosis or on the premise that a person is dying. The Anscombe Bioethics Centre characterised this objection as "vitalist" but agreed with the Review that there needed to be a greater recognition of uncertainty in relation to the diagnosis of dying. "In relation to diagnosis of imminent dying, and the decision to initiate a plan of care appropriate to the last hours or days of life, the Review again sets out a sound *via media*. The Review recognises the uncertainty of such diagnoses, and makes recommendations aimed both at improving their accuracy and at acknowledging their uncertainty (in relation to decision-making and in relation to communication). However, it rightly does not regard this uncertainty as reason to abandon the very idea of care specifically directed to patients who are dying. Care for the dying requires the virtue of good sense (*prudentia*, principled but with an element that is experience-, circumstance-, and case-relative) if it is to work well in practice. Acknowledging the need for virtue here is ethically sounder, we think, than implicitly adopting the vitalist rule 'treat dying patients as though they are always curable'."(Anscombe Bioethics Centre Response to The Independent Review of The LCP, para 23) From this perspective the current draft NICE guideline Care of the Dying Adult needs revision.	'recognising when a person may be in the last days of life', as this reflects uncertainty and matches our review question. We feel we have acknowledged the uncertainty, and have rewritten our recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline. We have also emphasized the importance of clinical judgement in the NICE version of the guideline in section 1.1 and made a separate recommendation on seeking expert advice. The Committee purposefully drafted recommendations that advocate an individualised approach to assessment and management and care avoiding the suggestion of a 'tick box, pathway' approach as you have outlined.

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				In the section on the need for further research the guideline rightly states that "The Committee are aware that predicting the end of life is often inaccurate and that predictive tools and models are limited. The Committee consensus was that some level of uncertainty in recognising death is inevitable and that it is an on-going challenge" (page 19 lines 18-21). Similarly the first sentence accurately expresses the proper aim of the guideline by stating that "These recommendations are intended to help healthcare professionals recognise when a person might be entering the last days of their life, or if they may be stabilising or recovering." (page 3 line 3-5) The title of the section is therefore misleading, and should not read "**Recognising when a person is in the last days of life**" but "**Recognising when a person <u>may be</u> in the last days of life".** The difference though subtle is important throughout the guideline. Further thought should also be given about how to highlight the need for professionals to cultivate responsible prudential judgements based on the needs of the particular patient. The guidelines should remind professionals of the inadequacy of a rule-based "tick box" approach to clinical and ethical judgments. This was a failing repeatedly mentioned in the Independent Review of the LCP (Independent	

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				Review, page 29 and elsewhere). Such a reminder might usefully be inserted at the beginning after paragraph 1.1 (page 3 lines 3-8) but also throughout the document wherever there may be a danger that guidelines could be misinterpreted as blanket rules.	
Anscombe Bioethics Centre		4	11	As noted above (comment No. 4) the danger with taking "loss of appetite or and "progressive weight loss" (page 4 line 14) as a potential sign for entering the last days of life is that the decline in oral intake to weight loss may be due to other factors. In this regard the GMC guidance on *Treatment and Care towards the End of Life* is very helpful in emphasising the need to assess whether there may be treatable causes that are inhibiting someone from eating, as the Centre noted in its response to the Independent Review. "Healthcare professionals have an obligation to assess and address any underlying physical or psychological causes that could inhibit someone from eating or drinking; 'for example, some patients stop eating because of depression, or pain caused by mouth ulcers or dentures, or for other reasons that can be addressed'." (Anscombe Bioethics Centre Response to The Independent Review of The LCP, para 32 quoting GMC guidance para 110). If reference is to be made to the relevance of loss of	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Some examples based on the evidence review are included here, but we acknowledge that these are examples only and clinical judgement should be used. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline, and your example of treatable causes that are inhibiting someone from eating and reference to GMC guidance has been added. The guideline has not been able to address all issues relevant to the care of the dying adult. Assisted nutrition was not prioritised as part of the scope as other review areas were considered more likely, during scope development, to have a wider impact on clinical practice.

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				appetite this must be in conjunction with assessment of nutritional need and identification of possible causes of reduced intake that may be treatable.	
Anscombe Bioethics Centre		4	27	The phrase "if there is uncertainty about whether a person is entering the last days of life" may suggest that this situation is exceptional whereas some level of uncertainty seems inevitable (see comments 6 and 7 above). Hence this would be better phased "where there is uncertainty about…"	Thank you for your comment. We have amended the recommendation for greater clarity. The level of uncertainty is also discussed in the introduction and 'Linking evidence to recommendations' section of the full guideline.
Anscombe Bioethics Centre		7	2	The phrase "cultural, religious, social or spiritual preferences" underestimates the importance of religious commitments and spiritual need. For example, access to a chaplain of the person's own faith community is more than a preference. It is curious that the guideline refers to "needs for care after death, if any are specified" (page 7 line 26), presumably referring to religious rituals of respect for the body but makes no reference to needs of spiritual care for those who are still alive.	Thank you for your comment. The committee agree that religious and spiritual commitments are important. "..any cultural, religious, social or spiritual needs or preferences that should be considered." has also been added to recommendation 1.2.1 to allow exploration of the issues you outline Reference to the NHS Chaplaincy Guidelines has also been added to the 'Linking evidence to recommendations' section of the full guideline.
Anscombe Bioethics Centre		5-6	General	Within the context of communication there should be assessment of spiritual need. This is acknowledged in the GMC guidance on Treatment and Care towards the End of Life which states that discussion with patients who may be dying should cover "the patient's needs for religious, spiritual or other	Thank you for your comment. We agree and have added in "any cultural, religious, social or spiritual needs or preferences that should be considered" in recommendation 1.2.1

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				personal support" (paragraph 53(f)). The potential religious or spiritual needs of the dying adult should be mentioned in the list of communication needs (page 5 lines 6-12) and in what opportunities or contact details to provide to the dying person and those important to them (page 5 line 23 to page 6 line 2).	
Anscombe Bioethics Centre		19	9	Given the controversy that continues to surround clinically assisted hydration, and the limited character of the current evidence base as expressed in the appendix, thought should be given to recommendations for further research in this area. This research might also usefully consider the assessment and support of hydration across a range of care settings and across a range of conditions.	Thank you for your comment. The Committee recognise the limited evidence in this area, but consider other areas greater priorities for research to drive improvements in practice in caring for people at end of life. We believe the recommendations we have drafted will minimise any current controversy by ensuring that appropriate information is given to people regarding the findings of the evidence, discussing the risks and benefits of the intervention and tailoring a trial of benefit based on individualized assessment.
Anscombe Bioethics Centre		8	13	The guideline is correct to begin with the injunction "Support the dying person to drink if they wish to and are able to." However, there is no justification to omit the similar injunction "Support the dying person to eat if they wish to and are able to." The inclusion of the former without the latter could easily have the unintended consequence that the offer and provision of adequate nutrition in a suitable form was optional. This was the experience of earlier iterations of the	Thank you for your comment. Nutrition is beyond the remit and scope of this guideline.

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				LCP which omitted mention of oral nutrition and hydration.	
Anscombe Bioethics Centre		9	4	Similarly, if there is a requirement to "discuss the risks and benefits of clinically assisted hydration" then there will be a requirement, at least in some cases, "to discuss the risks and benefits of clinically assisted nutrition". The failure even to assess this possible need, let alone discuss it with the patient, could result in unnecessary distress and, in some (albeit rare) cases, failure of care. The value of such interventions (for example PEG tubes) is often misunderstood and the failure of the NICE guideline to examine this evidence is a missed opportunity.	Thank you for your comment. Nutrition is beyond the remit and scope of this guideline.
5. Anscombe Bioethic		6.	7.	8. In this context the phrase "the dying patient" may be misleading for it includes no acknowledgement of the uncertainty of this status. For this reason the reassurance that "death is unlikely to be hastened by not having clinically assisted hydration" (page 9 line 13-14) may be overstated, as it relies on the accuracy of the prognosis. If as acknowledged below "recovery from dying [may be] possible" (page 9 line 25) then failure to provide hydration could be detrimental. The guideline does encourage monitoring and openness to the possibility of recovery, but this should also be reflected in	Thank you for your comment. We have stated in the first chapter on recognising dying that there is uncertainty in the diagnosis and the possibility of recovery needs to be considered all stages. The Committee has amended the wording of its recommendation (now 2.4.5) to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. The Committee also wanted to highlight the lack of evidence around survival and the fact that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or

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s Centre				the language of "the dying patient". It can be quite appropriate to discuss "the dying patient" while later acknowledging that prognosis of death in more or less uncertain. However, where uncertainty affects the possible harm or benefit of an intervention (as for example in weighing the risks and potential benefits of clinically assisted hydration), then the fact of uncertainty should be explicit in the description of the patient who "may be dying".	hasten death if it is not given.
Anscombe Bioethics Centre	Short	1	5	While agreeing with the list of elements to be included in this guideline (also evident in the contents list page 2 line 3-8) there seem to be some notable omissions. In the first place while need for hydration is a separate issue from nutrition, and to be assessed separately, and while need for hydration is of more general relevance to people who are within the last days of life, the assessment of need for nutritional support should also have been covered. This is especially so because the guideline lists "loss of appetite" (page 4 line 11) and "progressive weight loss" (page 4 line 14) among the possible signs that a person is entering the last days of life (and similarly the long document lists "reduced oral intake", page 54 line 11 and elsewhere).	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult. Nutrition is beyond the remit and scope of this guideline. The GMC guidance on *Treatment and Care towards the End of Life has now been referenced in the full guideline section under Recognising dying.*

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				There are clear dangers in a guideline which includes reduction in oral intake as a possible sign that someone is dying and which does not include assessment of nutritional need as an aspect of care of people who may be dying. There is nothing in the NICE guideline that prevents assessment and provision of nutrition, and this is required already by the GMC guidance on *Treatment and Care towards the End of Life* (paragraphs 109-127). However, despite the presence of clear GMC guidance the Independent Review of the LCP found evidence of failures of adequate end of life care in relation both to nutrition and hydration, and both when given orally and when clinically assisted (Independent Review 1.52-1.64). If practitioners sometimes did not advert to the GMC guidance while following the LCP then there is a danger that the same pattern could emerge when professionals seek to follow the NICE guideline. The NICE guideline should therefore itself and overtly include support of oral nutrition, assessment of the reasons for decline in oral intake, when this occurs, and assessment of the need for some form of clinically assisted nutrition, when oral intake is reduced or is judged unsafe. There is an evidence base for this, especially in relation to clinically assisted nutrition for people with progressive conditions. NICE could and should have examined this evidence to help shape the	

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				guideline. These comments should also be read in conjunction with comments below relating to uncertainty in recognition of dying. In those patients who live longer than expected (days or weeks rather than hours), the neglect of assessment of nutrition could have serious adverse consequences.	
Anscombe Bioethics Centre	Short	16	General	Without anticipatory prescription there is a danger that distressing symptoms associated with death, which could have been anticipated, will not be addressed in a timely fashion, especially if someone is dying at home and/or in a setting where a doctor is not easily available. Hence there is clearly a value in allowing anticipatory prescribing. On the other hand a recurrent criticism of care supported by the LCP was that it was associated with over-sedation or over use of analgesia and, more generally, automatic anticipatory use of mediation unrelated to a patient need (Independent Review 1.65-1.67). Such practice did not reflect best use of the LCP but it seems that support for anticipatory prescription was, at least in some cases, confused with routine or automatic provision of medication not related to symptom control.	Thank you for your comment. The Committee recognised the complexities surrounding anticipatory prescribing, but do recommend that anticipatory prescribing be individualised for patients. Administration of medications prescribed in anticipation by a clinician involved in the dying person's care should be reviewed before administration in light of the current symptoms and treatment efficacy fed back to the lead health care professional as recommended in 1.6.5 and 1.6.6. The Committee discussion is captured in the 'Linking evidence to recommendations' section for this review area. We recognize that this is a balance between timely administration to avoid distress and the need for a tailored and individualised approach to anticipatory prescribing that avoids a blanket and repeated approach to prescribing. We hope that our recommendations build in a process for review before administration in the case of prescribing in advance of an event and make explicit the need to

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				The NICE guideline should therefore give more care to distinguishing between anticipatory prescription and the administration or not of the prescribed medication, who should make this decision, and under what circumstances.	monitor the efficacy of this treatment before continuing to administer. NICE is currently developing guidance in palliative care service delivery and the issue of multiprofessional team structures may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Anscombe Bioethics Centre		22	General	In regard to anticipatory prescribing. The NICE guideline recommends suggests future research on cost effectiveness but research also needs be done on the impact of anticipatory prescribing in relation to the dangers of overtreatment or undertreatment (see above comment 16), and how these dangers are to be ameliorated.	Thank you for your comment. The Committee chose to make a research recommendation surrounding anticipatory prescribing. A cost effectiveness evaluation would include also the risk of overtreatment and under treatment. It is hoped that patient and carer symptom ratings, and quality of life scales will provide information on under or over treatment if this piece of research is undertaken.
Arthur Rank Hospice Charity, Cam	Short	19-20	18-25	Recommendations for Research 1. Recognising Dying The guidance implies that there is always some uncertainty in recognising death. If this were correct then virtually the whole guideline would be null and void (how is inevitable dying determined on ITU?). Rather it is better put that	Thank you for your comment. We have edited this text.

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bridge				frequently effective MDT working can define the last days of life and the certainty of this, but that in some circumstances e.g. the frail elderly it is much more difficult to define.	
Arthur Rank Hospice Charity, Cambridge	Short	6-7	General	In terms of Shared Decision Making, the Leadership Alliance for the Care of Dying People in 2014 produced very helpful guidance. They confirm that the creation of a care plan should involve the person as much as they wanted to be coupled with the identification of key people whom the dying person would wish to be involved in their care. In this way, as well as recognising such key people, it also recognised that some person may have family members who they do NOT wish to be involved in their end of life care decision making. This was excellent guidance and would be very valuable to be incorporated.	Thank you for your comment. NICE do not refer to other non-NICE guidelines in its publications. However, the Committee agrees that the issues you mention are very important when delivering supportive, individualised care to dying people, and so have drafted recommendations that support these ideals. The guideline encourages healthcare professionals to establish the level of involvement that the dying person wishes to have in shared decision making, and in establishing the communication needs and expectations of people who may be entering their last days of life, take into account whether they would like a person important to them to be present when making decisions about their care.
Arthur Rank Hospice Charity, Cambridge	Short	9	1.4.6	Presented is that clinically assisted hydration is beneficial or at least neutral in effect. This is not a reflection of the (albeit limited available) evidence which rather shows that patients receiving artificial fluid not only may not benefit from its receipt but rather may be harmed. This must be reflected in any discussion.	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether providing

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					clinically assisted hydration will prolong life or the dying process or hasten death if it is not given. The order of the recommendations reflects the Committee's decision that the dying person should be supported to drink by oral means first if they wish and are able to before clinically assisted hydration is considered. Further detail is given in the full version of the guideline under 'Linking evidence to recommendations' statement in section 8.6.
Arthur Rank Hospice Charity, Cambridge	Short	10	1.5.1	Presented is that it requires agreement from a person or their family in order to stop any treatment. This is not an appropriate reflection of the law and an appropriate example is when a treatment is causing harm without benefit. The fact should also be recognised that such harmful treatment can and will shorten life. This leads onto a major omission from the guideline and that is the appropriate management of conflict or disagreement in end of life care for patients lacking capacity. The Mental Capacity Act 2005 determines that, in the absence of an appropriate valid and applicable Advance Decision to Refuse Treatment, decisions are to be made in a person's best interests. This is a legally determined process as defined by the checklist in Section 4 of the 2005 Act. Therefore, while consideration of patient's prior	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We have made an amendment to this

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				views and involvement/discussion with the relatives is mandatory, they are not absolute. It can thus be considered that inherent within the Act is a potential for best interests decisions to create conflict between professionals and families. Your guidance must recognise this and provide appropriate advice on this difficult area.	recommendation to prevent confusion.
Arthur Rank Hospice Charity, Cambridge	Short	27-28		You have provided doses of medication that does not reflect expert opinion. Why Morphine and not Diamorphine? The starting dose of 1.25-2.5mg SC morphine 2-4hly would frequently be inadequate. You seem to be perpetuating the myth that appropriate given and titrated doses of opioids kill patients. You have provided no recognition that in some circumstances e.g. a patient with an end-stage lung cancer choking to death that there will be a requirement for more frequent or bigger doses than you have outlined. There should also be a recognition that failure to provide adequate symptom control, as well as being deeply distressing and frequently the cause of complaints, can in itself shorten life.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Association for Palliative Medicine	short	19	27	Says "advanced care planning" when it should say "advance care planning" Advance care planning is a process rather than an entity – it is unclear whether the guidance is referring	Thank you for your comment. We have amended the guideline to refer to Advance Care plans and Advance care planning and have also now included reference to lasting powers of attorney where

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of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)				to Advance Decisions to Refuse Treatment, Advance Statements, appointment of a Lasting Power of Attorney or something else.	relevant.
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative	short	general	general	We welcome this document that describes many of the principles of current best practice in palliative care. It reflects points made in the Neuberger report and the "One Chance to get it Right" from the LADCP.	Thank you for your comment and for participating in the consultation process.

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Medicine (JSC)					
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)	short	3	4 & 5	There is of repetition of the word "recognise" / "recognised"	Thank you for your comment this has been amended.
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint	short	3	general	The guideline is unclear about who should make the diagnosis that the person is dying, lead discussions and documentation. In hospital it should be a doctor who is at least a registrar; in the community, a GP or senior district nurse; in all settings it could also be a palliative care clinical nurse specialist. This is an important omission.	Thank you for your comment. These recommendations apply to all healthcare professionals delivering care and may be different in each setting. The committee consider that expertise and experience is as important as seniority. NICE is currently developing guidance in palliative care service delivery and the issue of staff grade/role/seniority may be covered by that work. Please note that more detail about the development

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Specialties Committee for Palliative Medicine (JSC)					of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)	short	4	1-15	This is a list containing both specific and imminent signs (e.g. Cheyne Stokes breathing, Performance Status 4) mixed with non-specific signs and symptoms (e.g. fatigue, social withdrawal, weight loss). A statement saying something to the effect of "the recognition of a recent and persistent change, in performance status, conscious level, and reduction in oral intake which may be associated with Cheyne-Stokes breathing, reduced peripheral perfusion" would offer more clarity to the reader.	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (Please see section 5.8).
Association for Palliative Medicine of Great	short	5	13	Suggest this should start with 'explore whether the person wants to know how ill they are and their likelihood of recovery or whether they would prefer such conversations to be held with others'. Or instead of saying "discuss the dying person's	Thank you for your comment. The Committee believes the recommendation, as drafted, is clear and does not require further amendment.

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Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)				prognosis with them" perhaps it should say "broach the dying person's prognosis …" otherwise this may lead to insensitive discussions.	
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)	short	5	8 & 9	Instead of saying "their current level of understanding that they may be nearing death" it may be more appropriate to say "their current level of understanding of whether they may be nearing death"	Thank you for your comment. The Committee thinks this recommendation is clear as currently edited.

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Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)	short	7	4	The guidance says to identify a named lead healthcare professional. This may lead to dependence on one person. Would it be better to say a named team?	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. The Committee recognises that there may be challenges to its implementation, but that is an aspirational recommendation.
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties	short	general	general	There is no mention or guidance throughout the draft on how to assess a patient's capacity for decision making, nor any mention of the Mental Capacity Act (2005). This is obviously crucial to consider when caring for dying patients as it can change over time and impact on the decisions that are made for and with patients. This has been discussed in more detail in the response to NICE from the Committee on Ethical Issues in Medicine.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting

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Committee for Palliative Medicine (JSC)					decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We have made amendments to a number of recommendations to clarify that the important information of relevance from an advance care planning process includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties	short	9	1	The guidance says "review, preferably daily, with people at the end of life, the possible need for clinically assisted hydration…". It is unclear how a daily review of this would benefit patients and it would be logistically difficult at home. Staff that are less experienced in working with dying patients may misinterpret this as they *must* give artificial hydration if the patient / family request it. It would be preferable to phrase as "'Check daily that oral intake/mouth care is adequate for comfort".	Thank you for your comment. The wording of this recommendation has been amended to state "Assess hydration status, and review preferably daily,…" The Committee intend this recommendation to apply to all settings and are aware that clinically assisted hydration may take place in the community, but note that there may be challenges to its implementation. We feel our recommendations are sufficiently balanced to indicate that there is no direct suggestion to initiate clinically assisted hydration but rather consideration of individualized needs. Further detail has also been added to the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline. NICE is currently developing guidance in palliative care service delivery and this issue may be covered

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Committee for Palliative Medicine (JSC)					by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)	short	12	3	Says "seek specialist palliative care advice if ... there are undesirable side effects such as sedation". Using this example implies that sedation at the end of life is only due to medication, whereas it is likely to be multi-factorial, including the dying process. Specialist advice should be sought in any situation where attempts to reduce distressing symptoms have not led to improvement in the preceding 12-24 hours.	Thank you for your comment. This is an example relating to side effects that the group felt of importance to highlight. We are unable to be prescriptive as to a specific time point in the absence of conducting an evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in full guideline (please see 9.34).
Association for Palliative Medicine	short	12	8-9	The whole section on page 12 about pain is too general and therefore unhelpful. For lines 8-9, it would be more helpful to start the paragraph with something along the lines of "Assess	Thank you for your comment. As no review was prioritised for pain assessment we are unable to make more specific comment on this issue. We have added further detail in the 'Linking evidence to

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of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)				if pain is likely to be present –was regular analgesia needed prior to this phase?; if the patient is unable to communicate, assess evidence of frowning/grimacing, groaning, agitation and restlessness. Check if there is obvious distress associated with passive movements and if alleviated by repositioning. Check for urinary retention. If unsure, administer prn analgesia and reassess within 20-30 minutes"	recommendations' section in the full guideline (9.5).
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine	short	13	1	Additional options for managing breathlessness include fans (hand held and table mounted). There is evidence to support this and should be included as a non-pharmacological intervention.	Thank you for your comment. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.

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(JSC)					
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)	short	13	5-13	Simply listing possible causes for nausea and vomiting is not that helpful. Chemotherapy and radiotherapy are unlikely to be factors unless given in last 24-48 hours, Suggest starting the paragraph with "If the patient is able to communicate, establish if the problem is background nausea or vomiting or both. Check if this was an established problem recently. If nausea and vomiting is associated with bad headaches, consider raised intracranial pressure; if associated with dehydration and agitation consider biochemical cause (renal failure, raised calcium); if abdominal distention and reduced/absent bowel movement examine to exclude intestinal obstruction. Review drug chart-for any recently added medication such as a regular opioid".	Thank you for your comment. After careful consideration, the Committee felt it was helpful to outline the detail as currently drafted. We believe that this list may support the relevant action based on the likely cause or distinction between nausea and/or vomiting.
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialtie	short	14	3	Hyoscine butyl bromide is first line for colic, and may reduce volume of secretions but will not relieve nausea. First line should be a combination of Cyclizine 150mg /24 hours and haloperidol 3mg/24 hours in subcutaneous infusion via a pump.	Thank you for your comment. The recommendations as drafted reflect the limited evidence available for this issue and we are therefore unable to provide any more detailed recommendations.

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s Committee for Palliative Medicine (JSC)					
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)	short	14 31 32	7-20 Table 4 Table 5	Anxiety, delirium and agitation are together in the guidelines when they are quite separate symptoms. It should be made clear that there is evidence to support the use of benzodiazepines in the management of anxiety but for the management of delirium, other NICE guidance recommends *against* the use of benzodiazepines and instead recommends haloperidol followed by olanzapine Agitation can be a symptom of distress e.g. due to pain, a full bladder or it may relate to anxiety and or delirium. It should be managed according to the underlying cause	Thank you for your comment. We recognize the very individual nature of these issues. The recommendations drafted reflect the evidence considered and the Committee expert opinion. Further discussion can be found in Chapter 9 of the full guideline.
Association for Palliative Medicine of Great Britain	short	general	general	Throughout the document it refers to "syringe pumps" as a way to deliver medication. Different recent documents published by NICE refer to "syringe pumps", "continuous subcutaneous injections" and "syringe drivers" all to mean the same mode of medication delivery. This could lead	Thank you for your comment. The Committee discussed the terminology of pump versus driver and reached a consensus decision to use pump. This has been detailed in the full guideline glossary.

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and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)				to confusion for the reader of NICE guidelines and we would recommend NICE consistently adopt one term.	
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliativ	short	general	general	Throughout, the document refers to use of medication that do not have UK marketing authorisation and are being used off licence. It is correct to make this clear but should perhaps be balanced by saying medication outlined in this document being used this way is in accordance with a large body of expert opinion, is considered normal practice in palliative care and refer to the Palliative Care Formulary which contains much of the data to support the use of these medications in this way (Twycross R, Wilcock A, Howard P. 2014 Palliative Care Formulary (PCF5). The PCF contains a synthesis of evidence and established best practice and is an important and credible contemporaneous resource.	Thank you. NICE processes state that if a drug is recommended for an indication in which the medication is off licence then a footnote is required. The linking evidence to recommendation sections within the full guideline gives further detail including current practice and the Committee's expert opinion. Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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e Medicine (JSC)					
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)	short	27	Table 1	It is unusual to give intravenous opioids to dying patients. Subcutaneous is much more widely used. A statement clarifying this (and setting out when intravenous may be appropriate) would be helpful.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Association for Palliative	short	27 28	Tables 1-2	In the sections of the tables about "as required doses" of medication it says they should be given up to 2-4 hourly. Usual recommendations are to use up to 1 hourly	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)					being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Association for Palliative Medicine of Great Britain and Ireland (APM) and	short	27-33	Tables 1-6	All tables advise to increase doses up to the maximum dose of the medication if the symptoms persist. This is unclear advice for someone who is less experienced either with these medications or with caring for dying patients. It may lead to clumsy titration of medications, causing patients to get far greater doses than they require. It may be clearer and safer to say "titrate medication according to response. If symptoms do not improve, reassess the patient. Specialist advice should be sought in any situation where attempts to reduce distressing symptoms have not led to improvement in the	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Joint Specialties Committee for Palliative Medicine (JSC)				preceding 12-24 hours."	
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicin	short	28	Table 2	The dose range suggested for diazepam in patients not currently taking a benzodiazepine is very wide, which may be unsafe in patients with ventilator problems or respiratory failure	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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e (JSC)					
Association for Palliative Medicine of Great Britain and Ireland (APM) and Joint Specialties Committee for Palliative Medicine (JSC)	short	30	Table 3	This table is so vague it is unhelpful –if people really have no idea which anti-emetics to use and when, simply offering a list is of no use and will not support rational choices. There are better tables in standards texts such as the palliative care formulary. See comment 21 below for more deails.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Association of Chartered Physiotherapists in Oncology	References			Bausewein, C., Booth, S., Gysels, M. & Higginson, I.J. (2013) Non-pharmacological interventions for breathlessness in advanced stages of malignant and non-malignant diseases. The Cochrane Database of Systematic Reviews. 11, pp. CD005623. Booth, S., Moffat, C., Burkin, J., Galbraith, S. and Bausewein, C. (2011) Non-pharmacological	Thank you for your comment and the provision of these references. Non-pharmacological management of symptoms is beyond the remit and scope of this guideline and as such we are unable to provide detailed recommendations in these areas. The Committee acknowledge the importance of such

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and Palliative Care				interventions for breathlessness. Current Opinion in Supportive and Palliative Care. 5: pp77–86 Bott, J., Blumenthal, S., Buxton, M., Ellum, S., Falconer, C., Garrod, R., Harvey, A., Hughes, T., Lincoln, M., Mikelsons, C., Potter, C., Pryor, J. Rimington, L., Sinfield, F., Thompson, C., Vaughn, P. and White, J. on behalf of British Thoracic Society Physiotherapy Guideline Development Group (2009) Guidelines for the physiotherapy management of the adult, medical, spontaneously breathing patient. Thorax. 64 Suppl 1. Briggs, R. W. (2011) Clinical Decision Making for Physical Therapists in Patient-Centered End-of-Life Care. Topics in Geriatric Rehabilitation. 27(1): pp 10–17 Chartered Society of Physiotherapy (CSP) (2014) Physiotherapy Works: Chronic Pain. Available online from: http://www.csp.org.uk/professional-union/practice/your-business/evidence-base/physiotherapy-works Cronfalk, B., Strang, P., Ternestedt, B., Friedrichsen, M., Enheten (2009) The existential experiences of receiving soft tissue massage in palliative home care-an intervention. Supportive Care in Cancer. 17(9): pp. 1203-1211. Hurlow, A., Bennett, M., Robb, K., Johnson, M., Simpson, K. & Oxberry, S. (2012) Transcutaneous electric nerve stimulation (TENS) for cancer pain in adults. Cochrane Database of Systematic Reviews.	approaches and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.

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				3(3): pp. CD006276. Kumar, S. (2011) Cancer Pain: A Critical Review of Mechanism-based Classification and Physical Therapy Management in Palliative Care. Indian Journal of Palliative Care. 17(2): pp116-126 Lienert, B.F (2013) Physiotherapy in the terminal phase. In: Taylor, J., Simader, R. & Nieland, P. (eds) (2013) Potential and Possibility: Rehabilitation at end of Life. Physiotherapy in Palliative Care. Munich: Elsevier (Urban & Fischer) Pan, C.X, Morrison, R. S., Ness, J., Fugh-Berman, A. and Leipzig R. M. (2000) Complementary and Alternative Medicine in the Management of Pain, Dyspnea, and Nausea and Vomiting Near the End of Life: A Systematic Review. Journal of Pain and Symptom Management. 20(5): pp374-387 Powell, B (2014) Managing breathlessness in advanced disease. Clinical Medicine. 14(3): pp308–11 Singh, P. and Chaturvedi, A. (2015) Complementary and Alternative Medicine in Cancer Pain Management: A Systematic Review. Indian J Palliat Care. 21(1): pp105–115. Taylor, J (2007) The non-pharmacological management of breathlessness. End Life Care. 1(1): doi:10.1136/eolc-01-01.3 Zhao, I. and Yates, P. (2008) Non-pharmacological interventions for breathlessness management in patients with lung cancer: a systematic review.	

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				Palliative Medicine. 22: pp693–70	
Association of Chartered Physiotherapists in Oncology and Palliative Care	Full	All		We (ACPOPC) are pleased to see the Guideline Development Group (GDG) considered non-pharmacological symptom control modalities in places however it is disappointing that there was limited (if any) expertise in non-pharmacological symptom control on the GDG and thus only very minimal non-pharmacological content. In addition to the economic implications of rising NHS drug costs, excessive medication at end of life was one of the concerns highlighted by relatives and lay representatives in the Neuberger report into the Liverpool Care Pathway. Whilst physiotherapy at end of life will not be indicated for everyone, there is a growing body of evidence to support the role of physiotherapy in symptom control. Physiotherapists in hospices and palliative care teams around the country are successfully using a range of non-pharmacological modalities to contribute to the management of pain, breathlessness, anxiety, nausea & vomiting and other distressing symptoms at end of life. Techniques may include breathing control exercises, positioning, acupuncture, massage and therapeutic touch (Cronfalk, et al., 2009), gentle passive/active assisted movement (to joint and muscle pain), hot and cold therapy, TENS (Hurlow, et al., 2012), relaxation techniques, CBT, mindfulness and other cognitive techniques (ideally commenced earlier and	Thank you for your comment. Non-pharmacological management was outside the scope and remit of the guideline. The Committee acknowledged, however, the importance of such approaches and have made a number of consensus recommendations in the absence of a evidence review to reflect their importance. We do not target recommendations at any particular health care professional but make reference to the multiprofessional team as appropriate. Further detail of the Committee's discussions for each symptom can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.

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				then utilised during the dying phase). Patient-centred goals and balancing the benefits and burdens to the patient of any intervention would always be given careful consideration (Lienert, 2013; Briggs, 2011). Sadly, physiotherapy is not mentioned once in this document and the lack of weight given to the role of non-pharmacological modalities (like physiotherapy) could have a calamitous effect on the success of those trying to improve and develop palliative care physiotherapy services (and the role of physiotherapists) within hospice and palliative care teams.	
Association of Chartered Physiotherapists in Oncology and Palliative Care	Full	All		If the GDG was dissatisfied with the quality of evidence around non-pharmacological symptom control then perhaps the document could include research recommendations (as it has on other topics)	Thank you for your comment. We are unable to recommend research where we have not reviewed the existing evidence base.
Association of Chartered Physiotherapists in Oncology	Full	15 and 175	Point 35	Non-pharmacological management of breathlessness is mentioned briefly but no details are given in spite of growing support for efficacy (e.g., Booth, et al., 2011; Bott, et al 2008; Zhao & Yates, 2008; Taylor, 2007). Disappointed it doesn't suggest and discuss evidence for non-pharmacological interventions including those	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail

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and Palliative Care				provided by physiotherapists (e.g., 'physiotherapy' generally or mention specific physiotherapy techniques) either here or on p175 where further details on evidence behind this recommendation are given. Only facial fans and opening windows are discussed. There is no evidence that literature concerning physiotherapy management of breathlessness was considered in the development of this guideline.	can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline. Thank you for submitting references, but after careful consideration these do not meet the inclusion criteria for any of the evidence reviews.
Association of Chartered Physiotherapists in Oncology and Palliative Care	Full	158		Disappointed that this section gives no consideration to non-pharmacological pain relief modalities which have the potential to be used alongside pharmacological analgesia and potentially can reduce doses required (Singh & Chaturvedi, 2015; CSP, 2014; Hurlow, et al., 2012; Kumar, 2011).	Thank you for your comment. The Committee acknowledge the importance of such approaches and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. As no review was conducted we are unable to give examples in the recommendation. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline. Thank you for submitting references, but after careful consideration these do not meet the inclusion criteria for any of the evidence reviews. Further, the studies suggested in your comment, were not relevant to the reviews in the guideline.
Association of Chartered Physiotherapists in	Full	17 and 207	50	Same comment again regarding management of secretions. A respiratory –trained physiotherapist has a range of techniques they can employ for management of secretions depending on individual need (Bott, et al., 2009). Respiratory physiotherapy will not be indicated for all patients at end of life and	Thank you for your comment. The Committee acknowledges the importance of such non-pharmacological approaches and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. Further detail can be found in the

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Oncology and Palliative Care				need should be assessed on an individual basis	'Linking evidence to recommendations sections' in Chapter 9 of the full guideline.
Association of Chartered Physiotherapists in Oncology and Palliative Care	Full	10		We are disappointed that no physiotherapists co-opted on to the guideline development group considering the breadth of non-pharmacological symptom control modalities they can offer (in addition to now being able to train as independent prescribers)	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Association of Chartered Physiotherapists in Oncology and Palliative Care	Full	16 and 182	Point 41	No mention of specific non-pharmacological modalities for controlling nausea & vomiting (e.g., acupuncture/ acupressure) here or on p182 where further details are given.	Thank you for your comment. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.

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Association of Chartered Physiotherapists in Oncology and Palliative Care	Full	186		Disappointed that this section gives no consideration to non-pharmacological anxiety management modalities.	Thank you for your comment. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Association of Respiratory Nurse Specialists		General		ARNS welcomes the guidelines and believes the issues covered are those that matter to patients, relatives and healthcare professionals	Thank you for your comment and for contributing to the consultation process.
Association of Respiratory Nurse Specialists				ARNS believes that information for patients and carers should be promoted by NICE – given that HCP's and relatives will access the guidance. For example http://www.stchristophers.org.uk/patients/leaflets	Thank you for your comment. NICE guidance does not refer to external leaflets. NICE produces its own 'Information for the public' which will become available on publication of the guideline.

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Association of Respiratory Nurse Specialists	short		1.2.4	ARNS welcomes the subject of prognosis being included. We believe that adequate training around prognosis and communication is essential. We therefore believe a recommendation should be made to employers in all healthcare settings (including community nursing homes) to provide access to training on communication at the end of life and difficult conversations is essential.	Thank you for your comment. Service Delivery, including training, is not included in the remit of this guideline. NICE is producing palliative care service delivery guideline that may cover this topic. More details can be found at the following link: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Association of Respiratory Nurse Specialists	Short		1.3	ARNS is pleased that shared decision making is given a priority in the guidelines	Thank you for participating in the consultation process.
Association of Respiratory Nurse Specialists	Short		1.5.14	ARNS welcomes the suggestion of non-pharmacological management of breathlessness. ARNS believes the guideline should say "Consider non-pharmacological management of breathlessness (for example use of fan, positioning) in a person in the last days of life.	Thank you for your comment. The Committee acknowledges the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Association of Respiratory Nurse	Short		1.5.16	It is recognised that Oxygen is given inappropriately at the end of life for breathlessness. ARNS therefore welcomes the statement that oxygen shouldn't be given unless evidence of hypoxia. ARNS believes	Thank you. We have captured discussion on this issue in the relevant chapter of the full guideline (please see section 9.9)

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Specialists				that a saturation level of 92% would be of benefit in the guideline to steer health care workers and professionals.	
Bedfordshire and Luton Fairplay	Full	General	General	I support the Guidelines document as presented here with one recommendation for a necessary improvement. I have heard many patient histories which demonstrated inadequate cultural care for dying adults even when the clinical care was adequate. I strongly recommend that having cultural issues first mentioned in recommendation 14 is far too low down the list. Please can you consider adding the following text to recommendation 1: in the bullet points after "goals and wishes" add "including cultural issues". This would improve the compassionate care we require from those looking after people who are dying. As a former Non-executive Director for an NHS Ambulance Trust and current Governor of an NHS mental health and community services Foundation Trust, we have been very conscious of the key importance of cultural sensitivity. We know people are more than their clinical symptoms.	Thank you for your comment. We agree that cultural issues are important and have added this to the first recommendation on communication.

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Belfast Health and Social Care Trust	Short	General	General	No Northern Ireland representation on writing group.	Thank you for your comment. Recruitment for guideline development Committee, is advertised on the NICE website, and every effort is made to ensure the widest possible circulation to registered stakeholders, nationwide and profession wide. We believe the recommendations to be of relevance to all countries where NICE guidance is accepted.
Belfast Health and Social Care Trust	Short	General	General	There is a lack of reference to carers' pre and post bereavement needs.	Thank you for your comment. Service delivery including bereavement services was not included in the remit and scope of this guideline. NICE is currently developing a Palliative Care Service delivery guideline, which may address this area. Please note that more detail about this work can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Belfast Health and Social Care Trust	Short	General	General	Overall the guidelines appear quite unwieldy. It would be challenging for clinical staff to find the time to read them or to elicit the key points. It would be helpful to have a succinct summary of the key principles, for example a two page document, to which staff could refer.	Thank you for your comment. This is the standard length and structure of NICE guidelines.
Belfast Health and Social	Short	General	General	The content is, at times, too general and non-specific and could therefore be open to misinterpretation.	Thank you for your comment. We believe the strength of the structure of our recommendations underpins the importance of individualizing care for people at the end of their lives. Whilst not

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Care Trust					prescribing care for every eventuality, this individualized approach requires care professionals to identify those needs and tailor their care accordingly.
Belfast Health and Social Care Trust	Short	General	General	There is limited reference to addressing the holistic needs of the dying patient ie addressing their spiritual, psychological and social needs.	Thank you for your comment. Although outside the remit of this guideline to address in terms of a specific review of the evidence, the Committee has discussed these areas within the communication and shared decision making sections of the guideline and numerous references are made to these important issues in a number of our recommendations for example: 1.1.1, 1.3.2 and others. Further discussion is also available in the 'Linking evidence to recommendations' section of these chapters in the full guideline (Chapters 6 and 7).
Belfast Health and Social Care Trust	Short	General	General	No mention of situations where post mortem may be required.	Thank you for your comment. Service delivery including 'after death care' are beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic is covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
9. B	10.	11	12.	13. Suggesting use of ant-muscarinics is not	Thank you for your comment. We agree that

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elfast Health and Social Care Trust				supported by low quality evidence, and patients tend not to be distressed by same. However, surely distressed relatives will make the patient distressed? We do see evidence of anti-muscarinics working in practice. Agree that this could cause increased family distress and the feeling that nothing is being done to try and help this symptom. We will need further guidance regarding this re statements such as 'it is hard morally and economically to justify continued use'. Suctioning is mentioned which is invasive and often not appropriate for patients at end of life.	evidence in this area is lacking, and as such have prioritised this area for further research. Changes to the section have been made for clarity.
Belfast Health and Social Care	Full	General	General	Guideline summary is long.	Thank you for your comment.

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Trust					
Belfast Health and Social Care Trust	Full	General	General	Richness of full document is lost in the summary e.g. in the guideline re assisted hydration Point 27 on "advising the dying person…. " re clinically assisted hydration - there is no reference to that statement (the GDG) "felt it important that a full discussion of the harms and benefits of clinically assisted hydration tool place with the dying person or those important to them ……and that any preconceptions and concerns are addressed before initiating clinically assisted hydration" (page 153 of full guideline). Or that "people with cognitive disabilities (including those with dementia and leaning difficulties) may find the intervention invasive." Dying patients may be canulated repeatedly and painfully (see Dying Without Dignity- Ombudsman's Report) in order to maintain iv hydration in the imminently dying. The general guidance risks a standard, inflexible approach for all patients. The discussion that the provision of invasive treatment may be largely for the benefit of relatives is again lost in the guideline.	Thank you for your comment. We would hope that care providers would read the 'Linking evidence to recommendations' sections provided at the end of each evidence review chapter in the guideline as you have to access the type of information to which you refer. Recommendations are concise action orientated statements to guide practice and are necessarily focussed and directive.
Belfast Health and Social Care Trust	Full	General	General	The key clinical issue is recognising dying. Good that will be reviewing evidence on how to manage uncertainty related to the active process of dying, especially when chronic long term conditions. This document is to guide general palliative care for people in the last days/hrs of life, however it is very	Thank you for your comment. Please see the NICE version of the guidance or a shorter summary. This version includes the recommendations without presenting the evidence and related to committee discussions.

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				long and cumbersome. Unless very short succinct document results from this it is unlikely to be read by the generalists it is intended for.	
Belfast Health and Social Care Trust	Short	4	1 - 15	The list of signs and symptoms that indicate that a person is dying could be open to misinterpretation and indeed has already been criticised in the press.	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (Please see section 5.8).
Belfast Health and Social Care Trust	Short	4	1-15	The alphabetical listing of signs and symptoms is open to misinterpretation. Some of these symptoms relate to understanding of disease progression/ increased frailty over time e.g. weight loss; others are signs of imminent death e.g. mottled skin; still others are indicative of nearness to death only with specific contextualisation e.g. social withdrawal. Taken out of context it can be suggested that people could be taken to be dying on little evidence. – reported in the lay press already. These points need better contextualisation (as in the full guideline).	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (Please see section 5.8).
Belfast Health and Social Care	Short	4	26-28	Point is vague in relation to "colleagues with more experience in delivering end of life care". Who exactly does this refer to?	Thank you for your comment. The committee considered that this may include specialist palliative care teams or other relevant specialties who's input would reduce the uncertainty in recognising dying. This advice could equally be provided by GPs with

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Trust					expertise in end of life care. This is detailed in the 'Linking evidence to recommendations' section of the full guideline (5.8).
Belfast Health and Social Care Trust	Short	General	General	The guidelines do not indicate who is responsible for diagnosing that someone is dying.	Thank you for your comment. The Committee consider these recommendations to be applicable to whoever is to delivering care for people at the end of life. The committee noted that this may be a practitioner who is experienced in end of life care but did not wish to specify any one group.
Belfast Health and Social Care Trust	Full	General	General	Many references are made to "patient preference" without a supporting statement to ensure patients and relatives are "informed" in their preferences and given the information and opportunity to be informed.	Thank you for your comment. The Committee has drafted recommendations that encourage healthcare professionals to engage the dying person, and establish through discussions their needs, wishes and goals. The committee believes the recommendations address the opportunities to share information as described in your comment and that they do not need further amendment.
Belfast Health and Social Care Trust	Short	General	General	"Individualised Care Plan" – is there a template for this? If not, this could be a very long with numerous sections, depending on the number of issues to be addressed and monitored.	Thank you for your comment. It is the view of the Committee that it's best that the membership of the multiprofessional team and their approach to documentation be Trust led.
Belfast Health and Social	Short	5	13-16	Discussion with significant others "if the dying person wishes". Should have some clarity that discussions could take place in the patient's best interest if unconscious / lacking capacity.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further

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Care Trust					discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009
Belfast Health and Social Care Trust	Short	6	10-12	Record of care – difficulties in sharing info between acute and community settings.	Thank you for your comment. The Committee would consider this issue to be best dealt with at the Trust level as operations would vary across different trusts. Additionally, service delivery, including implementation matters, are outside the remit of the guideline. NICE is currently developing guidance on palliative care service delivery and this topic may be included in that guidance. More details can be found at the following link: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Belfast Health and Social Care	Full	13	41-45	There is no mention of patients changing their wishes.	Thank you for your comment. The Committee recognises this as important, and have drafted recommendation 19 (2.3.7 in the short version) to encourage healthcare professionals to recognise that the dying person's ability and desire to be

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Trust					involved in making decisions about their care may change as their condition deteriorates or as they accept their prognosis. The recommendations also encourage healthcare professionals to provide the dying person with opportunities to discuss their fears and anxieties and to continue to explore the understanding and wishes of the dying person and those important to them with a view to updating the person's care plan as required.
Belfast Health and Social Care Trust	Short	7	18-26	The guidelines repeatedly refer to "an individualised plan of care" as do other similar guidelines; however we still have not been given specific guidance or examples of what this care plan should look like, etc. This is one of the key issues that clinicians need strong direction on, yet no guidelines to date have really addressed it ie how are "individualised plan of care" operationalised?	Thank you for your comment. The design and delivery of care plans may be decided on at the Trust level. It is not within the remit of this guideline to provide this level of detail.
Belfast Health and Social Care Trust	Short	7	18-26	No reference at all to severity of symptoms – perhaps implying that all symptom management is unnecessary. Last bullet point – "needs for care after death, if any are specified"- a guideline should help providers recognise issues that they were not aware of- this question needs to be reformulated so that providers will enquire.	Thank you for your comment. This has been amended, The list now includes 'preferences for symptom control'. The recommendation outlines that the care plan captures these issues after discussion with the dying person. This list may form a list of issues to be discussed but is not considered fully inclusive or capturing the full detail that may be required on an individualized basis.
Belfast Health and	Short	General	General	No mention of communicating with GPs etc.	Thank you for your comment. The Committee consider that GPs are part of the multiprofessional team and as such several recommendations under

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Social Care Trust					communication apply.
Belfast Health and Social Care Trust	Short	General	General	It could cause confusion between use of terms such as advance care planning and individualised plan of care.	These have been defined in the glossary of the full guideline.
Belfast Health and Social Care Trust	Full	14	18-44	Are the group now suggesting that hydration is offered to everyone, unless contra-indicated on an individual basis? Not sure how effective regular reassessment of side effects of administration of fluids would be. Likely to potentially manage noisy secretions with intervention instead?	Thank you for your comment. The order of the recommendations reflects the Committee's decision that the dying person should be supported to drink by oral means first if they wish and are able to before clinically assisted hydration is considered. The decision to consider a trial of clinically assisted hydration should be based on an individualised approach taking into account benefits and harms.
Belfast Health and Social Care Trust	Full	15	1-7	Are the group now suggesting that hydration is offered to everyone, unless contra-indicated on an individual basis? Not sure how effective regular reassessment of side effects of administration of fluids would be. Likely to potentially manage noisy secretions with intervention instead?	The order of the recommendations reflects the Committee's decision that the dying person should be supported to drink by oral means first if they wish and are able to before clinically assisted hydration is considered. The decision to consider a trial of clinically assisted hydration should be based on an individualized approach taking into account benefits and harms.
Belfast Health and Social	Short	9	15-25	No reference to the potential harms of assisted hydration- see page 153 main document re the need better to inform patients and relatives.	Thank you for your comment. The Committee consider that this would be covered by recommendation 2.4.5 (discuss risks and benefits of clinically assisted hydration).

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Care Trust					
Belfast Health and Social Care Trust	Short	9	8-14	"Death is unlikely to be hastened by not having clinically assisted hydration". This statement has already been challenged in the press by a leading neurologist who feels it is factually incorrect.	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given.
Belfast Health and Social Care Trust	Short	10	14-18	Did not include as a general concept the potential value of having "as required" medication available.	Thank you for your comment. Please see the chapter on anticipatory prescribing in Chapter 10 of the full guideline.
Belfast Health and Social Care Trust	Short	10	19-23	Section 1.5.1 – "…after discussion and agreement with dying person and those important…" – It would be helpful to add "where possible".	Thank you for your comment. The Committee consider that it is very important to involve the dying person and those important to them in these discussions but have made a minor change to the recommendation to avoid confusion. The group understand that in some cases there may be exceptions, but consider that clinical judgement be used in these cases.
Belfast Health and	Short	11	10-16	Some of the bullet points are repetitive.	Thank you for your comment. The Committee have considered the recommendations and feel no change is required. They feel the issue of

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Social Care Trust					considering route of administration an important issue to highlight.
Belfast Health and Social Care Trust	Short	11	13-16	Confused statement re Syringe drivers. These have specific uses. However if a patient requires multiple PRN doses in 24 hours – they may need commencement/ review of longer acting medication not necessarily syringe drivers.	Thank you for your comment. This recommendation is a "consider" recommendation, which reflects its weaker strength and that there is some uncertainty around the evidence behind this recommendation, as detailed in the NICE methods manual: https://www.nice.org.uk/media/default/about/what-we-do/our-programmes/developing-nice-guidelines-the-manual.pdf The Committee considered that it is a useful option in some cases.
Belfast Health and Social Care Trust	Short	11	17-19	Syringe drivers may be used for other reasons other than just because the person requires 2 or 3 doses of any "as required" medication.	Thank you for your comment the content of which is noted
Belfast Health and Social Care Trust	Short	11	26	Assessing patient's symptoms daily. In the interest of producing a document that can be used in community as well as hospital / care homes – this is a retrograde step that reduces the assessment of potentially difficult symptoms to once daily.	Thank you for your comment. "At least daily" does not preclude more frequent reassessment. As no evidence review was conducted in this area the Committee are unable to be more prescriptive.
Belfast Health	Short	11	5	When discussing cultural views re symptom management – need to check not making cultural	Thank you for your comment. We agree and note that the communication and shared decision making

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and Social Care Trust				assumptions but individual informed choice.	chapters cover cultural views in more detail.
Belfast Health and Social Care Trust	Short	12	13	Preferred route of administration is OK if the patient can actually receive medication via that route – needs to be assessed as well as preference.	Thank you for your comment. This is an example given and the Committee consider assessing whether the route is viable is standard clinical practice. Minor amendments to the recommendation have been made to outline that this may not always be possible.
Belfast Health and Social Care Trust	Short	12	14-17	1.5.13 –examples of "validated behavioural pain assessment" tools would be helpful.	Thank you for your comment. An evidence review was not conducted on the use of pain assessment tools in the last few days of life, however the Committee chose to make a recommendation about their use based on their own clinical experience. Further detail has been added to the 'Linking evidence to recommendations' section of this chapter in the full guideline (please see section 9.5).
Belfast Health and Social Care Trust	Short	16	23	Catastrophic haemorrhage – only alluded to, no guidance given. Specific guidance needed for catastrophic haemorrhage.	Thank you for your comment. This is further detailed in the full guideline 'Linking evidence to recommendations' section of chapter 10.
Belfast Health and Social Care	Short	General	General	Symptom control guideline: these vary significantly from the Northern Ireland Palliative Medicine Group guidelines and therefore this would need addressed if the NICE guidance was to be considered in Northern Ireland context.	Thank you for your comment the content of which is noted. We would hope that Northern Ireland does make use of our up to date and thorough evidence review when considering its application locally,

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Trust					
Belfast Health and Social Care Trust	Full	217	1-2	Pain - orally PRNs – should paracetamol be before ibuprofen? -24hr starting dose continuous subcutaneous infusion if not already on analgesia suggests diclofenac & ibuprofen can be given subcutaneously continuously. -If person is not already prescribed opioids and can no longer take orally, surely 24 continuous subcutaneous infusion starting doses should be less than range 10-20mg/24hrs?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Full	218	1-4	Breathlessness – if person is already prescribed an opioid for shortness of breath, suggest there is a maximum dose for this indication. Also, suggesting PRN doses with decimal points -If still breathless with opioid are suggesting 24hr continuous subcutaneous infusion of clonazepam before midazolam (? National shortage? Right order).	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social	Full	219	1-5	Nausea and vomiting – first line – does not mention reassessing the cause of nausea and vomiting to assess if still appropriate antiemetic.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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Care Trust					being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Full	221	1-4	Delirium – cannot comment on olazepine/risperidone as have not suggested these.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Full	222	1-4	Noisy secretions – PRN doses of Glycopyronnium as 400mcg (is this a miss print?) - 24hr continuous subcutaneous infusion – is maximum dose of hyoscone hydrobromide not 2.4mg/24hrs?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain

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					targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	24	16-17	".. Documented informed consent" – what level of detail may be required here & for which drugs, routes etc?-Potential burden for symptomatic patient.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	25	20	Alphabet listing is confusing-the most commonly prescribed drugs should be listed first, following the same principle of the order of the symptoms in the point above.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health	Short	27	1-3	Table format can be improved as difficult to follow - suggest flow chart format instead. THIS APPLIES	Thank you for your comment on the prescribing tables. Because of the recognised importance of

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and Social Care Trust				TO ALL THE TABLES.	supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	27	1-3	Rectally-This route is very rarely used in practice - perhaps a footnote can be added that this route may be considered if necessary.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	27	1-3	Diclofenac and Ibuprofen continuous subcutaneous infusion-Ibuprofen is not available as an injectable form-Parecoxib can be used if needed but this would not be initiated as first line. Would normally prescribe low doses of opioids in this situation if patient unable to take oral drugs and in pain.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently,

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					they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	27	1-3	Orally opioid analgesics: there is no maximum dose for opioids, hence this statement is confusing.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	27	1-3	Morphine sulphate 1.25-2.5mg: would not use decimal points unless unavoidable. This is to reduce errors in prescribing. Suggest 2mg and 1-2 mg here.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Belfast Health and Social Care Trust	Short	27	1-3	Continuous subcutaneous infusion of morphine sulphate 10-20mg as starting dose: would prescribe lower doses-5-10mg.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	27-33	1-3 (all)	Guidance on drugs does not reflect the current Northern Ireland Regional Palliative Medicine Group guidance (see above).	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care	Short	27-33	1-3 (all)	Certain identified drugs should only be initiated by specialist palliative care or under the advice of specialists. We have some concerns that this is not clear in this guidance intended for wide general use.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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Trust					implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	28	1-2	Table format can be improved as difficult to follow - suggest flow chart format instead. THIS APPLIES TO ALL THE TABLES.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	28	1-2	Rectally-This route is very rarely used in practice - perhaps a footnote can be added that this route may be considered if necessary.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be

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					made available on the NICE website.
Belfast Health and Social Care Trust	Short	28	1-2	Orally opioid analgesics: there is no maximum dose for opioids, hence this statement is confusing.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	28	1-2	Would not use decimal points unless unavoidable in regards to doses. This is to reduce errors in prescribing.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and	Short	28	1-2	If still breathless with opioid (despite dose increases and switching), consider adding a benzodiazepine: Benzodiazepines added for anxiety related to	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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Social Care Trust				breathlessness and is not a treatment for breathlessness per se.	symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	28	1-2	Continuous subcutaneous infusion- clonazepam: Currently, Clonazepam injection does not have a UK marketing authorisation. Would not start Midazolam above 10mg unless patient was already taking regular oral benzodiazepines.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	28	1-2	Midazolam 5-20mg over 24 hours continuous subcutaneous infusion: would normally start at lower dose of 5-10mg.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This

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					important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	28	1-2	Midazolam Buccally- not commonly used route for breathlessness, recommend adding "up to" 4 times a day.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	30	1-2	Buccal route-if patients not able to take oral route for nausea and vomiting-usually not appropriate if patients not able to take oral route, especially in last few days of life.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast	Short	30	1-2	Proclroperazine-not commonly used, suggest insert	Thank you for your comment on the prescribing

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Health and Social Care Trust				buccal preparation in this column rather than "if unable to take oral drugs" column.	tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	30	1-2	Levomepromazine 6-6.25mg: suggest 6mg or 6.25mg 4-6 hourly (as 6-6.25mg implies dose range between 6 and 6.25mg).	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	30	1-2	Subcutaneously or intravenously Levomepromazine 2.5-5 up to mg 12 hourly-intravenous route not used, suggest Levomepromazine 2.5-5mg 4-6 hourly up to ?50mg daily.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	30	1-2	Note b) at bottom of page-cyclizine and site reactions-suggest: should be used "with Water for Injections" as diluent to minimise site reactions.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	31	1-4	Maximum dose of anxiolytic medication- difficult to determine what this dose is.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Belfast Health and Social Care Trust	Short	31	1-4	Midazolam 5-20mg over 24 hours starting dose: 20mg is a rather high starting dose especially if this is aimed at generalist staff, suggest 5-10mg.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	32	1-3	Maximum dose of antipsychotic is difficult to determine what this is.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social	Short	32	1-3	Olazepine and Risperidone-both these drugs are not commonly initiated in the last days of life; also has implications for dose adjustments in liver and renal failure.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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Care Trust					being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	32	1-3	Levomepromazine not used intravenously.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	33	1-3	Glycopyrronium doses-1200 micrograms of Glycopyrronium equivalent to 2400 micrograms of hyoscine, which is the maximum dose. For consistency, starting dose should be 600 micrograms for continuous subcutaneous infusion.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain

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					targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	33	1-3	Note a)-Monitor for unwanted sedation and other side effects- Due to unwanted sedation and other side effects, glycopyrronium is used first line- We do not tend to use Atropine.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	General	General	Would not use decimal points in regards to doses, unless unavoidable. This is to reduce errors in prescribing.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health	Short	General	General	Guideline suggests a reluctance to prescribe medication but little reference to the risk of under-	Thank you for your comment on the prescribing tables. Because of the recognised importance of

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	**Developer's response** Please respond to each comment
and Social Care Trust				treatment of symptomatic patients. Nausea/ vomiting /sedation and delirium may be disease rather than adverse effects of medication. Guideline does little to dispel misconceptions.	supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Belfast Health and Social Care Trust	Short	3-4	2-28	Will have a big impact – time, training, communication, all grades of staff to be able to correctly recognise the stage the patient is at, continuity of care in community (nurses, other professionals attending). Appropriately trained staff (home care workers, professional staff etc).	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	3-4	2-28	Overcoming challenges: Need training to recognise end of life (in particular, specific diseases). Staff need time and resources.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and	Short	3-4	2-28	Overcoming challenges: Key worker needs to be clearly identified and clearly communicated to all involved. Key worker needs sufficient time to	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and

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Social Care Trust				appropriately assess and put services in place.	resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	3-4	2-28	Overcoming challenges: Language – non English speakers.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	3-4	2-28	Overcoming challenges: Appropriate Trust-private providers training.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	5-6	1-15	Overcoming challenges: Keyworker needs to have way of effectively communicating with all staff involved.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would

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					specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	General	General	Biggest impact? Biggest challenges - Having an official document to allow discussion and support clinicians in "recognising dying"- (given recent Liverpool Care Pathway publicity). Issues will be to get clinicians to readdress discussing how to care for dying patients with patients and family. Educate and inform public re fact of eventual death and appropriateness of invasive interventions/ hospitalisation or alternatives.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	General	General	What would help? - Local educators/ champions not just to initiate the project but to provide on-going education – to avoid the risk of rigidity in practice.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	General	General	What would help? - National audit.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and	Short	General	Gener	What would help? - National provider / patient & carer conference for openness.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and

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Social Care Trust			al		resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	General	General	What would help? - Clarity re benefit of accessing specialist palliative care if uncontrolled symptoms / unacceptable side effects.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	General	General	What would help? - Research especially regarding artificial hydration at end of life.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	5-6	1-15	Overcoming challenges: Need interpreters available to ensure appropriate and timely communication	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.

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Belfast Health and Social Care Trust	Short	5-6	1-15	Overcoming challenges: Improved ICT systems	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	5-6	1-15	Overcoming challenges: Advanced communication skills training required for all staff	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	5-6	1-15	Overcoming challenges: Need a 'standard' for communication – Trust wide. Who needs to know and how this should be communicated.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care	Short	5-6	1-15	Overcoming challenges: Keyworker needs to have way of effectively communicating with all staff involved.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will

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Trust					have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	5-6	1-15	Overcoming challenges: Need central and accessible place (for all involved) to document this.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast Health and Social Care Trust	Short	3-4	2-28	Will have a big impact – time, training, communication, all grades of staff to be able to correctly recognise the stage the patient is at, continuity of care in community (nurses, other professionals attending). Appropriately trained staff (home care workers, professional staff etc).	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Belfast health and Social Care Trust	Short	5-6	1-15	Impact: Communication – consistency of sharing of info once assessment of last days of life has been made. How does the professional share this info? Poor ICT systems and support, repeated system failures and no joined up IT systems. Training of staff to effectively communicate with patient/family/carers.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would

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					specifically help users to overcome any challenges.
Board of Deputies of British Jews		11	4-5	There are concerns about the use of terminology. Whilst it may be correct to refer to "dying of cancer" one of the key issues later in this document is that people with dementia die, but not necessarily of dementia itself. This has important implications later in the document where issues about question such as the use of antibiotics and of pain relief are discussed – these may be applicable to the superadded condition, e.g. pneumonia, contracture immobility, where the patient with dementia, and their family, may wish to be considered like any other family with the superadded condition.	Thank you for your comment. All recommendations are applicable to all people at the end of life. The Committee does not believe any distinctions should be made for specific conditions or treatments withheld.
Board of Deputies of British Jews		General	General	The Board of Deputies of British Jews is the cross-communal organisation that exists to promote and defend the religious and civil liberties of British Jewry. Deputies are elected every three years. The Board provides a unique means through which British Jews can be represented and heard. Some parts of the Jewish community do not participate in the electoral and representational process, but wherever possible there is consultation and discussion with them about submissions to public bodies where there is a perception that there is a community of interest. The Board recognises that there are some areas, particularly in the biomedical field, where a wide range of views may be expressed within the community. Decisions are made by the individual (or	Thank you for your comment the content of which is noted. Service delivery, including spiritual care and training are not included in the remit and scope of this guideline. However, the dying person's spiritual needs are acknowledged and considered in our 'Linking evidence to recommendations' in the relevant sections of the guideline. NICE is currently developing guidance in palliative care service delivery and training needs may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-

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				the individual family) – even if that decision is to consult with and accept the view of a religious authority. Therefore, when making submissions on these topics, always the Board has to achieve a balance, but one that is nonetheless consistent with Jewish traditions and customs. The Board has been asked on several occasions to express views about different aspects of Care of the Dying applicable for Jewish people. These requests are considered carefully, and advice is sought from medical professionals who are members of the Board, from the lawyers involved in the Board's family law group, and from members of the community with related expertise. It is in this context that the Board made extensive submissions to Baroness Neuberger's investigation of the Liverpool Care Pathway, and strongly supported the resultant "More Care Less Pathway" document which resulted. In these previous submissions in turn the Board noted that they had been consulted and made submissions to the General Medical Council (GMC) "Treatment and Care towards the End of Life" document where the presumption of prolonging life (rather than hastening death) was reaffirmed and where a wide range of relevant topics - such as the withdrawal of futile treatment, and the role of clinically assisted nutrition and hydration – were discussed. This GMC document allowed for sensitivity to Jewish practices	cgwave0799

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				across our religious spectrum, and provides some useful and constructive background. The Board is conscious that in this sphere there is a responsibility not only to those who are the recipients of Care of the Dying but also to Jewish doctors, who might be confronted with situations and decisions which run contrary to their personal beliefs on a very sensitive topic. Although such issues are in general addressed by reference to the GMC's "Personal Belief and Medical Practice", the individual case may prove difficult for the Jewish doctor to resolve. The Board believes that an essential component of any recommendations, including those relating to economic issues and costings, is that adequate provision needs to be made for education and training of those handling the Care of the Dying Adult. This is in order to help them address faith and cultural diversity in a sensitive and supportive fashion.	
Board of Deputies of British Jews	Full	12	21-24	(1) The statement about "discussing the dying person's wishes with them" may reflect current views about medical transparency and practice. However, the relevance of this within a broader cultural, including Jewish, context remains a subject of debate, and an article by Jotkowitz et al ("Truth telling in a culturally diverse world", Cancer	Thank you for your comment. (1) The Committee agrees and is pleased that the recommendations encourage healthcare professionals to take into account any cultural, religious social or spiritual needs or preferences that should be considered.

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				Investigation 24:786-9, 2006) is pertinent. Traditionally the Jewish view has been that disclosure about impending death is contrary to religious practice; this has been modified to reflect medical advances, but the principle remains current to varying degrees within the community. Thus a formulation that states "in disclosing a poor prognosis to a patient the physician must do so with cultural sensitivity, compassion and letting the patient decide how much he or she wants to know" is commended. (2) This concept appears to be the basis for page 13, lines 6-11, so there is a contradiction. The assumption in the present formulation is that there is always medical certainty, and that the presence of other parties during these discussions is optional. A degree of humility about the first would be appropriate; and (3) from a Jewish perspective the concept that loss of consciousness may lead to failure to respect wishes and beliefs can be a cause for concern, so that the preferred default option should be to have others present.	(2) The issue of medical uncertainty is highlighted in the recognising dying chapter where guidance is provided on how to communication the presence of uncertainty to both the dying person and those important to them. (3) The presence of other parties during discussions on prognosis, shared decision making or any other aspect of care remains guided by patient choice. The guideline's recommendations apply to people at the end of life across all levels of consciousness, but does not replace the clinician's duties with respect to ensuring compliance with the Mental Capacity Act. It also makes clear the duties of the multiprofessional team regarding communication and involving those important to the dying person. Further information about mental capacity has now been added to the full guideline chapters 6 and 7 (section 6.6 and 7.6). Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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Board of Deputies of British Jews	Full	13	12-17	Based upon response 3, it would be helpful if item 14 should precede rather than follow.	Thank you for your comment. The Committee has considered the order of these recommendations and wish to prioritise the goals and wishes of the dying person and this starts with establishing what level of participation they wish to have in the shared decision making process.
Board of Deputies of British Jews	Full	13	29-37	There are several relevant items relating to this section i. One pattern does not fit all, and an individual approach for each patient is very important. Therefore fitting into a structured care of the dying pathway may not always be appropriate. ii. Dying patients who are Jewish may not declare themselves as having any faith, and then begin to feel that care has a secular/Christian point of view. This can mean that people might not disclose or discuss their faith until a late stage in their care. iii. The concept of "end of life" as a "transitional stage in life" is very strong in Judaism. iv. Bereavement and support for the bereaved has a traditional, structural aspect in Judaism, and patients may be more concerned about these than about any other aspect of Jewish practice. . v. As a minority community, Jews may feel vulnerable about exposing themselves to carers who are likely to have a different faith/view. vi. Jewish "Religious authorities" – in this context often local Rabbis - have always had a role in end of life care. Traditionally a Rabbi visits a patient before	Thank you for your comment. i. The Committee agrees and has drafted recommendations throughout the guidance that encourages an individualised approach to end of life care and not a pathway approach. ii. The Committee's recommendations encourage health care professionals to continue to explore the wishes of the dying person and to update the care plan as required, and this includes the need for volunteer support from other organisations. iii. Recommendations have been drafted that encourage healthcare professionals to take into account any cultural, religious social or spiritual needs or preferences that should be considered. iv. Service delivery, including 'bereavement support' was not included in the scope of this guideline. NICE is developing guidance on the service delivery

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				death rather than after, as expressed in the important "mitzvah" term "bikur cholim", which translates as "visiting the sick". vii. There may be needs for opportunities for prayer – both for the patient and the family; for contact with Rabbinic authorities; and for identification of Rabbinic nominees who the patient may wish to be consulted. viii. Handling of the body at the time of death, contact details for burial societies, awareness by those implementing the pathway of Jewish customs with regard to autopsy and swift issue of documentation to ensure more rapid burial are all matters which need to be taken into account.	aspects of palliative care and this area may be covered by that guidance. More information is available at: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799 v. The guideline is for healthcare professionals responsible for delivering end of life care in all settings where NHS services are provided. All healthcare professionals using this guidance are encouraged to prioritise the goals and wishes of the dying person irrespective of but considerate of their faith . vi. Thank you for highlighting the traditions of the Jewish community. The recommendations encourage healthcare professionals to establish the needs of the dying person as early as possible in the delivery of their care. vii. The communication recommendations highlight the importance of an individualised approach to delivering care in the last days of life. viii. We believe that the issue of needs for respecting pathways after death is addressed in recommendation17

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Board of Deputies of British Jews	Full	14 15	18-44; 1-12	With regard to clinically assisted hydration the Jewish tradition has been that the only reason for discontinuing it is where there is evidence that the hydration is causing harm, such as by resulting in fluid overload, or increasing secretions. This core statement is not made specifically in the document, but may have wide support. It is unclear what is meant by "recovery from dying" (14, line 41); why an infusion site cannot be changed (15, line 7) and why changes are only to be made "near death" rather than "as clinically indicated" (15, line 11-12).	Thank you for your comment. The harm of fluid overload has been added to recommendation 1.4.**6 (via cross reference).** We understand that different faiths have different stances (1.4.7) on hydration and feel this has been acknowledged. We have removed the example of "infusion site" from the recommendation. We agree that "recovery from dying" is unclear and this has been amended.
Board of Deputies of British Jews		18	36-44	The core Jewish concept is that unhelpful medication should be stopped, and decisions made carefully about starting either new medication or procedures. The simple principle has been stated that withdrawal of treatment is not acceptable, whereas withholding treatment is, but again such decisions need to be reviewed for the individual patient. There has traditionally been a distinction made between basic care (e.g. hydration, insulin for diabetics) and treatments / medications targeted at a specific illness. The former is essential; the latter may not be, for example in decisions to stop chemotherapy medication; but even in such instances a role for the chemotherapy as a medication for symptom relief may be important. Discussions with patients and their families need to	Thank you for your comment. The Committee agree, and have highlighted in recommendation 1.5.1 that reconciliation of medications are discussed with the dying person and those important to them.

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				be sensitive to these principles at a time of stress and vulnerability when spiritual and psychological needs may come to the fore.	
British Geriatrics Society	Full	189	9.18	I am concerned that there are no recommendations for the use of pain scores for people with delirium or dementia.	Thank you for your comment. We have made a recommendation in the pain section on assessing pain for those who are unable to communicate verbally e.g. who have dementia. Further detail is given in the 'Linking evidence to recommendations' section of the full guideline.
British Geriatrics Society	Full	219	9.352	I am concerned that the guidelines recommend the use of cyclizine for nausea despite stating that there is little scientific evidence for their benefit in nausea.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
British Heart Foundation	Full	General	General	In summary, whilst we welcome much of the content of the guideline, we believe that it is wrong to apply this only to the last few days of life and we would recommend widening this guideline to apply to the last months of life. BHF pilots have shown that it is both possible and economically beneficial to identify people with heart failure at this stage and if we do	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult. Providing guidance before the last few days of life is beyond the remit and scope of this guideline. Thank you for your comment. We agree that many

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				not do this, we risk not only failing to harness the economic benefits of providing quality end of life care to all, but, most importantly, we also risk exacerbating the inequity that already exists in the quality of end of life care received.	of our recommendations apply to the timeframe you refer to in your comment and are addressed by other initiatives e.g. the Amber Bundle Gold Standard Framework. http://www.ambercarebundle.org/homepage.aspx However, this is outside the remit of the scope.
British Heart Foundation	Full	General	General	The British Heart Foundation (BHF) is the nation's leading heart charity. Our vision is of a world in which no one dies prematurely or suffers from cardiovascular disease (CVD).Cardiovascular disease, which includes diseases of the heart and circulation such as heart failure, coronary heart disease (angina and heart attack) and stroke, kills more than one in four people in the UK. We are concerned that the focus, throughout this guideline, on identification of people who are in their last few days of life is likely to exacerbate the existing inequity in delivery and quality of end of life care for people with heart failure. The BHF estimates that heart failure, which is often the final outcome of a variety of cardiac diseases, currently affects around 550,000 people in the UK. Despite therapeutic advances, heart failure is a progressive clinical syndrome. The National Heart Failure Audit shows that of those heart failure	Thank you for your comment. We recognize the difficult and unpredictable trajectory at end of life for patients with heart failure. Our guideline addresses the clinical care required by the dying adult in the last days of life. We recognize that people dying of heart failure may stabilize their condition and recover to a degree, however we believe our recommendations address this issue. The Committee were supported in their consideration of the evidence relevant to those people dying from heart failure by the advice of a co-opted expert who also supported and reviewed their recommendations.

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				patients that survived to be discharged in 2012/13, 25% died in the follow up period.1 Although heart failure survival rates are worse than for some cancers, unlike cancer patients, very few people with heart failure receive specialist end of life care. The National Heart Failure Audit shows that only 4% of heart failure patients were referred to palliative care services, although in some cases, palliative care is part of the role of the Heart Failure Nurse Specialist.2 The relatively small numbers of people with heart failure receiving quality end of life care is due, in large part, to the unpredictable trajectory of heart failure. Some patients with heart failure have repeated acute and severe exacerbations that respond effectively to treatment. For others, the decline is relentless with worsening symptoms that are distressing and debilitating. Some die suddenly without warning yet others can show signs of being at the end of life for over a year. GPs say that introducing palliative care was fairly straightforward for those with cancer, who typically had a clear	

[1] National Heart Failure Audit, April 2012 – March 2013, NICOR, British Society of Heart Failure, November 2013. Available at : https://www.ucl.ac.uk/nicor/audits/heartfailure/documents/annualreports/hfannual12-13.pdf
[2] Ibid.

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				terminal decline but much more difficult for patients with other life-threatening illnesses.3 If individuals are recognised as approaching the end of their life there can be proper planning for their needs and wishes. If individuals are not identified as approaching the end of life, however, this cannot happen. The Department of Health's survey of bereaved people shows clear discrepancies in the experiences of people whose loved ones died from CVD compared to those who died from cancer.4 In order to ensure that heart failure patients are identified for end of life care, and at a time far enough in advance for them to fully benefit, we believe that patients must be identified when they reach end stage heart failure. This will likely be in their last months rather than days of life. In order to ensure patients with heart failure receive quality end of life care in the place of their choice, discussion should not be left to the last few days of life. Whilst this varies greatly, the condition of some people with heart failure can deteriorate soon after diagnosis. Patients with end stage heart failure and end of life care needs will continue to receive on-going medical	

[3] Zheng L, Finucane AM, Oxenham D, McLoughlin P, McCutcheon H, Murray SA. (2013) *How good is primary care at identifying patients who need palliative care? A mixed-methods* study
4 National Survey of Bereaved People (VOICES), 2014 reference table, Office for National Statistics. Available at: http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-407293

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				therapy for their heart failure during this time.	
British Heart Foundation	Full	General	General	Providing the right care, in the right place, at the right time, is crucial, not only for improving individuals' wellbeing at the end of life but also economically. So we welcome the inclusion of economic evidence in the guideline but, again, believe that in order to see the full economic benefit, people with heart failure must be recognised in their last months of life. The majority of people, about 70%, indicate that they would prefer to die in their usual place of residence, yet, between 2004 and 2011 a large proportion (59%) of CVD deaths occurred in hospital.5 Whilst 65% of relatives of people who died from cancer felt that the person had enough choice over their place of death, this compared to 44% of relatives of people that died from cardiovascular disease.6 Hospital beds are expensive: the mean cost of hospital care in the last year of life for those who died in hospital	Thank you for your comment. We recognize the difficult and unpredictable trajectory at end of life for patients with heart failure. Our guideline addresses the clinical care required by the dying adult in the last days of life. We recognize that people dying of heart failure may stabilize their condition and recover to a degree, however we believe our recommendations address this issue. The Committee were supported in their consideration of the evidence relevant to those people dying from heart failure by the advice of a co-opted expert who also supported and reviewed their recommendations. We note the importance of place of death and the challenge in sometimes facilitating this. Service Delivery, including facilitating choice of place of death, is beyond the remit and scope of this guideline. NICE is currently developing guidance in

[5] National End of Life Care Intelligence Network (2013) *Deaths from CVD. Implications for End of Life Care in England*

[6] National Survey of Bereaved People (VOICES), 2014, Reference tables, Office for National Statistics. Available at: http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-407293

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				was £11,298. The mean cost of hospital care for those who died outside of hospital was £7,730.7 Heart failure accounts for 2% of all NHS inpatient bed-days and 5% of all emergency medical admissions to hospital. Hospital admissions because of heart failure are projected to rise by 50% over the next 25 years.8 Admissions might be avoided with anticipatory care planning and the provision of community health and social care support.9 The BHF has invested over £2 million in trialling models of care for improving end of life for people with CVD, The BHF's Better Together programme helped manage heart failure symptoms as well as wider care needs.10 In addition to reducing isolation and improving quality of life, this scheme was also cost saving. It helped 55 out of 74 patients spend the end of life in their place of choice, which was usually at home. Heart failure specialist nurses are a key component of multidisciplinary teams working in secondary care to meet the needs of people living with heart failure. An evaluation of BHF heart failure specialist nurses	palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799. We have however made a number of recommendations about the role of anticipatory prescribing believing that timely and individualized prescribing may assist people to remain in their place of choice.

[7] Abel J, Pring A, Rich A et al (2013) The impact of advance care planning of place of death, a hospice retrospective cohort study
[8] NICE (2010) *Guideline on Management of chronic heart failure in adults in primary and secondary care*
[9] Abel J, Pring A, Rich A et al. (2013) *The impact of advance care planning of place of death, a hospice retrospective cohort study for over 73,000 deaths in England*
[10] http://www.bhf.org.uk/publications/view-publication.aspx?ps=1001308

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				showed that they significantly improved the quality of life of their patients. The work of heart failure nurses led to a 35% drop in admissions and significant cost savings.11	
British Heart Foundation	Full	54	General	It should be noted here that the identification of people with heart failure, as well as other conditions with an uncertain prognosis, may be more difficult and should be given special consideration. BHF pilots, however, have shown how those with heart failure at the end of life can be identified. The draft guideline notes that the identification of specific signs and symptoms will help clinicians identify those in their final days of life. Our Caring Together programme has shown that by assessing patients against certain criteria, including existing needs, Heart Failure Specialist Nurses **can identify a significant proportion of those in their final months of life.** [12] Referral criteria used in our Caring Together project were: • The patient has advanced heart failure[13]	Thank you for your comment. We note your comments in the specific symptoms for a number of conditions as being important to recognizing dying. We agree but have been keen to ensure that our recommendations enshrine the importance of gathering information on the person's medical history and the clinical context as part of this process. Our recommendations and the principles we outline are generic and relevant to all people who may be dying and are intended to be especially helpful to the less specialized practitioner. As such, no recommendations have been made specific to the needs of patients with heart failure

11 An integrated approach to managing heart failure in the community, British heart Foundation. Available hre: https://www.bhf.org.uk/~/media/files/publications/healthcare-and-innovations/an-integrated-approach-to-managing-heart-failure-in-the-community---sirhf1.pdf
[12] For further details see here: http://www.bhf.org.uk/get-involved/in-your-area/scotland/caring-together.aspx
[13] New York Heart Association Heart Failure classification categories III or IV

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				• The patient has distressing or debilitating symptoms despite optimal tolerated medical therapy • The patient has supportive or palliative care needs. Supplementary considerations include: • Increasing age (>75) [frail and elderly] • Co-morbidities (one or more) • Increasing symptom burden/symptomatic • Hospital admissions or requiring increased home visits in last year • Assessment for transplant/advanced specialist intervention • Question: "Would you be surprised if this patient died in the next year?"	
British Heart Foundation	Full	111	General	We welcome the priority given by the guideline to multidisciplinary working and shared decision making at the end of life. Multidisciplinary working across health and social care is vital to quality, person-centred care at the end of life for people with CVD. Large numbers of people dying from cardiovascular diseases have coexisting medical conditions and with an ageing population, this is set to increase. **Primary, secondary and out-of hours services**	Thank you for your comment.

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				and social care will all be required to work together to support people approaching the end of life. It is vital that not only physical health needs but also the spiritual, psychological and social needs of patients are considered and addressed at the end of life. The identification, recording and communication of patient and carer needs and preferences for care to all members of multidisciplinary teams is essential to maintaining patients in their preferred place of care. Yet, only 38% of people whose loved ones died from cardiovascular disease felt that community services worked well together where they spent some time at home in the last 3 months of their life; and only 29% of relatives of those who spent some time in hospital in their last 3 months felt the hospital worked well with other services.[14] The BHF Caring Together programme's approach works across the acute, community and out-of-hours care teams enabling the delivery of consistent and coordinated services to people with heart failure and their carers in all care settings in their last months of life.	

[14] National Survey of Bereaved People (VOICES), 2013, Statistical Bulletin, Office for National Statistics. Available at: http://www.ons.gov.uk/ons/dcp171778_370472.pdf

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British Heart Foundation	Full	86	General	We welcome the recognition that communication between clinicians and patients at the end of life is currently poor. Again, however, we believe that these vital conversations must happen much earlier than the last few days of life, to ensure patients receive quality care in the place of their choice. Whilst this varies greatly, the condition of some people with heart failure can deteriorate soon after diagnosis. Research by Marie Curie showed that some GPs found it difficult to raise and discuss death and dying with patients, particularly with patients with a non-cancer diagnosis.[15] Further research studies have explored GP communication with people with heart failure approaching the end of life. The studies found that: • End of life care is rarely discussed, with conversations focusing largely on disease management. • Clinicians are unsure how to discuss the uncertain prognosis and risk of sudden	Thank you for your comment. The committee agree that communication is crucial between healthcare professionals and those dying. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799 Thank you for submitting references for our consideration. We have carefully considered these and unfortunately they do not meet our inclusion criteria for any review questions.

[15] Zheng L, Finucane AM, Oxenham D, McLoughlin P, McCutcheon H, Murray SA. (2013) *How good is primary care at identifying patients who need palliative care? A mixed-methods study*

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				death, fearing they may cause premature alarm and destroy hope. • Clinicians wait for cues from people before raising end of life care issues.[16] The VOICES survey found that 30% of people whose loved ones died from cardiovascular disease felt that the patient definitely didn't know they were likely to die, compared to just 5% for cancer.[17] We believe that **all clinicians must undertake end of life care communication training which directly addresses communication with people with an uncertain prognosis.** The BHF have funded guidance to help anyone caring for someone with heart failure to open up conversations about their end of life wishes and preferences. 'Difficult Conversations for Heart Failure' was published by the National Council for Palliative Care in May 2014. Time to allow this discussion between people with heart failure and clinicians must also be provided. Time for such discussions is often provided to cancer patients but must also be facilitated for	

[16] National End of Life Care Intelligence Network (2013) *What we know now*
[17] National Survey of Bereaved People (VOICES), 2013, Statistical Bulletin, Office for National Statistics. Available at: http://www.ons.gov.uk/ons/dcp171778_370472.pdf

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				people with heart failure to ensure that they are given the opportunity to discuss options and preferences can be recorded.	
British Psychological Society		52	2	We are concerned that there is no applied psychology input noted. This may reflect systemic bias/limitation in that the GDG membership is weighted to medical.	Thank you for your comment. The developers are mindful of the need for ensuring that a broad range of experience and knowledge is represented on the Committee. This has to be balanced with the need to ensure that the guideline Committee is a workable size and as such enables individuals to contribute effectively. The constituency of the Committee was subject to public consultation before development of the guideline started.
				References Speck, P. (2006). Team Work in Palliative Care: Fulfilling or Frustrating? Oxford: Oxford University Press. Chochinov, H.M. (2005) Evidence the use of brevity in intervention and yet client-directed self-efficacy: Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients near the End of Life. J Clin Oncol: 235520-5525; European Association for Palliative Care, Task Force on education for psychologists in palliative care. European Journal of Palliative Care 2010;	Thank you for submitting these references for our consideration. We have carefully considered these and unfortunately they do not meet our inclusion criteria for any review questions.

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				17(2) Kasl-Godley, J.E, King, D.A., & Quill, T.E. (2014) Opportunities for Psychologists in Palliative Care: Working With Patients and Families Across the Disease Continuum. American Psychologist, 69(4), 364-376. Ellershaw, J., Dewar, S., & Murphy, D. (2010) Achieving a good death for all. British Medical Journal; 341:c4861; doi: http://dx.doi.org/10.1136/bmj.c4861 Hjermstad, M., Loge, J., & Kassa, S. (2004) Methods for assessment of cognitive failure and delirium in palliative care patients: implications for practice and research. Palliative Medicine; 18, 494-506, Barclay, S., & Maher, J. (2010), Having the difficult conversations about the end of life - BMJ 2010-341-c4862. Fenwick, P., Lovelace, H., & Brayne, S. (2010) Archives of Gerontology and Geriatrics. 51(2), 173–179 Rost, A. D., Wilson, K. G., Buchanan, E., Hildebrandt, M.J., & Mutch, D. (2012). Improving	

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				psychological adjustment among late-stage ovarian cancer patients: Examining the role of avoidance in treatment. Cognitive and Behavioral Practice, 19(4), 508-517 Feros, D., Lane, L., Ciarrochi, J., & Blackledge J. (2011) Acceptance and Commitment Therapy (ACT) for improving the lives of cancer patients. Psycho-Oncology. DOI: 10.1002/pon2083 National Institute for Health and Care Excellence. (2004). Improving Supportive and Palliative Care for Adults with Cancer. London: NICE. World Health Organisation (2006). The World Health Report 2006 – Working together for health. World Health Organisation, Geneva.	
	20	General		The Society has concerns that the recommendations for research are within the medical/physical domain. Psychological research has a significant contribution to the care of the dying individual. (Chochinov et al, 2008)	Thank you for submitting these references for our consideration. We have carefully considered these and unfortunately they do not meet our inclusion criteria for any review questions.Psychotherapeutic Interventions were not prioritised for review.
British Psychological	Full	General		The Society has significant concerns that applied psychologists are not identified as a member of	Thank you for your comment. Recruitment for guideline development Committee members is

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Society				either the development group; NCGC technical team; or as Co-optee. We believe that this overly medicalises the dying process and is at odds with current research and practice regarding the multi-professional approach to care of the dying adult. The often complex needs of people diagnosed with life threatening disease will vary greatly over time, and it is extremely difficult for just one professional to be able to provide adequate care. In order to ensure a holistic approach in meeting the health needs of individuals, the whole multiprofessional team need be involved (Speck, 2006; WHO, 2006). Indeed as noted in NICE (2004, p3), "Poor Inter professional communication and co-ordination can lead to suboptimal care."	advertised on the NICE website, and every effort is made to ensure the widest possible circulation to registered stakeholders, nationwide and profession wide. The Committee constituency is also consulted on and for this guideline, it was not considered necessary to recruit an applied psychologist as a full Committee member or as a co-optee. We are grateful for your representation at this stage of the development process. We believe we have taken a multiprofessional approach to the development of our recommendations Including appropriate sharing of information and that these apply to psychologists.
British Psychological Society		23	6	Care of the dying adult is based on holistic care. This would be inclusive of psychological and emotional needs. The valuable contribution of the applied psychologist in care of the dying individual is reviewed by (Kasl-Godley et al, 2014)	Thank you for your comment. We agree.that applied psychologists have a valuable role to play in this context. We believe we have taken a multiprofessional approach to the development of our recommendations, including appropriate sharing of information and that these apply to psychologists.
British Psychological Society		26	2	The Society believes excluding applied psychologists may be to the detriment of the dying adult; family and carers; and multiprofessional team support. Cf references for point 1, 5, and 7.	Thank you for your comment. The Committee constituency is consulted on and for this guideline, it was not considered necessary to recruit an applied psychologist as a full Committee member or as a co-optee. We believe we have taken a multiprofessional approach to the development of

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					our recommendations, including appropriate sharing of information and that these apply to psychologists.
British Psychological Society		65	2	Table 17 has an impoverished inclusion of sources for 'spiritual and psychosocial changes,' how people die remains in the memories of those who live on. See for example, (Ellershaw, Dewar, & Murphy, 2010)	Thank you for your comment. We have included all identified papers that met the inclusion criteria for this review. The paper you mention is a discussion paper (not a qualitative study) and therefore not included in the review.
British Psychological Society		81	1	The Society believes that it is unclear who assess 'psychological needs'… implication of 'reduced cognition' and capability. Hjermstad, presents a critical review of 22 studies and note, "Delirium is a psychiatric syndrome that is mainly seen by non-psychiatric clinicians, which might be one of the reasons that it is reported as misdiagnosed or overlooked in 32-67% of cases" (Hjermstad. M et al, 2004). This emphasises the need for highly specialised applied psychology professionals to be included in all stages of care of the dying adult.	Thank you for your comment. The Committee intend this recommendation to be for any healthcare professional delivering care to a dying person. They note that this does not exclude psychology clinicians. Recommendation 5is about seeking advice from colleagues with more experience and recommendation 3 is about gaining information from the multiprofessional team, both of which may involve clinical psychologists. Thank you for providing this reference. After careful consideration it was decided that this does not meet the inclusion criteria for any of our review protocols.
British Psychological Society	Full	12	9	As referred to in point 2 above, the Society welcomes that reference is made to psychological needs assessment but has concerns regarding who is trained to conduct this. In order to ensure that this	Thank you for your comment. The Committee intend this recommendation to be for any healthcare professional delivering care to a dying person. They note that this does not exclude psychology

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				undertaken appropriately specialist trained professionals in applied psychology.	clinicians. Recommendation.5 is about seeking advice from colleagues with more experience and recommendation 3 is about gaining information from the multiprofessional team, both of which may involve clinical psychologists.
British Psychological Society		85	1	The Society welcomes the valuable research that is identified here. However, we are very concerned by the lack of inclusion of applied psychologists in multi-professional teams and in the research.	Thank you for your comment. Although we have not made specific reference to psychologists, or any other specialty apart from palliative care, we consider they may be included in the multi-professional team.
British Psychological Society	Full	14	4	We would emphasise the need to include reference to applied psychologists as a source of 'specialist support.' This is reported in the European Association for Palliative Care, Task Force on education for psychologists in palliative care (2010).	Thank you for your comment. The Committee consider "specialist support" to include psychologists or any other specialty who are able because of their specialist experience to aid shared decision making.
British Psychological Society		108	1	The Society believes that clarification is needed on who assesses 'cognitive status'. Fenwick notes that the limited research into the end of life experiences of the dying individual. One recommendation from this article is the need for specialist training to identify and respond to such experiences. The applied psychologist, with this skill-set, would add value to the multiprofessional team and the dying adult, their family and carers. (Fenwick et al, 2009)	Thank you for your comment. The Committee consider that the points listed under 'establish communication needs' can be conducted by any healthcare professional delivering care. Further detail has been added to the full guideline 'Linking evidence to recommendations' section to state that simple assessments of cognitive status, such as orientation to time or place, could be conducted by any healthcare professional delivering care, without the need for specialist help.

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British Psychological Society		11	12	The Society believes that it needs to be made explicitly clear who is qualified to assess psychological needs as this is a specialised role. Psychological assessment in end of life care is not a 'one-off' event, it is a dynamic and fluid process over time and within a professional and therapeutic relationship managed by a highly skilled applied psychology professional within a speciality – this valuable role of the applied psychologist is not recognised in this document (Chochinov, 2005).	Thank you for your comment. The Committee consider that the points listed under 'gather information on' can be conducted by any healthcare professional delivering care. However, other members of the multiprofessional team or other specialist input may be sought, as detailed in recommendation 5 (where healthcare professionals are encouraged to seek advice from colleagues).
British Psychological Society		86	2	The Society recommends that the introduction includes the specialist input from applied psychologists in regards to communication between clinicians, relatives, carers, and the dying adult, as noted by: (Barclay & Maher, 2010)	Thank you for your comment. This is the general introduction to the communication introduction and we are unable to add any specific advice here.
British Psychological Society	Full	12	13	We believe that it needs to be made explicitly clear who will be responsible for communication needs, expectations of the dying adult and their cognitive status. This is an important role as the professional needs to be aware what the client wants. The Society believes that End of life care professionals need to be included in the process to consider not only the factual information provided to the dying individual, but also the emotional components of	Thank you for your comment. Further detail is given in the 'Linking evidence to recommendations' section of the full guideline. NICE is currently developing guidance in palliative care service delivery and the issue of staff roles may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link:

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				communication.	http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
British Psychological Society		186	20	The Society believes that clarification is needed on who 'psychological causes' of anxiety in the dying adult. The GDG note 'other considerations' and an inclusion of 'holistically' managing these symptoms (including psychological) which we believe lacks specificity and clarity. This may lead to unrealistic expectations placed on medical and nursing professionals. Some help in responding effectively to anxiety is reported in: (Rost et al, 2012)	Thank you for your comment. The Committee recognise that exploring the possible causes of anxiety or delirium are important and have given further detail in the 'Linking evidence to recommendations' section. We are unable to comment on specific psychological causes as an evidence review was not prioritised in this area, The Committee has made a recommendation to seek specialist advice if the diagnosis is uncertain as would expect this to include specialist psychologist input if appropriate. Thank you for submitting a reference, but unfortunately this does not meet the inclusion criteria for any of our reviews.
British Thoracic Society	Full	General		We have some concerns regarding the omission of end of life issues for people dying from respiratory disease. This is an extremely common scenario and it is a patient group who have often failed to receive adequate palliative care input despite significant symptom burden. 1) Page 8 (summary) – last para: this should include a third, unpredictable, trajectory of dying associated with COPD where patients may have had repeated exacerbations / recovery with	Thank you for your comment. The focus of this guideline is on the clinical care of the dying adult in the last 2-3 days of life. As such we believe that our recommendations apply across clinical conditions. 2) The factors reflected in recommendation 1.1.2 reflect the evidence considered and we do not consider it appropriate to add in the statement you provide. 3) The Committee has discussed ceilings of care in

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				uncertain prospect of recovery each time. 2) Recommendation 1.12 – the bullet list should include failure to improve/wean from non-invasive ventilation where this has been established as a ceiling of care. 3) We would welcome some explicit mention of ceilings of care, the possible use of NIV as a palliative intervention and issues around whether blood gas testing should be continued or stopped.	the 'Linking evidence to recommendations' section of this chapter.
British Thoracic Society	Full	General		Overall more explicit reference should be made to the time and resources needed to deliver quality care to people at the end of life as well as to the skills and knowledge needed.	Thank you for your comment. Each 'Linking evidence to recommendations' section in each chapter will capture impact of time and resources required to implement recommendations. NICE is currently developing guidance in palliative care service delivery and resources required to deliver quality care may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
British Thoracic Society	Full	173-174		Non-pharmacological approaches to breathlessness –should outline what non-pharmacologic approaches actually refers to. Physiotherapy may be helpful with sputum clearance. There is evidence to support the use of fans to relieve breathlessness. It is important that these as well as drug therapies are cited in the	Thank you for your comment. The Committee acknowledges the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific

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				recommendations given that the evidence base for the latter is weak.	examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
British Thoracic Society	Full	174		"breathlessness is not usually related to hypoxia" rather than "not always". We felt it would have been better for the GDG to have discussed fan therapy formally e.g. http://www.ncbi.nlm.nih.gov/pubmed/26262829	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
	259	3		Much work has been involved with sifting appropriate references to underpin this evidence-based guidance. However, the following notable, well-recognised sources are omitted: Craig G. (2004). Challenging Medical Ethics 1 No Water – No Life. Hydration in the Dying. Pegasus Print Ltd. An eminent writer, Dr Gillian Craig has written widely on the important subject of medical hydration for those unable to take fluid themselves but no reference is included…. Ross D, Alexander C .(2001) Management of Common Symptoms in Terminally Ill Patients: Part II. Constipation, Delirium and Dyspnea. Am Fam	Thank you for submitting these references for our consideration. We have carefully considered these and unfortunately they do not meet our inclusion criteria for any review. For the review questions on clinically assisted hydration our protocol specifies comparative studies only, such as randomised controlled trials. We are unable to include discussion papers or editorials.

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				Physician. 2001 Sep 15;64(6):1019-1027. (This paper is also not included which contains 3 important sources below, none of which are included in the total references listed by NICE): Lawlor PG, Gagnon B, Mancini IL, Pereira JL, Hanson J, Suarez-Almazor ME, et al. Occurrence, causes, and outcome of delirium in patients with advanced cancer: a prospective study. Arch Intern Med. 2000;160:786–94. Inouye SK. Prevention of delirium in hospitalized older patients: risk factors and targeted intervention strategies. Ann Med. 2000;32:257–63. Shirreffs SM, Merson SJ, Fraser SM, Archer DT; Merson; Fraser; Archer (June 2004). "The effects of fluid restriction on hydration status and subjective feelings in man". Br. J. Nutr. 91 (6): 951–8. doi:10.1079/BJN20041149. PMID 15182398 One other important reference not included in the Draft guidance: 6. Lo B, Rubenfeld G. Palliative sedation in dying patients: "we turn to it when everything else hasn't worked". JAMA 2005 Oct 12;294(14):1810-6. NB. This essential maxim needs to be given much more focus, relating to the sedationpractice within this guidance	
CAMPAI				Patients, their loved ones and their health	Thank you for your comment. The commissioned

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GN FOR BETTER END OF LIFE CARE				professionals warrant clear, unambiguous and humane guidance to ensure: 1. Health professionals are accountable for the care they give with the support of clear guidance and evidence based medicine. 2. The focus throughout this guidance needs to be holistic. Problems that appear to be physical should be managed ethically and holistically and start with thorough assessment of the patient so as to do them no harm. 3. The terrible experiences of the LCP for both patients and their families should be replaced with humane management and care of all patients in need of palliative care. This should not be confined to the last few hours or days of life but should start much earlier in the patient's journey as the diagnosis and evidence-based treatment options become apparent.	remit of this guideline was to address the clinical care of the dying adult in the last days of life. The Committee agree that holistic care is important across a time frame from diagnosis to death. We believe that within the remit of our work, we have made clear references to the need to manage care with due consideration of the holistic (physiological, social, spiritual and psychological) needs of the dying person and those important to them.
CAMPAIGN FOR BETTER END OF LIFE				Inappropriate, thus unethical sedation practice will disallow the important issue of spiritual needs to be met which nurses want and need to address, together with relevant members of the team. The importance of spiritual care applies whether patients	Thank you for your comment. We agree. The Committee has gone to great length to elicit the importance of appropriate sedation and have made a number of recommendations that support the dying person's preferences (1.5.3), appropriate

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CARE				are imminently dying or not. Therefore, the need for caution with sedation is important in line with this aspect of holistic care required by patients. Spiritual needs cannot be met if patients are routinely and inappropriately sedated to death. Spiritual well-being is a concept, well recognised for its importance by the NHS and is incorporated in NHS guidance for professionals and patients. The Nursing and Midwifery Council expects nurses to be able: "In partnership with the person, their carers and their families, to make holistic, person centred and systematic assessments of physical, emotional, psychological, social, cultural and spiritual needs, including risk, and develop a comprehensive, personalised plan of nursing care" (NMC 2009). In 2010, the RCN commissioned an on line survey on spirituality and spiritual care in nursing practice. http://www.rcn.org.uk/__data/assets/pdf_file/0017/391112/003861.pdf This guidance needs to reflect what nurses taking part in the survey considered important: education and guidance about spiritual care, clarification about personal and professional boundaries and support in dealing with spiritual issues. One of the respondents summarised the role of the health professional in relation to spiritual needs of I believe that spiritual care is not only an essential component of nursing practice but often	titration of medications used for symptom management (1.5.7) and the avoidance of undesirable effects of medications such as unwanted sedation. We have also made a number of recommendations which encourage the multiprofessional team to consider the broader holistic needs of the dying person when planning care. Further details of the Committee's discussions in this area are provided in the 'Linking evidence to recommendations' sections in the full guideline.

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				the arbiter of how a patient responds to their illness and life experiences. It would appear that when people encounter certain life events like serious trauma and illness, fundamental spiritual issues often emerge that question their very existence".... Such need for spiritual support as part of expected, holistic care by health professionals may be denied patients if the healthcare team are solely concerned with the need for extreme sedation in the last stage of life. Such inappropriate practice, as so often occurred with the LCP, is a serious breach of the duty of care.	
CAMPAIGN FOR BETTER END OF LIFE CARE		111	3	A distinct set of guidance with a sub set (for adults in the last days of life) is unnecessary as good Palliative Care Guidance would include an individualised approach to each patient from prognosis to death during which trajectory, these points may be more appropriate, sensitive and applicable. At this stage of imminently dying, appropriate care for symptoms would, no doubt, be welcomed by any patients and their family. No right-thinking health professional would give inappropriate care. Health professionals need to be thoroughly aware of the needs of their patients without burdening them with wholly inappropriate questions at so sensitive a time (ie. last days of life).	Thank you for participating in the consultation process. We agree with your comment.

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CAMPAIGN FOR BETTER END OF LIFE CARE	Full	54	26	The Neuberger review of the Liverpool Care Pathway: More Care Less Pathway (2013) states: *'End of life' can mean any period between the last year of life of a person with a chronic and progressive disease to the last hours or days of life. Unless this lack of clarity is addressed, there is the very real risk that a person deemed to be at the 'end of their life' may be placed onto the LCP too early'* (More Care Less Pathway 2013). Therefore, this warning needs to be heeded for this guidance which must ensure clarity on this last point. Health professionals must be attentive to all aspects of care requirements and never again deem patients to be imminently dying (days only) when it is not clear and then justify management decisions on a false premise, as occurred with the use of the LCP. Even patients truly being in the last days of life do not necessarily warrant the use of such a pathway as a non-individualised management approach.	Thank you for your comment. The remit of this guideline is last days of life (see section 4.24.1) and we are unable to provide guidance outside of this time period. We agree that recognising dying is a challenge, as stated throughout the chapter. The Committee purposefully drafted recommendations that advocate an individualised approach to assessment and management and care avoiding the suggestion of a 'tick box, pathway' approach as you have outlined. The recommendations are intended to help minimise uncertainty with the caveat to seek specialist advice when/if needed.

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				The LCP was put into place across the country without a clear plan for its ethical implementation. The criteria listed for 'dying' in this guidance are too reminiscent of the demised LCP's vague criteria. Therefore, the scope of this guidance should not be addressed to the 'last days of life'. Patients being considered as in the last *days* of life may receive less care, attention and review, particularly when we know that it is universally-recognised that prognosis of dying is notoriously difficult. Self- fullfilling prophecies are an abiding danger when days left can so often be solely supposition. Days can give way to many weeks months or years as seen in the criticisms of the use of the LCP.	
CAMPAIGN FOR BETTER END OF LIFE CARE		6	3	What happens if the ACP is only known by some families and not shared. Although being prepared for urgent need seems sensible, often this is not a realistic plan. There will always be a need for additional/ represcription. Such prescribing can be a dangerous practice. Nurses must remember that the Nursing and Midwifery Council expects nurses to act as patient advocates and to be evidence-based in their practice. Carrying out any inappropriate orders, renders nurses unethical practitioners, answerable to the patient, relatives and their	Thank you for your comment. We understand that the ACP might not be known of, but feel that it should be attempted to be identified. We feel that a number of our recommendations identify the need to review the dying person's wishes in the last days of life particularly recommendation 2.3.7.

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				registration body.	
CAMPAIGN FOR BETTER END OF LIFE CARE		7	27	We are concerned that the MDT might incur some shift changes and that these MDT's become different to the earlier MDT in which case how do changes get through to them and where is this documented? Not all patients will have been in Oncology settings which is why Palliative Care experts are not necessarily the only ones to be able to help the patient with perhaps a multiplicity of problems. The members of relevant specialist teams need to be consulted for particular advice and expertise and not just at time of prognosis as seems to be suggested by this guidance. 'Last days' can often mean weeks or months and new problems can arise which can be outside the scope of Palliative Care Specialists	Thank you for your comment. The members of the multiprofessional team will vary according to patient need, healthcare setting and across Trusts. The guideline has been drafted with the remit of the last few days of life (2 – 3 days, see section 4.2.4.1 of the full guideline) and we have written guidelines that seek to ensure that the broadest multiprofessional team are engaged. Recommendation 2.3.6 describes the need to document decisions and share that information across the team. We believe that this should address any change in the multidisciplinary team that you refer to
CAMPAIGN FOR BETTER END OF LIFE CARE		6	1	The major concerns of families involved with the LCP was the lack of contact with the consultant/doctor and this should be changed to reflect this	Thank you for your comment. The Committee agrees and have addressed this in the recommendations on Shared Decision Making, where healthcare professionals have been encouraged to identify a named lead healthcare professional responsible for encouraging shared decision making and this includes providing information about how that lead person can be contacted.
CAMPAIGN FOR BETTER END OF		7	4	We are concerned that the named lead healthcare professional might not be the same person as the Multi Disciplinary team member	Thank you for your comment. The named lead healthcare professional is a member of the multiprofessional team responsible for the care of the dying person.

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LIFE CARE					
CAMPAIGN FOR BETTER END OF LIFE CARE	Short	5	17	We are concerned that the "Most Available" Multi Disciplinary team member might be a junior doctor or one who does not know the patient as well as their consultant/doctor	Thank you for your comment. The Committee agrees that this is an important issue and have sought to address this in its communication recommendations. As the multidisciplinary team would vary according to patient need, care setting and across Trusts, the Committee thought it best to recommend that 'the most appropriate available' multiprofessional team member be identified to explain the dying person's prognosis. It has also been recommended that the multiprofessional team should be supported by experienced staff at all times and have the ability to seek further specialist advice if additional support is required.
CAMPAIGN FOR BETTER END OF LIFE CARE		108	1	6.6 Recommendations and link to evidence 10. Explore with the dying person and those important to them: □ whether the dying person has an Advance Care Plan or has stated preferences about their care in the last days of life (including any anticipatory prescribing decisions or advance decisions to refuse specific treatments) □ whether the dying person has understood and can remember the information given about their prognosis. The above appears unecessary if the patient is so close to death (within days). It appears inappropriate and insensitive when at such a stage, a patient	Thank you for your comment. Although the remit of the guideline is last days of life, the Committee do consider these recommendations valid prior to this time point and would hope they are implemented as early as possible, as discussed in the full version 'Linking evidence to recommendations' section.

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				should be allowed peace and trust in the skill and good will of their health professionals in particlar relation to hydration needs. Palliative care should not be confined to the last few days of life but should ideally have started much earlier during the patient's journey e.g. when the diagnosis of cancer is being made. It is not good practice to be discussing the diagnosis and outlook only in the last few days of life unless, of course, it was not possible to know of the patient's diagnosis or prognosis before then, as is sometimes the case.	
CAMPAIGN FOR BETTER END OF LIFE CARE	full	150	1	A more practical approach to hydration is needed rather than a risk averse approach with over focus on the possible burdens rather than possible benefits. We know that the experience of the LCP audits revealed only a minimal percentage of patients had their hydration needs addressed. *1.4.6 "Death is unlikely to be hastened by not having clinically-assisted hydration".* This is a questionable statement in view of the fact that diagnosing of dying is so difficult. Long term dehydration is not a good or compassionate death. This is not just guidance for oncology patients who are perhaps more obviously dying. Dying people do eat and drink!	The Committee has amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether clinically assisted hydration will prolong life or the dying process or hastens death if it is not given. The order of the recommendations reflects the Committee's decision that the dying person should be supported to drink by oral means first if they wish and are able to before clinically assisted hydration is considered.

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				The General Medical Council Guidance (GMC 2002) provided guidance on the provision of artificial nutrition or hydration in patients who are not imminently dying: "*Where death is not imminent, circumstances may arise where you judge the patient's condition is so severe and the prognosis so poor, that providing artificial nutrition or hydration may cause suffering or be too burdensome in relation to the possible benefits"*. This guidance was criticised in 2004 by Mr Justice Munby as it failed to recognise the heavy presumption in favour of life (Craig 2004). The Draft guidance has not given a specific focus to patients with dysphagia or weak patients who are unable to take oral fluids or nutrition. Oral feeding may well be impractical, unsafe or impossible and clear guidance must address this point. The guidance questions the effectiveness of oral hydration. A more appropriate question should include the feasibility of weak, elderly or dysphagic patients being able to take oral hydration and if not, the guidance should specifiically address this point. Moreover, suggestions for family members to help patients with oral feeding where safe to do so,	Nutrition is beyond the remit and scope of this guideline. . NICE is currently developing guidance in palliative care service delivery and the issue of education and training may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799. Thank you for providing these references. After careful review we are unable to include them as they do not meet the inclusion criteria for any evidence review.

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				presupposes the family is available to all vulnerable patients. Therefore, compassion dictates that in many cases where oral hydration may not suffice, contingency plans need to be included where oral means for sustenance are not possible. Reference to training for staff competence in feeding all patients in need should be made. The possibility of subcutaneous hydration for dying patients has been advocated in the past by Baroness Finlay, an eminent Professor of Palliative Medicine and President of the BMA. All competent health professionals will know how to adjust the hydration needs of their patients for comfort and safety. In view of the above points and in terms of prognosis difficulties, assisted food and fluids needs urgent renewed focus to ensure humane approaches to this basic human need. *Biological consequences of dehydration* Research on animals, volunteers, older people and advanced cancer patients shows acute dehydration leads to malaise, headache and contributes to myoclonus and sedation (Shirreffs	

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				et al, 2004) a reference not included in the guidance.	
CAMPAIGN FOR BETTER END OF LIFE CARE		8	12	Where are the checks done to see whether the person can swallow?	Thank you for your comment. Swallowing is one factors to be considered and we have included this in rec 2.4.1. This recommendation also states to Discuss the risks and benefits of drinking with the dying person, the multiprofessional team and others involved in the care of the dying person. Further discussion on this issue can be found in section 8.6 of the full guideline.
CAMPAIGN FOR BETTER END OF LIFE CARE		8	24	Who is going to give advice to the family members to help with mouth care and how will this be checked on by the professionals?	Thank you for your comment. This recommendation is for any healthcare professional delivering NHS care and we feel this should be covered as a basic nursing or care skill.
CAMPAIGN FOR BETTER END OF LIFE CARE		9	8	Who is going to advise families about clinical hydration?	Thank you for your comment. This recommendation is for anyone delivering care.in settings where NHS care is provided.
CAMPAIGN FOR BETTER END OF LIFE		189	3	Much effort has been made to appropriate evidence throughout the guidance. However the following needs consideration from an American paper (Ross D, Alexander C. 2001) a reference also not mentioned in the guidance. They include the	Thank you for your comment and suggestions. We have reviewed the papers you have highlighted and unfortunately none meet the inclusion criteria for our review questions. The paper by Alexander C. 2001 does Lawlor et al 2000 and Inouye 2000, were

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CARE				following from work of authors also not listed within the NICE guidance: as follows: : "A study by Lawlor et al (2000) importantly found that delirium was reversible in approximately 50 percent of dying patients. In this study, opioids, psychoactive medications and dehydration were the most frequent causes of reversible delirium. In addition to reducing risk factors for delirium, the physician may be able to prevent its onset in an elderly patient by avoiding five precipitating conditions: the use of physical restraints, malnutrition, the additionof more than three new medications in one day, the use of bladder catheterization, and iatrogenic events such as frequent room or staff changes or a disruptive environment with excess noise that may disrupt sleep" (Ross, Alexander 2001). Another study by Inouye (2000), a reference also not included in the guidance, identified factors associated with an increased risk of delirium in patients older than 80 years. One of the risk factors included dehydration (blood urea nitrogen level higher than 18 mg per dL [6.5 mmol per L]). All suggested, additional references are documented in point J.	excluded due to the use of prospective cohort study design, which was also an exclusion criteria in this evidence review. The Committee recognise the importance of identifying the cause of the delirium and whilst evidence was not identified for inclusion in the systematic review, the Committee chose to make a consensus recommendation 1.5.24 to highlight this.
CAMPAIGN FOR BETTER END OF	Full	158	3	*"Consider using a syringe pump to deliver medications for continuous symptom control if more than 2 or 3 doses of any 'as required' medication is needed within 24 hours".*	Thank you for your comment. The Committee recognised concerns that were raised in the Neuberger review when drafting the recommendations in this guideline.

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LIFE CARE				The guidance recommends Midazolam (unlicensed for syringe driver use) as a sedative. In my professional experience, the imminently dying process does not necessarily require extremely strong sedative intervention such as this drug used on a continuous basis. ◦ Relatives upset by overmedication of their loved ones on the LCP, report incomprehension as to why, when having been walking and talking and certainly not suffering from delirium or psychosis, their loved one was suddenly unresponsive, never to regain consiousness due to extremely strong sedation with LCP practice. This possible scenario must never be normalised again as it was by use of the LCP. It can render patients unnecessarily comatose denying them the opportunity for holistic care needs to be met, e.g. spiritual needs, addressing unfinished business and saying goodbyes. This consequence was a very serious criticism of the LCP in the Neuberger Review**Antimuscarinics** A more appropriate method to a '24 hour starting dose' can be by an 'as required' approach via sub cutaneous cannula administration. This can prevent over-drying of the patient with subsequent distress,	Recommendation 1.5.2 addresses these concerns, advising clinicians to involve the dying adult and those important to them in making decisions about symptom control in the last days of life and advises that harms of any medication offered be discussed with them. Recommendation 1.5.6 advises clinicians to consider a syringe pump to deliver medications for continuous symptom control if more than 2 or 3 doses of any as required medication is needed within 24 hours. In addition the routine regular assessment of unwanted side effects is advised in the prescription of antimuscarinics for noisy respiratory secretions to avoid the clinical scenario you describe. Drugs for symptoms other than pain, breathlessness, anxiety agitation and delirium, nausea and vomiting and noisy respiratory secretions are out of the scope of this guideline. The Committee recognise that many of these symptoms may be caused by reversible conditions and have made recommendations 1.5.10, 1.5.15, 1.5.21,1.5.25 and 1.5.31 to advise that these causes be treated where possible.

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				leading inevitably, to chest infections. This is feasible and more appropriate rather than used as part of continuous syringe driver drug combination (hyoscine infusions are not licensed) as was common in use of the LCP (most often without hydration). This ensures that patients are not rendered uncomfortably dehydrated for long periods. The combination of a dry mouth in an already dehydrated patient must be intolerable for any conscious patient, producing the degree of desiccation of the mucous membranes that was common on the LCP. • ***Other drugs*** Drugs for comfort to manage distressing symptoms should not be overlooked such as antibiotics for symptom relief. Again, strict emphasis of the guidance for the last days of life will deny patients this often pain-relieving treatment option together with any other drugs that can provide comfort, though not cure. Health professionals need to be inventive and evidence based in their approach to all patients rather than relying on a disastrous, blanket approach at this time of a patient's life as occurred with the LCP use.	
CAMPAI	Short	16	1	Concerns remain high about anticipatory prescribing	Thank you for your comment. We have given

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GN FOR BETTER END OF LIFE CARE				of drugs seeing as this was a huge criticism of the LCP	guidance based on evidence review and Committee consensus and recommended an individualised approach to anticipatory prescribing avoiding a 'blanket' approach.
CAMPAIGN FOR BETTER END OF LIFE CARE	Short	16	12	Is there a conflict between line 1 and this line as one refers to individualised approach and the other refers to what "might" be required	Thank you for your comment. We do not see a conflict and consider they complement each other. We state assess what each individual might need and then encourage an individualised approach to prescribing.
CAMPAIGN FOR BETTER END OF LIFE CARE		18	16	There is a concern that specialists do not have end of life care experience and this guide is aimed at them as a cop-out for proper training	Thank you for your comment the content of which is noted in relation to the introductory text. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
CAMPAIGN FOR BETTER END OF LIFE CARE	Short	10	19	What happens if a loved one has to have heart meds/diabetic meds etc essential to keep them going, does this not feature still?	Thank you for your comment. The Committee recognises this as an important issue, and so, have drafted recommendations which encourage clinicians to assess drugs prescribed to the dying person. The Committee also considered it important to discuss this with the dying person and those important to them before rationalising medication and explain which medications are not providing

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					symptomatic relief. The group also stressed the importance of respecting the wishes of the dying person, if they should want to continue the use of regularly prescribed drugs. These discussions and considerations are reflected in the 'Linking evidence to recommendations' tables in chapter 9.
CAMPAIGN FOR BETTER END OF LIFE CARE	Implementation			Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. I believe that the whole concept of being able to identify a dying patient remains the most challenging and difficult to implement through lack of training and inexpert staff. However implementing better communication will also have the biggest impact on practice but this relies heavily on the medical professionals being able to overcome the embarrassment of being able to talk freely. They need to become more human! What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.

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				good practice.) Being able to see excellent examples of good communication taking place and regular practising sessions to ensure staff are comfortable with being able to give good news or bad news.	
Carers Trust	short	14	14	Maybe add consultation with the carer or person close about signs of pain changes etc, as they are experts by experience. This would be especially helpful with dementia patients or those with Learning disabilities	Thank you for your comment. We have added additional detail to the full guideline 'Linking evidence to recommendations' section to highlight this.
Catholic Medical Association (UK).	Equality Impact assessment			We are concerned about several issues missing from the Equality Impact Assessment which can affect clinical practice Vulnerable people and people with cognitive impairment We commend the GDG for having carefully thought through issues around dementia. But other groups such as those with learning disabilities, very frail patients and those with other forms of cognitive impairment are also vulnerable. We think Equality Impact Assessment needs to be enlarged to include specific reference to these groups and to state how	Thank you for your comment. We acknowledge the needs of those with learning disabilities and the needs of the frail elderly in a number of our discussion areas in the full guideline. We do not feel that additional recommendations are required to support the needs of these groups but have added them to our equality Impact Assessment Form We agree that the needs of those who are dying alone with no family or friend in support requires addressing and we have added further detail in the 'Linking evidence to recommendations' section in Chapter 7 of the full guideline.

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				the risks are to be mitigated. Once again, this requires strong clinical leadership to ensure the needs of these patients are met appropriately and sensitively. Patients with no family members or advocates Those with no family members, attorneys or advocates are at greatest risk as they die. The guidelines recommendation of the anticipatory use of potent sedatives before symptoms merit their use means that those who are weak, alone or frail may well be at increased risk of poor care, over sedation and death by dehydration as was seen so often with the LCP. The guidance needs to consider how to safeguard against this, so that people can be comfortable but also prepare appropriately for death, whilst not being unduly deprived of consciousness. Senior second opinion in cases with doubt When families fear or question a prognosis of imminent death or are concerned about poor care a senior second opinion can be very helpful. Mental Capacity Act There needs to be clear reference to where the Mental Capacity Act applies and must be	We believe that we have made clear recommendations linked to the issue of the use of potent sedatives. The Committee has gone to great length to elicit the importance of appropriate sedation and have made a number of recommendations that support the dying person's preferences (1.5.3), appropriate titration of medications used for symptom management (1.5.7) and the avoidance of undesirable effects of medications such as unwanted sedation (1.5.9). We acknowledge your point regarding a second opinion but do not believe any additions to our guidance are required. Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at:

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				considered by clinicians. This should include guidance about seeking second opinions and assuring that treatment decisions are taken at an adequately senior level . The GDG should also make it clear that it is important to make positive enquires as to whether the patient has appointed an attorney who may have the legal powers to make decisions for the patient .	www.nice.org.uk/guidance/indevelopment/gid-ng10009. Recommendation 1.1.5 outlines circumstances when seeking advice from more senior colleagues may be relevant.
Catholic Medical Association (UK).	FULL	General	General	EXECUTIVE SUMMARY We welcome this opportunity to contribute to the consultation on the draft NICE guidelines on the care of the dying adult and would like to start by summarising our overall position. • One of our main concerns is that the guideline focuses upon the belief that the diagnosis of dying can be accurately and safely made. Prognosis is particularly difficult in non malignant conditions such as heart and respiratory failure and dementia. • Palliative care should be based on the patient's needs rather than the perceived prognosis which is at best a subjective judgment. • Patient management should be holistic and address the medical, psychological and spiritual needs of the patient. • Palliative treatment should be evidence-based wherever possible. Further research is clearly	Thank you for your comment. We deal with each in turn. • We disagree. We inherently recognize the uncertainty in diagnosing dying. A number of our recommendations reflect this by encouraging monitoring and re-assessment in case of stabilization or recovery. • We agree and our recommendations reflect a need to involve the dying person in communicating and making decisions about their care. • We agree and a number of our recommendations make reference to the importance of considering the holistic needs of dying people linked to physiological, social, spiritual and psychological needs. • We agree. This guideline and the consequent recommendations have been made following a systematic review of the evidence in a number of areas of relevance to the clinical care of the dying adult.

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				needed and should be compared to best available practice. • The focus of palliative care should be the relief of symptoms and where possible should include the restoration of mental and physical function and psychological and spiritual wellbeing. • Good communication with the patient is fundamental to all clinical practice. • Discussion of the patient's condition and treatment with relatives should not be a substitute for dealing with the patient directly. Communication with relatives and carers is especially important in the care of the dying. However, this should always be done in a timely manner and with the consent of the patient unless the patient lacks capacity. • Good palliative care requires good communication and timely intervention. It must start early as the patient's condition and circumstances become clearer and should not be confined to the few last remaining days of life. • Consent to treatment is necessary in palliative care as in other fields of medicine and should always be sought in a timely fashion where the patient has capacity regarding the diagnosis and treatment of their condition throughout the patient journey and not just in the last few days of life. This is particularly true of palliative care where the needs and wishes of patients should	• We agree. Chapter 9 of the full guideline details the evidence reviewed linked to pharmacological management of symptoms. • We agree. All of our recommendations prioritize discussion primarily with the dying person although recognizing that it may be appropriate to involve those important to them. • We agree. We have made a number of recommendations linked to effective communication in this time period. • We agree. Please see chapter 7 of the full guideline for more information on shared decision making. • We agree that the care of the dying adult should be provided by those with experience. We recommend that where professionals are uncertain about how to recognize dying or manage symptoms, they refer to more experienced staff promptly. • We agree. Our guideline makes recommendations about the development and sharing of care plans. We recommend seeking specialist advice in case of need for additional support. • The RCP undertakes an annual audit of end of life care and we would hope that that audit if funded further would measure implementation against our recommendations. • We agree. Whilst nutrition has been outside of the scope of this guideline, we have made a

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				be actively determined before the patient looses capacity as a result of the underlying condition or treatment. • The responsibility for patient care normally rests with the Consultant or General Practitioner. The overall responsibility for palliative care should not rest with unsupervised junior doctors. • Treatment plans should be endorsed by senior medical personnel who should be available for further help and advice as the patient's condition changes. • There should be regular audit of the care of the dying which takes into account medical treatment, nursing care, spiritual support and the concerns of relatives and carers • Hydration and nutrition should not be withheld or withdrawn with the intention and purpose of bringing about the death of the patient. This is both unethical and unlawful. • There should not be financial incentives and targets for placing patients on an 'end-of- life' pathway.. • There should be appropriate funding made available for training of healthcare professionals in palliative care. • It is particularly important that healthcare professionals attend to the spiritual needs of the dying and help to arrange the appropriate pastoral care.	number of recommendations around marinating hydration in the last days of life. • We agree but financial incentives have not been discussed in the context of this guideline. • We agree about the importance of effective training. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799 • We agree. We have made a number of recommendations where the care provider is encouraged to attend to the spiritual needs of the dying person. We were supported in this discussion by a co-opted expert advisor in spiritual care.

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Catholic Medical Association (UK).	FULL Appendix E Appendix J	P 54-85 P75 P234		**5. RECOGNISING WHEN A PERSON IS IN THE LAST DAYS OF LIFE** **Assessment of prognosis: paucity of available and reliable data.** There are a number of problems inherent in assessing prognosis. The most obvious is the paucity of studies. Of the 7 studies reviewed by the GDG, 4 papers were written by the same two groups of investigators (Chiang et al (2009) and Kao et al (2009) and Loektio et al 2013. The Loekito papers were excluded as they involved laboratory parameters in large numbers of patients (n=47,701 and n = 71,453) admitted as emergencies to hospital. The Matsunuma (2014) paper was regarded as being of low quality and looked at mortality within 14 days. Only the Hui (2014) paper looked specifically at mortality within the last 3 days of life . The Chiang and Kao studies looked at mortality at 1 week. Of 102 full text articles assessed for eligibility only 5 were selected for analysis. (Appendix E. P 75). There were no GRADE scores for any of the studies (Appendix J GRADE scores p 234). The available evidence is therefore limited to studies in selected groups of known cancer patients admitted to palliative care units and undergoing palliative care	Thank you for your comment. We agree that there is limited evidence identified in this area and that the evidence identified was of low to moderate quality, as detailed in the evidence statements in the full guideline. Please note that quality assessment of diagnostic and prognostic studies was conducted using QUADAS-2 and the NICE checklist for prognostic studies, respectively. These are detailed in the methods section and within tables in the chapter on recognising dying. As GRADE is only appropriate for intervention studies it was not applied to these studies. Detail of the specific populations of the studies has also been provided in the quality if evidence section. Prognostic scores were not prioritised for this review, with the Committee deciding to focus on individual prognostic factors. The Committee were aware of the limited evidence and as such conducted a mixed methods review to also capture qualitative evidence. Functional observations have been discussed within the 'Linking evidence to recommendations' sections of the full guideline. The Committee agree that recognising dying is difficult and have discussed this within the introduction to the chapter and in the 'Linking evidence to recommendations' section and note the importance of using clinical judgement and seeking

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				treatment which may be expected to alter the profile of the prognostic factors under review. The pathophysiology of dying may be very different in different malignant diseases compared to non-malignant conditions. For example respiratory parameters are more likely to be important in those with lung cancer, compared with ascites, jaundice and hyoalbuminaemia in those with gastrointestinal malignancy. None of the studies involved patients with chronic non-malignant conditions such as motor neurone diseases, heart failure or dementia. Nevertheless, the NICE guidelines are recommended for a variety of malignant and non-malignant conditions including dementia. There are now over thirty prognostic scales or screening tools for predicting the risk of death in a variety of settings which depend on laboratory parameters, clinical observations and judgment to varying extents. The best known are perhaps the Karnofsky Performance Score (KPS); Acute Physiology and Chronic Disease Evaluation or ;APACHE scores, Palliative Performance Scale, various Early Warning Scores, Rothman Index and the Palliative Prognostic Index. None of these were specifically evaluated by the GDG group, although the Chiang paper examined the Eastern Cooperative Oncology Group scale. There are also important speciality specific scores such as the Rokall Score	advice when appropriate. We have been keen to ensure that people are reviewed regularly to re-assess condition and that this information is shared with the team providing care so that appropriate management can be initiated. The Committee considered treatment when a person is dying would be different, but that symptom control is always the priority. We note your comments in the specific symptoms for a number of conditions as being important to recognizing dying. We agree but have been keen to ensure that our recommendations enshrine the importance of gathering information on the person's medical history and the clinical context as part of this process. Our recommendations and the principles we outline are relevant to all people who may be dying and are intended to be especially helpful to the less specialized practitioner. Thank you for providing references. After careful consideration it was decided that they do not meet the inclusion criteria for any of our review protocols.

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				for upper gastrointestinal bleeding which are not included in the draft guidelines. **Inherent difficulties in the use of prognostic indicators.** There are a number of inherent difficulties with the use of prognostic indicators: First, Prognostic tools apply to group statistics and do not take into account inter-individual variability. Generally, the extrapolation of group statistics to individuals introduces a further element of bias and subjectivity. Second, whilst the number of prognostic factors will increase in any individual as death approaches (as shown by the Hui study), not all patients will develop prognostically significant signs or symptoms. Moreover, patients may die suddenly for example from an unexpected pulmonary embolus. Third, whilst the emphasis in the report has been on attempting to identify those likely to die within 3 days, there will be both false positives – those thought likely to die who would not in fact die within 3 days and false negatives – those who will in fact die but do not have the relevant prognostic signs. If treatment is predicated on prognosis it will be given	

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				to those who are falsely thought to be dying and might exclude those who are in fact dying but have not been identified using the prognostic tool. Fourth, there are problems with extrapolation of group statistics to individual cases and a failure to recognise inter-individual variation[18]. There was no attempt by the GDG to estimate inter-individual variation and to prospectively evaluate the accuracy of the timing of death. Fifth, there is a need to take into account not only individual variation but also disease trajectories. The value and danger of prognostic tools is they rely on the presence or absence of what are considered to be prognostically relevant factors to predict future outcomes. In practice, knowing the trajectory of different diseases and the changing condition of the patient are important in predicting the likely outcomes for individual patients. Sixth, it is important to separate the natural history of disease from the effects of treatment on disease progression. No attempt was make to estimate the effects of treatment even when the patients were	

[18] See for example, Brabrand M, Folkestad L, Clausen NG, et al. Risk scoring systems for adults admitted to the emergency department: a systematic review. Scand J Trauma Resusc Emerg Med 2010;18:1–8.

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				undergoing intensive palliative care treatment. This is particularly true of the effects of opiates and sedation on respiratory parameters, consciousness and oral intake. Seventh, the reliability of any diagnostic tool needs to be evaluated prospectively for different healthcare professionals in different settings. For example are nurses more or less reliable than doctors, or generalists more accurate than specialists? There is very little evidence about the accuracy of predicting death in the last 3 days of life which was the focus of the GDG review and only the Hui (2014) study specifically examined mortality within this time frame. **Basing treatment upon need and not prognosis.** One of our greatest worries is that the guideline still focuses upon the belief that the diagnosis of dying can be accurately and safely made. It is very clear that this is difficult with evidence that the diagnosis of dying is especially difficult in dementia, heart failure and respiratory failure. The guideline therefore unquestioningly replicates one of the key failings of the Liverpool Care Pathway and suggests to clinicians that they can accurately and reliably make a diagnosis that someone is dying.	

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				The GDG might wish to amend the content of this section and we would suggest the following text: *Clinicians must therefore be aware that if a possible or likely death is predicted, then the care that is provided must be based both upon the palliation of symptoms and provision of appropriate care. Medical treatment and personal care should be based on a careful clinical assessment and tailored to the individual needs of the patient.. Treatment is not indicated simply because someone is thought likely to die n the next few days* The guidance in this section should flow from the overarching principle that treatment should be based upon need and not prognosis. Palliative care should be based upon the relief of symptoms and the needs of the individual patient and not merely on the premise that the clinician thinks someone is dying. We advise that the GDG should state clearly that the diagnosis of dying is inaccurate. The safest course in terms of patient outcome and the available evidence is that palliative care should be based upon need and not prognosis	
Catholic Medical Associati	Short Guideline	P8	1.3.9	**Spiritual and holistic care** In our experience, families will usually want to see	Thank you for your comment. The Committee are aware of spiritual needs and have recognised this under rec 1.3.2. Spiritual and holistic care are

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on (UK).				that people die in a way that is compatible with their life-long faith. For example, many will have specific hopes that sacraments, prayers or other rituals will be offered as they are dying. The spiritual care of the dying person is crucial and we recommend the updated NHS Chaplaincy Guidelines (2015) published by NHS England. We therefore recommend that the GDG adds a section on Spiritual and Holistic care to its summary document and that there should be a reference to the NHS Chaplaincy Guidelines, "Promoting Excellence in Pastoral"(March 2015), The GDG should therefore considering add a section on spiritual care and we would suggest "Spiritual care should be offered to all who are dying. Friends, relatives and those who are important to them should also be involved wherever possible. Clinicians should therefore refer those who have a faith and who it is thought would want spiritual care to the relevant priest, pastor or minister of religion. The guidance of the Chaplaincy service, who have special expertise in issues relating to the pastoral care of the dying, should be sought at an early stage. We recommend the NHS Chaplaincy Guidelines (2015) for further help and assistance in	discussed under the communication and shared decision making chapters. Thank you for providing reference to the NHS chaplaincy guidelines, we have added this into the 'Linking evidence to recommendations' section of the shared decision making chapter.

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				this important aspect of care and compassion for the dying."	
Catholic Medical Association (UK).	FULL	P 86-108		**6. COMMUNICATION.** The GDG found no studies "that elicited experiences or perceptions of the dying person" p87 line16. There was one study "which interviewed bereaved careers and healthcare professionals about people that that died in acute hospital settings, about the general care they received including communication of prognosis." P87. L20-22. However the GDG reports that this had "very poorly reported methodology" and that "the context of the quotes and themes was hard to ascertain." Nevertheless, the GDD acknowledges that "much of the distress and controversy surrounding the Liverpool Care Pathway could have been prevented by sensitive and timely communication between clinicians, relatives and other carers. The More Care Less Pathway report highlighted this as a "non-negotiable aspect of best practice in end of life care." Despite the paucity of studies on communication, there is no doubt from the last Audit of the Liverpool Care Pathway (NADH 20010/11) showed that the	Thank you for your comment. We agree that communication is crucial and have given further detail in the full guideline. We note the audit data provided within your comment, but unfortunately they do not meet our inclusion criteria for any review questions and as such have not been utilized.

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				degree of communication about the Liverpool Care Pathway was poor as shown below. **NATIONAL AUDIT ON LCP 2010/11 NCDAH R3 TABLES** **COMMUNICATION WITH PATIENT.** **Patients in audit 7058 (100%)** **Patients deemed able to take a full and active part in communication 2725 (39%)** **Patients aware that they were dying 1548 (22%)** **Patients given the opportunity to discuss what was important to them 1303 (18%)** **Patients given a full explanation of the LCP 1249 (18%)** **Patients who took the opportunity to discuss what was important to them 389 (5.5%)** **COMMUNICATION WITH RELATIVES/CARERS**	

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				Patients in audit 7058 (100%) **Relatives/carers aware that they were dying 5586 (79%)** **Relatives/carers given a full explanation of the LCP 4737 (67%)** **Relatives/carers given the opportunity to discuss what was important to the 4189 (59%)** **Relatives/carers who took the opportunity to discuss what was important to them 1889 (27%)** The LCP appeared to be implemented without the consent of the patient or the knowledge or agreement of relatives in a significant proportion of patients. A large proportion of patients were either deemed to be 'unconscious' at the instigation of the LCP (45%) or were otherwise unable, or not given the opportunity, to give their consent. As many as one in 5 patients on the LCP have dementia either as their main diagnosis (4%) or as a significant co-morbidity (16%). The GDG makes a number of recommendations (recommendations 6 to 21 inclusive) regarding communication and shared decision-making.	

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				We agree that communication is key to good palliative care and commend the recommendation of the Neuberger Review: "Respectful treatment of the dying patient and the carers requires time to be taken over the difficult tasks of providing information, including the difficult task of delivering the news that the person is dying, understanding the person's needs and capacity to assimilate bad news and providing the opportunity to reflect on that information and to ask questions. This should be a non-negotiable aspect of best practice in end of life care. (More Care Less Pathway. 2013)"	
Catholic Medical Association (UK).	FULL	P111-134		**7. SHARED DECISION MAKING AND CONSENT** a) "I would add that we should not "give up" on any patient, terminal or not terminal. It is the one who is beyond medical help who needs as much if not more care than the one who can look forward to another discharge." Dr Elizabeth Kubler-Ross. "How people die lives on in the memory of those who live on." b) The guidance makes only a brief reference to the involvement of family and friends in decision making. The GDG needs to	Thank you for your comment. a) This clinical guideline is intended for people in the last days of life. In the recognising dying section, we have amended our recommendation to encourage healthcare professionals to use the knowledge gained from the assessment and other information gathered from the multiprofessional team, the person and those important to them, to help determine whether the person is nearing death, deteriorating, stable or improving. a) The Committee's intention is to present a framework of recommendations that encourage healthcare professionals to consider the needs

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				highlight the importance of discussion with the mentally competent patient and with family and those important to the patient when they lack capacity to make decisions for themselves. It cannot be assumed that clinicians may make decisions on behalf of mentally incapacitated patients. Therefore it is important to mention in the recommendations the importance of enquiring whether the mentally incapacitated patient has appointed a donee of Lasting Power of Attorney (or Welfare Attorney in Scotland) to make decisions on their behalf. The Neuberger Review recommended an independent advocate for those without relatives who lacked capacity. The Neuberger review stated "For each patient on an end of life care plan that has no means of expressing preferences and no representation by a relative or carer, views on their care should be represented by an independent advocate, whether appointed under the Mental Capacity Act 2005, a chaplain, or an appropriate person provided through a voluntary organisation. This applies to people of whatever age who lack capacity". [19] We would suggest that this recommendation	of the dying person and those important to them. Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. b) The purpose of our evidence review in this area was to understand how the dying person, their loved ones and their multiprofessional team could best work together to ensure that decisions made considered and met (where possible) the dying person's wishes (see 7.1 for further information behind the intention of the evidence review that informed these

[19] Neuberger Review "More Care Less Pathway, 2013) Recommendation 32.

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				concerning an independent advocate is added to the guidance. Patient management should be holistic and should address the medical, psychological and spiritual needs of the patient. Consent to treatment is especially important in palliative care as in other fields of medicine and should always be sought in a timely fashion where the patient has capacity. As in any other field of medicine, consent should be sought from patients for the diagnosis and treatment of their condition throughout the patient journey and not confined to the last few days of life. This is particularly true of palliative care where the needs and wishes of patients should be actively determined before the patient looses capacity as a result of the underlying condition or treatment. Decisions about palliative care must be made or supervised by senior clinicians who should be available for further help and advice as the patient's condition changes. It must be clear to the medical team and relative who is the named responsible consultant. The Neuberger Review recommended that "A named consultant or GP, respectively, should	recommendations). We have not undertaken a review of capacity or 'best interests' or 'consent' as these issues are defined in law. We agree that care of the dying person should be undertaken holistically and a number of our recommendations require that care and management is individualised after consideration of the issues you suggest (see recommendations 1, 10,14,16,17,19) We are aware of the end of life care audit conducted by the Royal College of Physicians but are unable to comment on this or other nationally funded research activity.

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				take overall responsibility for the care of patients who are dying in hospital or the community"[20]. Neuberger also recommended "the name of a registered nurse responsible for leading the nursing care of the dying patient should be allocated at the beginning of each shift. This nurse will be responsible also for communicating effectively with the family, checking their understanding, and ensuring that any emerging concerns are addressed".[21] There should be regular audit of the care of the dying which takes into account medical treatment, nursing care, spiritual support and the concerns of relatives and carers. We also agree with the Neuberger Review that "The National Institute for Health Research fund should fund research into the experience of dying. Research priorities must extend also to systematic, qualitative and mixed methods research into communication in the patient and relative or carer experience".[22]	
Catholic Medical Associati	Short Guideline	5	1.2	Communication	Thank you for your comment. We have added additional text to the full guideline under shared decision making to state that: Increasingly, people

[20] Neuberger Review "More Care Less Pathway, 2013) Recommendation 26
[21] Neuberger Review "More Care Less Pathway, 2013) Recommendation 27.
[22] Neuberger Review "More Care Less Pathway, 2013) Recommendation 5.

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on (UK).				We recognise that poor communication was one of the major problems with the implementation of the LCP in practice. Indeed, the Neuberger Review noted that "preventable problems of communication between clinicians and carers accounted for a substantial part of the unhappiness reported to us. Relatives and carers felt that they had been "railroaded" into agreeing to put the patient on a one-way escalator. We feel strongly that if acute hospitals are to deal with dying patients – and they will – whether or not they are using the LCP – they need to treat patients, their relatives and carers with more respect". We therefore agree with the GDG in stressing the importance of discussing the care of the dying patient with the family and chosen next of kin unless it is clear that the patient does not wish them to be involved. It is also important for doctors to act in the best interests of any patients who lack the mental capacity to make decisions for themselves. We agree with the GDG that families and the chosen next of kin should normally be fully consulted and closely involved in the decision making process. In particular we agree with the GDG that it is important to involve those that the person considers important to them so that they can be present when making decisions about their care (recommendation 6); to	may have expressed and recorded their preferences for end of life care in advance care plans. They may have appointed someone to have an Enduring power of attorney (which would only be valid if made before 1st October 2007), or a Lasting Power of Attorney for health and welfare which came into effect after the introduction of the Mental Capacity Act in 2005. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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				consider with the dying person and those important to them their stated preferences about their care (recommendation 10) and whether the dying person or those important to them have any cultural, religious, social or spiritual preferences that should be considered (recommendation 14). The GDG should also make it clear in the guidance that it is important to make positive enquires as to whether the patient has appointed an attorney who may have the legal powers to make decisions for the patient (i.e. donee of Lasting Power of Attorney or Welfare Attorney in Scotland).	
Catholic Medical Association (UK).	FULL	P 137-154 P152 P154		8. **PROVISION OF HYDRATION AND NUTRITION.** 1 The GDG questioned the overall validity of the evidence available due to the risk of bias in the study design in all papers and the imprecision of a large proportion of the outcome measurements. They noted that the randomised clinical trials (RCTs) were terminated early due to recruitment or financial problems and were therefore underpowered. (p152). We also agree "that a trial of assisted hydration should more readily be started when there is uncertainty that a person is dying and might recover but is currently unable to take oral fluids. This would	Thank you for your comment. 1. Thank you for confirming your agreement with the guideline related to the overall validity of the evidence and the importance of initiating a trial of clinically assisted hydration in cases where its benefits are uncertain. 2 Laboratory tests may indicate dehydration and deteriorating renal function, but their use in the last days of life as predictors of being able to recognize dying have not been reviewed as they are outside the scope of the guideline. The Committee noted that

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		P151		be important to prevent death from dehydration in a potentially reversible condition. (p 154). 2. The third Cochrane review on the provision of hydration by Good and colleagues was repeated in 2014.[23] Six studies were identified including three RCTs (222 participants) and three prospective controlled trials (360 participants). The authors concluded that the small number of studies and heterogeneity of the data meant that a quantitative analysis of the data was not possible. However, qualitatively one study showed that sedation and myoclonus scores improved in the intervention group and another study showed that dehydration was greater in the non-hydration group. However, some symptoms related to fluid retention e.g. pleural effusions, peripheral oedema and ascites worsened with hydration. The other four studies did not show significant differences in outcomes between the two groups. The authors concluded that "the studies published do not show a significant benefit in the use of medically assisted hydration in palliative care patients; however, there are insufficient good-quality studies to inform definitive recommendations for practice with regard to the use of medically assisted hydration in palliative care patients".	there is a need to minimise the unnecessary intrusion of testing in the last days of life to allow for a peaceful death. The committee has now drafted an additional recommendation that draws the healthcare professionals attention to the fact that changes in signs and symptoms may indicate recovery and believe that clinicians would act appropriately in undertaking necessary testing to confirm this.

[23] Good P, Cavenagh J, Mather M, Ravenscroft P. Medically assisted hydration for adult palliative care patients. *Cochrane Database of Systematic Reviews* 2008, Issue 2.

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		P154		The studies are difficult to interpret because of their heterogeneity, short duration and reporting of data. In particular, the amount of oral intake and details of fluid balance were often missing. For example, in the latest study by Burera (2013) the oral intake in the two groups was simply not documented which is a significant omission in a study to examine dehydration. The GDG group were broadly in agreement with the Cochrane Reviews. They noted that "the experience of the GDG was that there is benefit in some circumstances, such as in the case of managing thirst or managing delirium caused by dehydration, this was not captured by the evidence" (p. 151). The GDG also noted that patients "may develop symptoms of dehydration including dry mouth, thirst, confusion and agitation, particularly if there are associated conditions such as hypocalcaemia and opioid toxicity due to impaired renal clearance. This can cause considerable distress to the patient and those important to them particularly if hydration is not adequately assessed and managed." (p152). The issue of increased midazolam toxicity due to accumulation of the drugs and its active metabolite	

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				in those who are dehydrated or oliguric has also been recently recognised.[24] The GDG recognise the importance of opioid toxicity due to impaired renal function.[25] Morphine and its metabolite (morphine 6 glucuronide which is also pharmacologically active) accumulate in the body, especially if the patient is becoming dehydrated (as the active metabolite is excreted in the kidneys). The GDG concluded that the management of hydration in the dying person should always be individualised and be provided wherever possible by oral means. We disagree with the view regarding the use of laboratory tests, that "there was not always additional benefit to performing these tests in the last days of life. They agreed that the principle should be that these tests not be routinely undertaken as hydration status could be assessed clinically" (p. 154). The GDG does state that if laboratory test results are present then they may guide decisions around assisted hydration but no recommendation was made as this was considered to be outside the remit of this guideline. We feel that a proper assessment of hydration is important which may	

[24] Quail M A. Continuous infusions of midazolam and interrupted hydration – like insulin infusions without glucose? The international journal of clinical Practice. Int J Clin Pract, April 2014, 68, 4, 410–412
[25] Ibid. P 152.

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				require both a clinical and laboratory assessment. Many sick elderly patients will not complain of thirst even when dehydrated. Indeed, symptoms of dehydration may include confusion, agitation and delirium which are well recognised in healthy individuals who become dehydrated. Laboratory tests may indicate dehydration and deteriorating renal function and also alert the clinician to the increased susceptibility of dehydrated patients to the effects of opiates and sedatives.	
Catholic Medical Association (UK).	FULL	P155-222 P158-160		**9. PHARMACOLOGICAL INTERVENTIONS** **(i) Pain.** The use of opiates for pain is well established and supported by several Cochrane reviews. The guidelines emphasise that "the management of pain in the last days of life should follow principles of pain management used at other times."[26]. Indeed, the GDG chose "not to make any specific recommendations about pain management in different patient groups and suggested the clinician	Thank you for your comment. Nerve block techniques for pain management in the last days of life were not included in the protocol for the pharmacological evidence reviews. Whilst the Committee acknowledged specialised pain relief strategies they chose not to include them in the protocol for this review. Thank you for your comment. The Cochrane review by Jennings and colleagues in 2001 on the use of opiates for the palliation of breathlessness in terminal illness was withdrawn in 2012 and therefore not included in our review.

[26] Ibid. Recommendation 33. P. 160

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		P164-175		should follow the normal prescribing practices present any other time of life."[27] We would agree that pain management strategies should follow the principles of pain management used at other times. However, we would also point out that there are a variety of specialised pain relief strategies which tend not to emphasised but which are evidence based e.g. nerve block techniques. But note that doses may need to be lower in non cancer situations such as renal failure, dementia, frailty and old age. See our comment no 9 . **(ii)<u>Breathlessness</u>** Opiates are widely used for breathlessness.. However, it is of interest that there was a Cochrane review by Jennings and colleagues in 2001 on the use of opiates for the palliation of breathlessness in terminal illness which was withdrawn in July 2012. Therefore, whilst opiates are still used in breathless patients, further evidence on this subject is awaited with interest. A Cochrane review in 2010 by Simon and colleagues[28] tried to determine whether	The 2010 Cochrane review on benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases was reviewed for inclusion in this review. However owing to the population used for the Cochrane systematic review being wider and including patients outside of the last days of life, this was not included in the systematic review for this guideline. The Cochrane also utilised a different search strategy explaining the difference in papers identified in their study and the evidence review included in this guideline. The Committee recognised the paucity of clinical trials in the last days of life in the pharmacological management of breathlessness review. However, a specific research recommendation was not prioritised for this area. The Committee discussed the quality of the various outcomes that were extracted from clinical trials using the GRADE system. They combined this information with their own clinical experience and formulated several consensus recommendations. A statement has been added to the 'Linking evidence to recommendations' section for this review to

[27] Ibid. P. 163.

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				benzodiazepines relieve breathlessness. They identified circumstances including 200 participants with advanced cancer and COPD. They concluded that "There is no evidence for a beneficial effect of benzodiazepines for the relief of breathlessness in patients with advanced cancer and COPD. There is a slight but non-significant trend towards a beneficial effect but the overall effect size is small. Benzodiazepines caused more drowsiness as an adverse effect compared to placebo, but less compared to morphine." The review supported "the use of benzodiazepines only if other first-line treatments, such as opioids and non-drug treatments, have failed". They noted conflicting results in the comparison of midazolam to morphine based on two studies within the same research group (Navigante et al 2006). There is still an urgent need for more studies to find better ways to relieve this burdensome symptom in patients with advanced diseases. The studies comparing the use of oxygen versus room air and with the use of morphine or hydromorphine were regarded as of 'very low' quality. *The GDG examined 3 studies for breathlessness. The two examining the effects of oxygen and opiates*	highlight that benzodiazepines and opioids are off license for the management of breathlessness in the last days of life. The section you have referenced is part of an introduction aimed at explaining the rational for the review question. The lack of an existing evidence based guideline for this population is one reason why the evidence review was undertaken. Thank you for your comment. The Committee agree that there is a lack of evidence for many of the pharmacological agents that are currently used for nausea and vomiting in the care of the dying adult. Because of this the Committee chose not to make specific recommendations for which agent to use to manage nausea and vomiting in conditions other than bowel obstruction where evidence was available. Thank you for your comment. The Committee agree that the evidence base for agitation, anxiety and delirium is poor in the last days of life. The Committee chose to make consensus recommendations based on their clinical experience

[28] Simon ST, Higginson IJ, Booth S, Harding R, Bausewein C. Benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases in adults. Cochrane Database of Systematic Reviews 2010, Issue 1. Art. No.: CD007354. DOI: 10.1002/14651858.CD007354.pub2

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		P176-185		*were regarded as being of 'very low' quality. In the third study, the GDG considered that there was moderate and low quality evidence to suggest that a combination of morphine and midazolam was beneficial compared to the use of either intervention alone. This effect was more apparent at 24 rather than 48 hours. This view was not shared by the Cochrane Reviews. There was no evidence concerning survival outcomes in any of these studies.* *The paucity of information on the management of breathlessness is striking and in identifying 3 studies for analysis the GDG had examined 144 articles on pharmacological interventions. Simon et al had excluded 74 out of 79 reviews for the Cochrane Review.* *The GDG was therefore right to consider non-pharmacological management of breathlessness and to try and identify and treat reversible causes of breathlessness e.g. pulmonary oedema. Whilst not recommending the routine use of oxygen for breathlessness in the absence of hypoxaemia, the GDG did recommend consideration of an opioid, benzodiazepine or combination of the two even though there was no UK marketing authorisation for this indication whilst recognising that monitoring "would minimise the risks of clinical harm in using these medications."*	Thank you for your comment. The Committee discussed the quality of the various outcomes that were extracted from clinical trials using the GRADE system. They combined this information with their own clinical experience and formulated several consensus recommendations regarding treatment of noisy respiratory secretions. A statement has been added to the 'Linking evidence to recommendations' section for this review to highlight that the recommended drugs are off license for the management of noisy respiratory secretions in the last days of life. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.

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		P186-191		*We are concerned that NICE has not been more cautious in recommending drugs for unlicensed indications in the absence of a sound evidence base. The hallmark of good prescribing is a sound evidence base. In the absence of such evidence we would suggest NICE should be more cautious in its recommendations.* **(iii) Nausea and vomiting** The GDG notes that "there is no evidence- based guidance on best practice in the pharmacological management of nausea and vomiting in the last few days of life and current practice has been extrapolated from our knowledge of treating these symptoms at other stages of illness in different diseases." (p 176, lines 17-19) Nevertheless, the GDG reviewed 3 randomised controlled trials which examined the effects of octreotide and hyoscine butylbromide. The clinical evidence showed that octreotide was more clinically effective than hyoscine butylbromide in 1 study and less clinically effective in another. Two of the studies were small and the third had a high attrition rate. Not surprisingly, the GDG noted that there "was currently wide national variability in the management of nausea and vomiting in the last days of life. They were particularly surprised that a recent national audit of care for the dying adults in hospitals found that cyclizine was the most commonly prescribed	

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		P192 P17		antiemetic given. In the GDG's opinion this drug had lower efficacy compared with others, was often poorly tolerated by people at the end of life, is incompatible with many other drugs in a syringe driver and is frequently associated with site reactions if administered subcutaneously. No evidence was identified for cyclizine and no recommendations were make" (p 183). Perkins and Dorman concluded in their Cochrane review that "There is not enough evidence to be able to recommend haloperidol for the treatment of nausea and vomiting in adult patients suffering from incurable progressive medical conditions". In the Cochrane Reviews, there was no clear evidence of benefit for levopromazine,[29] haloperidol,[30] or droperidol.[31] There is a lack of good quality evidence for the use of anti-emetics and antipsychotics for nausea and vomiting. We would emphasise that good practice in prescribing should be evidence-based wherever possible. We agree that non-pharmacological methods of treating nausea and vomiting should be considered (but not	

[29] Darvill E, Dorman S, Perkins P. Levomepromazine for nausea and vomiting in palliative care. *Cochrane Database of Systematic Reviews* 2013, Issue 4. Art. No.: CD009420. DOI: 10.1002/14651858.CD009420.pub2

[30] Perkins P, Dorman S. Haloperidol for the treatment of nausea and vomiting in palliative care patients. Cochrane Database 2009.

[31] Dorman S, Perkins P. Droperidol for treatment of nausea and vomiting in palliative care patients. Cochrane Database of Systematic Reviews. 2010.

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				only in the last few days of life). There should be a search for reversible causes and drug toxicity and the use of nasgastric suction considered for bowel obstruction. **(iv) Agitation and anxiety** A trial of a benzodiazepine (Recommmendation 45) and an antipsychotic (Recommendation 46) is suggested. Despite the widespread advocacy of benzodiazepines and antipsychotics such as haloperidol and levomepromazine in the Liverpool Care Pathway, this is not evidence based and the review by Candy et al (2012) concluded: *"There remains insufficient evidence to draw a conclusion about the effectiveness of drug therapy for symptoms of anxiety in adult palliative care patients. To date no studies have been found that meet the inclusion criteria for this review. Prospective controlled clinical trials are required in order to establish the benefits and harms of drug therapy for the treatment of anxiety in palliative care"*[32]. *Hirst and Sloan concluded their review (in 2002) by stating: "Despite a comprehensive search no*	

[32] Candy B, Jackson KC, Jones l, Tookman A, King M. Drug therapy for symptoms associated with anxiety in adult palliative care patients. Cochrane Database of Systematic Reviews. 2012.

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				evidence from randomised controlled trials was identified. It was not possible to draw any conclusions regarding the use of benzodiazepines in palliative care"[33] *.* We agree that possible sources of anxiety and agitation should be sought e.g. metabolic disturbance and psychological causes (Recommendation 45). The evidence base for the use of benzodiazepines and antipsychotics is poor. **(v) Respiratory tract secretions.** Antisceretory drugs such as glycopyronium and hyoscine are used for respiratory secretions. Approximately half of those relatives and friends who witness it, as well as hospital staff, find the noise of 'death rattle' distressing. Dr Bee Wee and Hellier (2008) concluded: *"In our original Cochrane review, we concluded that there was no evidence to show that an intervention, be it pharmacological or non-pharmacological, was superior to placebo in the treatment of noisy breathing. This conclusion has not changed"*[34] *.*	

[33] Hirst A, Sloan R. Benzodiazepines and related drugs for insomnia in palliative care. Cochrane Database of Systematic Reviews 2002, Issue 4. Art. No.: CD003346. DOI: 10.1002/14651858.CD003346
[34] Wee B, Hillier R. Interventions for noisy breathing in patients near to death. Cochrane Database of Systematic Reviews 2008, Issue 1. Art. No.: CD005177. DOI: 10.1002/14651858.CD005177.pub2

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				Despite the absence of evidence for their efficacy, it is recommended (recommendation 51, p 17, lines 4-11) that atropine, glycopyrronium and hysoscine are considered even though they have no marketing authorisation for this indication. We agree that (as per recommendation 50, p 17, lines 1-3) non-pharmacological measures should be considered to manage pharyngeal secretions and that medication should be stopped if it is not helpful or causing side effects. However, the guidelines do not specifically mention suctioning, positioning and physiotherapy.	
14. Catholic Medical Associ	15.	P223		**10.Anticipatory Prescribing** We are seriously concerned at the prospect of anticipatory prescribing, which would appear to allow the introduction of pre-prescribed medication by insufficiently senior staff for what others might regard as inadequate reasons. It appears to presuppose that the senior person in charge of the case may not be available for a relatively long period of time. As you, yourselves, express it (Long Draft, p 223, l 32ff) the danger is of "injudicious administration and prescription of medication by inexperienced staff, possibly unfamiliar with the person" however careful the original prescriber have been. Anticipatory prescribing must not be allowed to	Thank you for your comment. The Committee recognised the complexities surrounding anticipatory prescribing, and recommend using an individualised approach. Administration of medications prescribed in anticipation by a clinician involved in the dying person's care should be reviewed before administration in light of the current symptoms and treatment efficacy fed back to the lead health care professional as recommended in 1.6.5 and 1.6.6. The Committee discussion is captured in the 'Linking evidence to recommendations' section for this review area. We recognize that this is a balance between timely administration to avoid distress and the need for a tailored and individualised approach to anticipatory prescribing that avoids a blanket and

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ation (UK).				substitute for proper ongoing assessment and care for the patient. We do not accept that anticipatory prescribing should be 'as early as possible' but rather should be limited to the period of 24 or 48 hours before the likely need, and then only when there is expected to be a serious and significant delay in obtaining the medication (for example in general practice over a weekend when chemists may be shut).	repeated approach to prescribing. We hope that our recommendations build in a process for review before administration in the case of prescribing in advance of an event and make explicit the need to monitor the efficacy of this treatment before continuing to administer. The Committee felt the recommendations encourage healthcare professionals to consider the setting and the time it takes to access the drug and felt that stating "as early as possible" was appropriate. The group were unable to be any more specific in regards to timing as there was no evidence to support this, As there are uncertainties in this area the Committee also chose to make a research recommendation. (see section 10.9 in the full guideline).
Catholic Medical Association (UK).	Short Guideline	10	1.5	We recognise that pharmacological interventions may be necessary for the alleviation of distressing symptoms. However, prescribing should be evidence based as a matter of good clinical practice wherever possible. As the GDG and Cochrane reviews demonstrate, the evidence base for many of the pharmacological interventions currently in use is often lacking with the exception of the use of opiates for pain control. Nevertheless, opiates, benzodiazepines and hyoscine can cause sedation . In those who contacted us about the use of these medicines, it is clear that there is a real concern that having started them, relatives and friends see their	Thank you for your comment. The Committee agree that it is important to consider the benefits and harms of any medication prescribed in the last days of life, as stated in recommendation 1.5.2 and 1.5.3. The issue of unwanted sedation is discussed in the 'Linking evidence to recommendations' section of the pharmacological interventions chapter and advice to avoid this is provided in recommendation 1.5.9. The Committee felt that additional recommendations were not needed.

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				loved ones become comatose and die. For those who are dying the last few days with their love ones are very precious. Loss of conscious awareness can deny patients the opportunity to be with friends and family as when they are dying. We recall the words of Dame Cicely Saunders that "You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die." The GDG should consider adding the following statement: "Deprivation of consciousness "While it is often essential that medication is given as part of appropriate symptom alleviation, care must be taken to avoid unnecessarily use of drugs which cause patients to be deprived of their conscious awareness as they die. Balancing the control of symptoms with avoiding over-sedation should be a clear priority. Patients should die peacefully but also be allowed to live well until they die with those who are dear to them".	
Catholic Medical Association (UK).	Short guidance	Pp27-33	Tables 1-6	The doses recommended appear to be relevant to cancer care. We think that risks of oversedation and over treatment are likely to be higher in those with dementia, severe frailty, low body mass, renal failure , dehydration and other non cancer conditions.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently,

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				Morphine requires additional caution in renal impairment. We suggest that the doses of medication in supporting documentation for the LCP were too high. Those with dementia may be very sensitive to morphine . . Pace, Treloar and Scott[35] recommended starting with 2.5mg of morphine when pain was uncontrolled, and not the 2.5-5mg recommended by these guidelines Table 5 helpfully mentions reduced doses in older and frail people, We think that the GDG might consider adding cautions relating to illnesses such as renal failure and dementia, as well as age, frailty and low body mass to all tables in the Short Guidance.	they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Childhood Bereavement Network	Short	5	22	After 'and those important to them' insert 'including children and young people OR Include new bullet point in list after line 29 'information about ways of talking to children and young people in the family about what is happening'	Thank you for your comment. It has been recommended that the multiprofessional team seek further specialist advice if additional support is needed. For the challenging circumstances described in your comment, it is also recommended that the healthcare professionals delivering end of life care also have access to experienced staff at all times.

[35] Pace V, treloar A, Scott S. (2012), Dementia, from advanced disease to bereavement. Oxford Specialist Handbook, Oxford University Press.

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Childhood Bereavement Network	Long	87-107		In the section on **communication**, we were disappointed not to see a review of the evidence on the need for – and recommended ways of – supporting families to communicate specifically with children and young people when someone important to them is dying. We recognise that this section cross-references with Guideline CG138 on Patient experience in adult NHS services: improving the experience of care for people using adult NHS services but we are aware that this earlier guidance does not look at the specific information and support needs of patients' children. Each year in England and Wales, we estimate that 20,400 parents die, leaving dependent children (CBN, 2015). Many other children and young people are bereaved of someone else important in their lives each year. Children and young people facing the terminal illness of a parent have elevated levels of depression and anxiety: the most stressful time for them seems to be before the death (Seigel et al 1996). Their levels of anxiety are inversely correlated with the quality of communication in the family (Beale et al 2004) and with their perception of the well parent's general openness (Raveis et al 1999).	Thank you for your comment. The remit and scope of this guideline did not cover this area. This guideline focussed on the needs of the dying person and has not reviewed the evidence around support for carers or those important to the dying person, including children. Unfortunately care after death and bereavement are outside the scope of this guideline and we are unable to comment. We are aware of guidance currently being produced by the National Collaborating Centre for Women and Children's health. This work is entitled: End of life care for infants, children and young people and covers the populations you mention in your comment. Further details can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0730.

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				Many children are not told when their parent is dying (Barnes et al 2000) and even families with open communication styles can struggle to communicate specifically about the parent's illness and impending death (Siegal et al 1996). Understandably, parents can struggle to have open supportive conversations with their children when they are facing the death of someone close: dealing with the complexities and disruptions of treatment and crisis can mean there is little time to talk about what is happening and to reassure children. There are emotional barriers to talking too: sometimes parents are worried about breaking down in front of their children or don't want to upset them with difficult news. The uncertainties of the illness or trauma can leave parents struggling to give children clear and consistent information. Young people themselves talk about their need to be kept informed, but say they find it difficult to open up conversations because they don't know how to, or because they are worried about upsetting people. Children and young people have specific information needs when preparing for the death of someone important in their lives. These may include reassurance on very specific concerns such as who will care for them after the person dies. They also need careful, age-appropriate explanations of	

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				specific terms and situations, including conditions, treatments and prognoses. Adults in the family can benefit from advice about how to talk to the children, and information about their children's reactions which may be disconcerting. Basic information can be helpful in itself, and can help parents support their children more effectively (Kennedy &Lloyd-Williams, 2009). Clinical guidelines exist to support healthcare professionals help parents and carers to communicate with their children about the illness and death (Christ, 2000; Winston's Wish 2001; Fearnley 2012). A controlled study found that good quality support from healthcare professionals, including helping families communicate about the facts of the illness, treatment and death, reduced children's anxiety and improved their perception of their surviving parent's competence: outcomes with long term significance for how children learn to live with the loss (Christ et al 2005). 'Everyone was trying to stop telling me things, trying to hide stuff from me saying 'it will be better if you don't know these things' but I feel that if they'd have told me I'd have coped better. Because not knowing it was like, obviously it wasn't sudden because it was cancer but it was quite sudden because I didn't know how ill he was because nobody would tell me. Two	

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				days before he died I went to see him, and before I went everyone was telling me he was ok. And I went to see him and he was wired up to every machine possible and that just made me even more upset to feel that nobody could trust me to tell me. It felt to me as if they couldn't tell me, and I wanted to know.' Bereaved young person. 'He was in a big ward…the nurses didn't talk to me, they didn't help, they just walked about with needles and things. They could have told me what was happening and said what was going to happen, instead of just walking past me'. Child bereaved of her father. References • Barnes J, Kroll L, Burke O, Jones A, Stein A (2000) Factors predicting communication about a diagnosis of maternal breast cancer to children Journal of Psychosomatic Research 52, 209-214 • Beale EA, Sivesind D, Bruera E (2004) Parents dying of cancer and their children. Palliative and Supportive Care 2, 387-393 • CBN (2015) Key Statistics on Childhood Bereavement http://www.childhoodbereavementnetwork.org.uk/research/key-statistics.aspx	

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				• Christ, G (2000) Healing Children's Grief New York: Oxford University Press • Christ G, Raveis V, Siegal K, Daniel K, Christ A (2005) Evaluation of a preventive intervention for bereaved children Journal of Social Work in End-of-Life and Palliative Care 1,3, 57-81 • Fearnley R (2012) Communicating with children when a parent is at the end of life London: Jessica Kingsley Publishers • Kennedy, Vida L.; Lloyd-Williams, Mari Information and communication when a parent has advanced cancer. Journal of Affective Disorders. Vol 114(1-3), Apr 2009, 149-155. • Raveis V, Siegel K, Karus M, (1999) Children's psychological distress following the death of a parent Journal of Youth and Adolescence 28, 165-180 • Siegal, K; Karus, D: Raveis, V (1996) 'Adjustment of children facing the death of a parent due to cancer' Journal of the American Academy of Child and Adolescent Psychiatry 35: 442-450	
Childhood Bereavement Network	Long	108		Recommendation 9: After 'and those important to them' insert 'including children and young people OR Include new bullet point in list 'information about ways of talking to children and young people in the family about what is happening'	Thank you for your comment. The Committee consider "those important to the dying person" to also include family members such as children and young people and therefore feel no change is required.

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Childhood Bereavement Network	Long	134		Recommendation 17: After 'if any are specified' insert new bullet point: 'family and carers' (including children and young people's) support needs before and after the death'.	Thank you for your comment. The Committee consider "those important to the dying person" to also include family members such as children and young people and therefore feel no change is required. 16. As care after death is outside of the scope we are unable to provide further detail.
Childhood Bereavement Network	Short	7	26	After 'if any are specified' insert new bullet point: 'family and carers' (including children and young people's) support needs before and after the death'.	Thank you for your comment. As care after death is outside of the scope we are unable to provide further detail.
Christian Action Research & Education (CARE)	Short	18	13-19	We are encouraged that these guidelines are designed to help all healthcare professionals who might be involved in the care of a person nearing death in a NHS setting, with a specific focus on non-specialists providing a baseline for setting standards of care. This is absolutely critical and the guidelines should ultimately shape the basis of continuous professional development and training for health and social care professionals in recognizing and providing care for terminally ill and dying people. As we all face the implications of a rapidly ageing population and the expected rise in numbers of people dying each year the demand for high quality and compassionate palliative and end of life care will only increase. Appropriate training of healthcare staff is therefore essential if the NICE guidelines are to be embedded and failure of care is to be avoided.	Thank you for your comment.

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Christian Action Research & Education (CARE)	Short	7	4	Taking steps to identify a named lead healthcare professional who has responsibility for encouraging shared decision- making is welcomed, but it does not go far enough. The Neuberger report clearly recommends that every patient who is diagnosed as dying should have a clearly identified senior responsible clinician accountable for their care during any 'out of hours' period (Independent Review of the Liverpool Care Pathway 2013: 22). The Review panel goes on to recommend that the GMC, the Health and Care Professions Council (HCPC) and the NMC ensure their professional standards clearly place the responsibility for such decisions on the senior responsible clinician, and that they take steps to emphasize how clinicians will be held to account against these standards (Independent Review of the Liverpool Care Pathway 2013:22). The NICE guidelines should reflect this and whilst multidisciplinary team working may be promoted, accountability and responsibility must be placed with the senior responsible clinician.	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section.
Christian Action Research & Education (CARE)	Short	9	13	We disagree with this sentence. Not giving hydration is certain to kill someone if they cannot take hydration by mouth. There is also no mention or reference to nutrition in the NICE document. We note that the Neuberger report addressed the critical provision of both nutrition and hydration and yet the consultation document makes little reference (if at all) to this need. The Neuberger report clearly stated	Thank you for your comment. This recommendation refers to clinically assisted hydration, not hydration as a whole. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the

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				that failing "to support oral hydration and nutrition when still possible and desired should be regarded as professional misconduct" (Independent Review of the Liverpool Care Pathway 2013: 28).	lack of evidence around survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given. Nutrition is beyond the remit and scope of this guideline.
Christian medical Fellowship		19-22	General	We applaud the commitment to further research into better management of delirium and agitation and respiratory 'noises' so that care can be as evidence-based as possible. Evidence concerning the place of hydration is conflicting, and there appears to be no plan for further research into this area. We question why this is excluded from the general commitment to further research and recommend including the need for more research into the issue of hydration in dying patients.	Thank you for your comment. As we have made recommendations in this area, the Committee felt that these will guide practice sufficiently to ensure that high quality care is offered. Given that there is evidence in this area, although limited, and that there is a recent Cochrane review, the Committee wanted to prioritise other areas in which less research has been conducted.
Christian medical Fellowship		General	General	CMF welcomes the new guidelines as an attempt to improve the care of those who are thought to be dying. The guidelines recognise that it can be very difficult, in practice, to determine when a dying patient is entering the last few days (or weeks) of life. That uncertainty does not remove the need to continue to provide care but leads to the recognition that such care will necessarily be inimical to a programmatic approach. Care for those who may be dying will be relative to the individual circumstances of each case, and liable to constant adjustment in	Thank you for your comment. Our recommendations suggest monitoring and reassessing the patient regularly during the course of their care and this addresses your concerns. The 'Linking evidence to recommendations' section of chapter 5 provides further detail of the Committee's discussion on the uncertainty of certainty that you outline. We recognize that recovery is possible in many cases and have reflected this in a number of our recommendations in addition.

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				the light of ongoing review, including the possible need to revise the diagnosis of dying. Virtuous good sense must be the defining characteristic of such care, not slavish adherence to protocols. We welcome the guideline's commitment to research ways of reducing the impact on clinical care of the uncertainty surrounding the diagnosis of dying. At some points in the guidance, this uncertainty is well described, but at other points the language used fails to convey this uncertainty. We suggest that whenever the diagnosis of dying is described or implied, the 'uncertainty of certainty' be clearly admitted.	
Christian medical Fellowship		General	General	CMF welcomes the draft guidelines, the emphasis on evidence-based care, and the commitment to ongoing research. However, we believe that, in their present form they will lead to the same 'pathway' mentality, in practice, as was discredited in LCP.	Thank you for your comment. We do not believe that we are describing a pathway or care plan in this guideline. We feel that we have always placed an emphasis on individualizing care for the dying adult.
Christian medical Fellowship		3-4	General	The list given of signs or changes that might suggest a patient is entering that final stage of care might be helpful, but will tend towards the notion of care during this final phase of life as a 'pathway'. The appearance of such signs or changes will be interpreted as the first step along this pathway leading to the implication that a protocol should now be followed. This was one of the criticisms of the Liverpool Care Pathway (LCP), and it is difficult to	Thank you for your comment. The Committee purposefully drafted recommendations that advocate an individualised approach to assessment and management and care avoiding the suggestion of a 'tick box, pathway' approach as you have outlined. We believe that we have been clear enough in this respect and do not wish to make any further additions to the recommendations. After careful consideration the Committee have

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				see how the present guidelines will avoid generating the same, heavily-criticised mind-set. ' Less pathway, more care' was the title of Baroness Neuberger's report, and we would suggest that greater emphasis is given in the guidelines to the recognition that such signs and changes can come *and go again*, and do not necessarily imply the final stages of life the first time they appear. It is essential that the new guidelines do not lend themselves to being interpreted as another pathway – compassionate care and kindness requires built-in flexibility, in the mind-sets of carers as well as in the guidelines themselves.	rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline. We have also emphasized the importance of clinical judgement in the NICE version of the guideline in section 1.1 and made a separate recommendation on seeking expert advice.
Christian medical Fellowship		5	26-27	No explicit mention is made of the patient's spiritual needs in this section about communication. The GMC guidance states that discussion with patients who are dying should cover "the patient's needs for religious, spiritual or other personal support". We recommend that those who enjoy positions of trust, spiritual care and guidance in patients' lives, as well as those employed as hospital/hospice chaplains, be seen as part of the multiprofessional team. Quite often such a person will be the most appropriate person to explain prognosis and treatment options, and provide opportunity for the dying person to talk about their fears and anxieties, or prepare them for death. We would like to see specific reference made in the guidelines to the particular role such 'ministers'	Thank you for your comment. We agree and have added in "any cultural, religious, social or spiritual needs or preferences that should be considered" in recommendation 1.2.1 As the focus of this guideline is care of the dying adult, we are unable to recommend providing spiritual support to those important to the dying person.

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				can fill, encouraging clinical staff to welcome and value their contribution. It should be recognised also that some healthcare professionals, especially those who have a personal faith, may well be competent to provide such spiritual support themselves. We also recommend that family members and carers be specifically offered or invited to have access to that sort of spiritual support.	
Christian medical Fellowship		9	General	a. Dehydration was a central concern of Baroness Neuberger's report, and was a recurring criticism of the LCP *as implemented.* The NICE guidelines fail to make any reference to supporting oral nutrition or to assessing the need for clinically assisted nutrition. Both the Review of the LCP and GMC guidance on *Treatment and Care towards the end of life* make clear that nutritional need must be assessed. Unless the NICE guideline specifically requires the assessment of nutritional needs, it is likely that reduced oral intake will be interpreted as a sign of dying, whereas it may be the result of nothing other than a sore mouth or ill-fitting dentures. b. Clearly, it is essential to distinguish those who are dying *of* dehydration from those who are	Thank you for your comment. a. Nutrition is beyond the remit and scope of this guideline. The scope of the guideline was subject to a public consultation process in 2014. Given time and resource constraints, this topic was not prioritised for this guideline as other review areas were considered more likely, during scope development, to have a wider impact on clinical practice. b. Our recommendations are aimed at maintaining hydration at the end of life and we have not reviewed specific evidence on those dying of dehydration. The Committee did not want to endorse clinically assisted hydration for all patients and recommend that this should be based on risk versus benefit, the person's preference and other factors listed in

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				dying and who may experience no sense of thirst. The guidelines recognise the limited nature of the current evidence base for assisted hydration but fail to propose further research in this area. In general, the guidelines appear to 'lean away' from hydration unless distressing symptoms or signs of dehydration, such as delirium, are clearly present. Even in that situation, it is more likely that sedation, not hydration, would be given to manage the delirium. We suggest that the guideline should lay greater emphasis upon the need for ongoing assessment of hydration. Monitoring urinary output is not mentioned but would be simple to do and would help avoid the need for monitoring frequent blood tests of renal function.	recommendation 2.4.7. We agree that sedation should not be used if hydration would treat the person's agitation. We cannot give guidance on assessing hydration as this has not been prioritised for review. Recommendation 1.4.4 (2.4.4) has now been amended to state "assess hydration status". Further details on monitoring hydration status are given in the 'Linking evidence to recommendations' section in 8.6 of the full guideline.
Christian medical Fellowship		16	27-28	The guidelines call for daily monitoring and assessment of side-effects by the lead healthcare professional. In care home or patient's home settings, it is very unlikely that daily visits by doctors will routinely happen, but in the final days of a dying person's life changes must be monitored by someone able to interpret those changes accurately and prescribe accordingly. Doctors cannot delegate that responsibility to others and the NICE guidelines, we suggest, should address this issue as it applies not only in hospitals but in primary care settings.	Thank you for your comment. The Committee intend this recommendation to apply to all settings, including the community. We do not state that the lead healthcare professional does the monitoring. We disagree that clinicians cannot delegate this responsibility and consider this could be a nurse, especially in the community.

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Christian medical Fellowship		16	General	Our primary concern with this guidance lies in the area of anticipatory prescribing. This was another heavily criticised aspect of LCP, and we are concerned that the new NICE guidelines carry the same inherent weakness. When physicians write up sedatives and narcotics ahead of time, but are not called or present to confirm the appropriateness of their use at a particular moment, then the responsibility for decision-making falls to someone very junior. The fact that these medications have been written up in advance is too often interpreted as reason enough to use them, rather than making a careful assessment of the patient's needs at the time. What is intended as permission-giving can be interpreted as pathway protocol. We recognise that guidance has to apply across a range of care settings and that in some of those settings a doctor is not immediately available to assess and prescribe. Not to have medication prescribed in anticipation could, in these settings, lead to a delay in providing symptom relief. Where assessment would be quickly available, the practice of anticipatory prescribing should be discouraged to minimise the risk of overtreatment. Where there is no feasible alternative to anticipatory prescribing, assessment of patient needs by the most senior available care staff, and investment in training at all	Thank you for your comment. The Committee recognised the complexities surrounding anticipatory prescribing, but do recommend that anticipatory prescribing be individualised for patients. Administration of medications prescribed in anticipation by a clinician involved in the dying person's care should be reviewed before administration in light of the current symptoms and treatment efficacy fed back to the lead health care professional as recommended in 1.6.5 and 1.6.6. The Committee discussion is captured in the 'Linking evidence to recommendations' section for this review area. We recognize that this is a balance between timely administration to avoid distress and the need for a tailored and individualised approach to anticipatory prescribing that avoids a blanket and repeated approach to prescribing. We hope that our recommendations build in a process for review before administration in the case of prescribing in advance of an event and make explicit the need to monitor the efficacy of this treatment before continuing to administer. The Committee hope that this will avoid the situation that you have described. The Committee chose to make a research recommendation surrounding anticipatory prescribing. A cost effectiveness evaluation would include also the risk of overtreatment and under

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				levels, would help ameliorate the risks of inappropriate use of pre-prescribed medication. In regard to anticipatory prescribing, the NICE guidance suggests future research on cost effectiveness but research also needs to focus on the dangers of overtreatment or undertreatment and how these could be offset.	treatment. It is hoped that patient and carer symptom ratings, and quality of life scales will provide information on under or over treatment if this piece of research is undertaken.
Christian Voice	Full	General		We were highly critical of the Liverpool Care Pathway (LCP), and remain critical of any 'pathway' to death. We are disappointed that one page 150 of the NICE draft guideline, it says: "Death is unlikely to be hastened by not having clinically assisted hydration". This is palpably untrue. If someone is unable to drink, not giving hydration will kill them. We are also astonished that there is no mention of nutrition that we can see in the draft guideline. We wish to remind NICE of the independent review on the LCP carried out by Baroness Neuberger and her highly critical report in 2012. It was particularly critical of the withdrawal of nutrition and hydration. Lady Neuberger said "the default course of action should be that patients be supported with hydration and nutrition unless there is a strong reason not to do so".	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given. The order of the recommendations reflects the Committee's decision that the dying person should be supported to drink by oral means first if they wish and are able to before clinically assisted hydration is considered. Further detail is given in the full version of the guideline under 'Linking evidence to recommendations'.

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				That must be reflected in the NICE guidance if the public are to have any confidence in it. In too many reported cases, elderly patients were sedated, starved and dehydrated to death under the LCP. Relatives reported being told in a matter-of-fact way that their relative was dying when they weren't at all. You will be aware, or should be, of the personal testimony of Fiona Bruce MP about how her own father was treated. She was told he was dying, she moved him to a nursing home, and he recovered. So we are also concerned that there is still a 'pathway' element to the NICE draft guidance. The whole idea of a 'pathway' leads one to question its destination. The object of the exercise must not be to 'free up beds'. Hospitals should be obliged under any NICE guidelines to give nutrition and hydration adequate for patients' physiological needs at all times and regardless of prognosis. There appears to be no structure in the draft guidance for a clinical decision on whether or not a patient is actually dying. Such a decision should be led by evidence, if there is no evidence, then the patient should be cared for as if recovery were expected. We also believe the guidance should specify that a consultant doctor, not a nurse, should make every decision, in consultation with relatives, about	Nutrition is beyond the remit and scope of this guideline. The Committee have drafted these recommendations to provide an individualized approach to caring for the dying person and have avoided a pathway approach. Please see the chapter on recognizing dying which has a strong emphasis on assessing whether the person is deteriorating or in fact improving. The title of the guideline reflects the referral from NHS England. Whilst acknowledging that people may recover, it is also important to focus clearly on the clinical care required by those who are recognized to be dying.

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				treatment for vulnerable or elderly patients. So finally, we question the very title of the draft guidance: 'Care of the Dying Adult'. Is this a 'dying adult' or simply a 'very ill adult'? Unless there is clear clinical evidence that someone is actually dying, such an expression should never be used. It risks making the outcome follow a hospital manager's desire and is quite out of place in modern care. We repeat that the public must have confidence in the medical profession. The LCP did much to destroy such trust. NICE has an opportunity to put matters right. It is an opportunity which we hope and pray is seized with enthusiasm.	
Church of England: Mission and Public Affairs Division	Full	11	25	Add: '….or urgently seeking spiritual support'	Thank you for your comment. This list reflects the evidence identified in the review. The Committee recognise that there are many other signs and symptoms that could go in this list and the ones given are examples only. We do not feel it necessary to add this issue in our list.
Church of England: Mission and Public Affairs Division	Full	11	10	The recommendation ought to read 'review and gather information….'as it is important that prior information, particularly with regard to the spiritual, social and psychological needs of a patient are fully taken into account.	Thank you for your comment. We have made our recommendations in order so that information is gathered, the person assessed and then the individual reviewed.

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Church of England: Mission and Public Affairs Division	Full	12	1	24 hours is a long time in the care of a dying person. We are concerned that a limit of 'at least 24 hours' might, in practice, become a target and recommend that the time interval is shortened.	Thank you for your comment. The recommendation states 'at least every 24 hours' and does not preclude more frequent monitoring.
Church of England: Mission and Public Affairs Division	Full	12	13	After 'establish' add 'and review'. Patient wishes might change in the course of their final days; it is important that their communication needs are kept up to date.	Thank you for your comment. Detail on reviewing communication needs and recording these has been added to the 'Linking evidence to recommendations' section of the full guideline (please see section 6.6).
Church of England: Mission and Public Affairs Division	Full	12	42	It is important to check that patients continue to agree with any stipulations they might have made in an Advanced Care Plan; a sentence ought to be added to this effect.	Thank you for your comment. We agree. We feel that a number of our recommendations identify the need to review the dying person's wishes in the last days of life particularly recommendation 19 (please see section 2.3.7).
Church of England: Mission and Public	Full	14	18	'Preferably daily' is too imprecise a term when reviewing the possible need for assisted hydration. This guideline could lead to a patient in need of assisted hydration not having their needs met for a considerable period of time.	Thank you for your comment. The Committee have given their minimum requirement here and it does not preclude more frequent reviews.

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Affairs Division					
Church of England: Mission and Public Affairs Division	Full	14	21	'Risks and benefits'; please see point 6.	Thank you for your comment. Further detail of risks and benefits are in the 'Linking evidence to recommendations' section of the full guideline.
Church of England: Mission and Public Affairs Division	Full	14	28&30	'Unlikely' is much too imprecise a term to use. How unlikely is 'unlikely'?	Thank you for your comment. The Committee wanted to highlight the lack of evidence around survival and have amended "unlikely" to state that it is "uncertain" whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given
Church of England: Mission and Public Affairs Division	Full	14	44	'At least once a day'; please see points 3 and 7.	Thank you for your comment. The Committee have given their minimum requirement here and it does not preclude more frequent reviews.
Church of England: Mission and Public Affairs	Full	14	8	'Risks and benefits' ought to read 'benefits and risks'; it is important to begin with potential positives rather than potential negatives (as p17, lines 33&35).	Thank you for your comment. The Committee believe this is clear as stated.

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Division					
Church of England: Mission and Public Affairs Division	Full	15	5	Omit 'possible'.	Thank you for your comment. We have carefully considered the recommendation and feel that no change is required.
Church of England: Mission and Public Affairs Division	Full	15	9&10	'Risks and benefits'; please see point 6.	Thank you for your comment. Further detail of risks and benefits are in the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
Church of England: Mission and Public Affairs Division	Full	18	18	'At least daily'; please see point 3	Thank you for your comment. The Committee considered, in the absence of an evidence review, that at least daily was appropriate. This does not preclude more frequent monitoring.
Cicely Saunders Institute, King's College London	Full	general	general	At 266 pages, we have concerns that the length of this NICE guidance makes it unimplementable in practice. A shorter document is likely to be more effective.	Thank you for your comment and for participating in the consultation process. Please see the NICE guideline for a summary of the recommendations.

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Cicely Saunders Institute, King's College London	Full	21	21	Typo '23 92%'	Thank you for your comment. This has been amended.
Cicely Saunders Institute, King's College London	Full	20	12	Typo 'dos'	Thank you for your comment. This has been amended.
Cicely Saunders Institute, King's College London	Full	22	1	The NICE guidance is described as providing an 'evidence based set of recommendations'. Given the often weak / lack of evidence found through the review process, we are concerned that readers may assume that there is an evidence base which is not present. We recommend that the specific level of evidence should be presented with each recommendation.	Thank you for your comment. It is not NICE process to distinguish the levels of evidence behind recommendations. The full guideline provides details of the levels of evidence you allude to. The recommendations are drafted in light of the evidence reviewed and are structured according to the principles outlined in section 4.4 of the full guideline and in light of the NICE guidelines manual, section 9.2 http://www.nice.org.uk/article/pmg20/chapter/1%20Introduction%20and%20overview. Some of our recommendations are made with more certainty than others. We have worded our recommendations to reflect this. We have used 'consider' to reflect a recommendation for which the evidence of benefit is

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					less certain.
Cicely Saunders Institute, King's College London	Full	34	11	Under Guideline Population it states 'studies that include groups of people described as dying within a timeframe of longer than one month were excluded.' We are concerned that this has resulted in exclusion of many potentially relevant studies where patient prognosis was >4 weeks. Evidence from patients with 6 months left to live is better than no evidence at all. We recommend the inclusion criteria be broadened, for example to patients in the last year of life.	Thank you for your comment. The clinical focus is the care provided in the last two to three days of life. Section 4.2.4.1 defines the guideline population in this way. When considering the evidence, the Committee also agreed a number of parameters to guide the protocols developed and therefore the types of studies included and the data retrieved. For example, studies that captured data within 14 days of death would be considered directly applicable. Recognizing that prognosis may be uncertain at the end of life , the Committee felt that it would be appropriate to consider evidence up to 30 days as indirect evidence .
Cicely Saunders Institute, King's College London	Full	general		We welcome the focus on future research, but we have concerns about the process leading to these recommendations. How do these recommendations fit in with the recent James Lind Priority Setting Partnership, and which research recommendations should be prioritised? We recommend greater clarity is included on the methods of selecting these research priorities.	Thank you for your comment. The process for formulating research recommendations is outlined in section 9.5 of the NICE guidelines manual which can be found at the following link: http://www.nice.org.uk/article/pmg20/chapter/1%20Introduction%20and%20overview. Further detail is also provided in section 4.4.1 of the full guideline. The Committee have prioritized four recommendations for further research further to their review of the evidence. These are linked to recognizing dying, agitation and delirium and noisy respiratory secretions. Full discussion is provided in Appendix O.

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Cicely Saunders Institute, King's College London	Full	general	general	There is no mention of discussion of CPR. We recommend that this is included.	The guideline has not been able to address all issues relevant to the care of the dying adult. This issue is beyond the remit and scope of this guideline.
Cicely Saunders Institute, King's College London	Full	12	5	The guideline advises 'seek advice from colleagues with more experience of providing end of life care if…'. We recommend a clear indication of which colleagues should be consulted (for example specialist palliative care teams) should be provided, taking into account different settings (community, hospital etc).	Thank you for your comment. Further detail is provided in the full guideline 'Linking evidence to recommendations section'. Colleagues with more experience may be specialist palliative care teams, but may also be other specialties such as cardiologists or renal physicians or non-specialists with significant experience with providing care at the end of life such as GPs.
Cicely Saunders Institute, King's College London	Full	general	general	Throughout, there is no mention of the issue of whether patients have capacity for making decisions, or explicit mention of the Mental Capacity Act.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental

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					capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009
Cicely Saunders Institute, King's College London	Full	153	7	Typo 'putingt'	Thank you for your comment. This has been amended.
Cicely Saunders Institute, King's College London	Full	172	10	To illustrate our comment above (4): The Cochrane review by Simon et al (2010) of benzodiazepines in patients with breathlessness due to advanced disease has not been included in this guidance. The reason stated is 'not guideline condition' – since the patients had 'advanced disease' rather than <4 weeks to live.	Thank you for your comment. The Cochrane review on benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases was reviewed for inclusion in this review. However owing to the population used for the Cochrane systematic review being wider and including patients outside of the last days of life, this was not included in the systematic review for this guideline.
Cicely Saunders Institute, King's College London	Full	177	6	Currow et al (2015) RCT of octreotide in malignant bowel obstruction is not included, and reason for this is unclear (not listed under 'excluded studies' in appendix)	Thank you for your comment. The Currow et al 2015 paper mentioned was not included in the evidence review as it was published after our search strategy cut-off date. The technical team have reviewed the paper, and as its population is not in the last days of life, the study would have been excluded from this evidence review.
Cicely Saunders Institute,	Full	156	18	Fatigue is not listed in the common symptoms in the last days of life, or considered in this guidance. Given the high prevalence of fatigue in the dying, we	Thank you for your comment. This was not identified at the scoping stage as a priority for the guideline and is a symptom of other issues. Fatigue

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King's College London				propose this should be included.	is discussed in the section on recognising dying and included in the evidence review in chapter 5.
Cicely Saunders Institute, King's College London	Full	164	1	This part of the guidance searched for 'studies that addressed pharmacological management of breathlessness in the last days of a person's life'. We recommend that non-pharmacological interventions are included in the search, especially since these are subsequently included in the recommendations.	Thank you for your comment. The Committee acknowledge the importance of such approaches and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Cicely Saunders Institute, King's College London	Full	general	general	Throughout the guidance there is no mention of the consideration of renal impairment, in particular how renal impairment should influence prescribing. At the very least this should be highlighted, with advice to consider both reduction in dose and increased dose interval for drugs that are predominantly renally cleared. In addition we recommend that special mention of assessment of people with dementia be made.	Thank you. Additional detail has been added to the guideline about those with renal impairment. Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Cicely Saunder	Full	217	Table 1	We have concerns about this table for prescribing. 1. The structure of the table does not give an option of people who are taking analgesics	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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s Institute, King's College London				but unable to continue these (eg due to reduced oral intake), which we recommend is added for clarity. 2. The table instructs patient's opioid should be increased to the 'maximum dose' – with no indication of what this maximum dose is. This is unworkable and potentially dangerous. 3. Regular IV paracetamol for people with days to live is unusual, and would necessitate admission to a hospital / hospice. 4. We recommend that it is made clear that drugs and doses may need to be modified in renal failure 5. We recommend addition of information on how to convert oral to s/c opioid doses.	symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Cicely Saunders Institute, King's College London	Full	218	Table 2	We have concerns about this table for prescribing. 1. Reference to a 'maximum dose' of benzodiazepine is made, which is unclear. 2. The recommendations on drugs / doses / routes include high doses, which may be unsafe for some patients. The table suggests up to 60 mg / day midazolam (5 mg 2 hourly) for breathlessness before the need for specialist palliative care team advice. This is not evidence based, and it is not safe and may encourage inappropriate doses being used.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Cicely Saunders Institute, King's College London	Full	219	Table 3	Typo '2.5 – 5 up to mg 12 hourly' Typo 'or' needed between haloperidol and metoclopramide We would not recommend PRN s/c cyclizine, which can be a painful injection.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Cicely Saunders Institute, King's College London	Full	220	Table 4	We have concerns about this table for prescribing. 1. Reference to a 'maximum dose' of benzodiazepine is made, which is unclear. 2. The recommendations on drugs / doses / routes include high doses, which may be unsafe for some patients (see comment 13)	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Cochrane Pain, Palliative and Supportiv	Short Draft guideline	12	14-17	We are concerned that this implies easy choice of and access to 'validated' behavioural pain assessment. The various tools are poor to moderate quality and hardly 'validated'. Use of a poor quality tool is unhelpful, possibly harmful. It would be more	Thank you for your comment. An evidence review was not conducted on the use of pain assessment tools in the last few days of life, however the Committee chose to make a recommendation about their use based on their own clinical experience. The

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e Care Review Group				helpful to suggest one of the better ones, or to recommend observation of facial expression ('grimacing'), or even to try analgesia in the case of unexplained behavioural change or distress to see if it returns to(wards) normal.	Committee were particularly concerned that pain may be undertreated in a dying person who cannot effectively verbally communicate and that other signs and symptoms that may be a sign of pain, may be treated inappropriately with sedatives rather than analgesics. Further detail has been added to the 'Linking evidence to recommendations' section of this chapter in the full guideline (please see section 9.5)
Cochrane Pain, Palliative and Supportive Care Review Group	Full guidelines	160	17	Recommendation 9.5 says much the same as the draft guideline, so the same concerns apply. Reference is made on p161 to the NICE dementia guidelines but they are no more specific about what should be used to assess pain in the presence of cognitive impairment than the recommendation itself, so it is redundant.	Thank you, assessment of pain was not prioritised as part of the scope.
COLLEGE OF HEALTH CARE CHAPLAINS				Overall, I was quite stunned by the size of the Guideline. I am glad that there is a short version. However, it is all-encompassing and the group who have formulated the document are to be commended on their work. I do think, though, that as the document rightly concentrates on the physical aspects of dying, it is a pity that there is not a wider consideration of the place of spiritual care for these patients and those who are important to them. As a nursing colleague in the acute hospital frequently said to me: "You are of far more use at this time than	Thank you for your comment. Spiritual care was beyond the remit and scope of the guideline. The Committee chose to co-opt a spiritual advisor to consider the spiritual needs of the dying person when considered against the topics that were included in the scope.

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				we are."	
COLLEGE OF HEALTH CARE CHAPLAINS	Short	9	10-12	After speaking with clinical colleagues, I would like to suggest that the dying person and to them are also advised that giving clinically assisted hydration may also cause problems, e.g. pooling. I do not think it is ethical to only advise of the positives when there is also possibly a negative. Without having full information, an informed decision cannot be given.	Thank you for your comment. We agree that both the harms and benefits of clinically assisted hydration should be discussed with the dying person and those important to them, as stated in recommendation 2.4.5. Also, recommendation 2.4.9 advises clinicians to reduce or to stop in the event of harm. Further detail has been added to the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
COLLEGE OF HEALTH CARE CHAPLAINS	Short	12	19	As this document will largely be used by non-specialists, would it be possible to give examples of non-pharmacological management of breathlessness? e.g. putting on a fan; opening windows etc.	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
COLLEGE OF HEALTH CARE CHAPLAINS	Short	12	5-17	In this section on pain, there is no mention of the concept of Total Pain i.e. that although pain may manifest itself as physical, there may be a spiritual cause. When a patient is on massive amounts of medication and the physical pain is not reducing, then one must think "outside the box". I can give you several examples of situations where patients have been in physical pain and it is only when the	Thank you for your comment. We believe our recommendations that support shared decision making (particularly 1.3.2) will support this aspect of pain management if identified.

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				underlying cause has been addressed by a chaplain, that this has reduced; in each case the amount of pain medication has been significantly reduced. See my unpublished dissertation from my MA in Healthcare Chaplaincy, held at the University of Leeds: "The role of the chaplain in the multidisciplinary palliative care team" 2004. See also: Kuhl, D. (2003) *What Dying Patients Want*.	
COLLEGE OF HEALTH CARE CHAPLAINS	Short	13	17	As this document will largely be used by non-specialists, would it be possible to give examples of non-pharmacological methods for treating nausea and vomiting? e.g. sipping peppermint tea, making sure patient is not near food preparation areas etc.	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
COLLEGE OF HEALTH CARE CHAPLAINS	Short	14	8-12	In my experience, agitation in isolation may also be caused by spiritual distress. If the patient is conscious, they may be helped by speaking with someone experienced in these matters, e.g. a chaplain. In an unconscious patient, I have found the playing of quiet music, of the genre normally enjoyed by the patient, to be of immense help. As in no. 2 above, when a patient is on the maximum amount of medication and is still agitated, one must think "outside the box". I have experienced patients who	Thank you for your comment.

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				are unconscious and very near to death, and who are extremely agitated, become calm within 30 minutes and die peacefully 2 hours later, when music was played. I saw it yesterday in the hospice where I work, with a lady who has been very agitated, who is noticeably more relaxed now the music she enjoys is playing quietly in the background.	
COLLEGE OF HEALTH CARE CHAPLAINS	Short	26	6-7	Would it be possible to add to this section a round-up of the examples given elsewhere in the document, as a reminder of the non-pharmacological suggestions of interventions?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Compassion in Dying	Short	1.1.1.		We support the aims of the NICE guidance to ensure that a person's goals and wishes are listened to; however it is vital to acknowledge the importance of having end-of-life support and treatment discussions before the last days of life. This was recently mirrored by Claire Henry (National Council for Palliative Care) who emphasised the importance of conversations needing to start much earlier on - before people become ill	Thank you for your comment, we would agree that it is important, where possible to have discussions as early as possible about end of life support. This guideline focusses on the clinical care of the dying adult in the last 2- 3 days of life. We make clear reference to the importance of shared decision-making (where appropriate and possible) and documentation in a number of our

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				(http://www.bbc.co.uk/news/health-33701339). Compassion in Dying believe that everyone should have the opportunity to create an end-of-life care plan setting out their needs and wishes for the end of life, and should have access to good advice services to inform their choices. We provide free information and support to people to plan ahead for their future medical care and treatment. We believe that Advance Decisions should be recorded in a central national health register so that health professionals can take them into account in treatment, and that health and social care professionals should have access to training on end-of-life issues. Care professionals should be supported to help people to record their wishes.	recommendations.
Compassion in Dying	Long	7.1	34	a) It is important to note that 'enduring power of attorney' only relates to a person being able to make decisions on behalf of another about their property or financial affairs. The relevant document in the context of end of life care would be the Lasting Power of Attorney for Health and Welfare. In this document it is possible for someone ('the donor') to appoint another person ('the attorney') to make decisions about their health and personal welfare on their behalf should they lose mental capacity to make	a) Thank you for your comment. This has been amended in the guideline. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues. We have also made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. b) The Committee agrees that shared decision making are relevant in all circumstances regardless of the dying person's capacity. c) Service Delivery, including training, is not

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				these decisions for themselves. Within this document it is possible for the attorney to be given the authority to make decisions about giving or refusing consent to life-sustaining treatment on the donor's behalf. The attorney is also able to make decisions about where the donor is cared for and their daily routine. All decisions made by the attorney must be made in the donor's best interests (and therefore in consultation with other relevant individuals including healthcare professionals involved in the donor's care). b) Shared decision-making is therefore just as important when the individual lacks capacity but has appointed a health and welfare attorney as when the individual has capacity. c) It is important that all staff are aware of the different tools that an individual can use to make their wishes for their care and treatment (especially at the end of life) known about. Lack of understanding about these different documents (as highlighted by the use of 'enduring power of attorney' rather than lasting power of attorney), can mean that the patient's wishes for treatment	included in the remit of this guideline. NICE is producing palliative care service delivery guideline that may cover this topic. More details can be found at the following link: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.

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				and care are either not known about or not followed.	
Compassion in Dying	Long	7.1	41	We support the acknowledgement of the barriers and facilitators around shared decision-making and personalised care plans and the examples covered in the longer document are important. Good communication is essential in the doctor-patient relationship including the ability of healthcare professionals to initiate conversations about a person's end-of-life wishes and preferences. Also integral is the provision of accurate information about a person's rights and choices for end of life care. All staff should have the knowledge and understanding to be able to talk about these issues with their patients, and to implement this knowledge when it is needed.	Thank you for your comment. . We have already provided a cross reference to the NICE guideline on patient experience in adult NHS services where recommendations already exist to support effective communication skills.
Compassion in Dying	Short	1.2.2.		Prognosis should, as much as possible, be discussed before it reaches a critical stage, e.g. the last few days of life. Not only does this give the patient and their family time to consider future care for when the patient has lost capacity, but it should help care professionals deliver patient-centred care and actually realise the vision of 'no decision about me, without me'. The earlier prognosis is done the better it is for patients, who can then have appropriate care (e.g. palliative/end-of-life) delivered and they can input into decisions. According to the	Thank you for your comment. The guideline has been drafted to address the delivery of care in the last few days of life. The Committee's intention behind this recommendation is to ensure that these discussions take place in a timely fashion if this has not happened before the last days of life. The committee feels it is important to have these discussions with the dying person and to also offer an opportunity to individuals who have made an advance statement or an advance decision to refuse treatment to revise this if their needs,

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				recent VOICES survey of bereaved people, 38.5% of patients probably did not or definitely did not know they were dying in the last three months of their life. Figures are not available for deaths in the last few days, demonstrating an evidence gap. A handful of studies report that early palliative care is associated with clinical benefits and at least one health economic study has found that earlier palliative care consultation during hospital admission is associated with lower cost of hospital stay for patients admitted with an advanced cancer diagnosis. http://www.ncbi.nlm.nih.gov/pubmed/24698057 http://www.biomedcentral.com/1471-2377/14/59?utm_campaign=29_04_14_BMCNeurol_MailingArticle_PA_REG&utm_content=7389471880&utm_medium=BMCemail&utm_source=Emailvision http://jco.ascopubs.org/content/early/2015/06/08/JCO.2014.60.2334.short	wishes and goals have changed. With regards to the economic paper you cite, this would have been excluded from the guideline as it does not cover a particular review question the guideline sought to answer. Also as it is a US study this would be judged as not applicable to the UK NHS setting.
Compassion in Dying	Short	1.2.5.		We support that recorded care preferences are referenced. What needs to be stressed is that hospitals, care teams etc. need access to patient preferences around the clock, using an appropriate system.	Thank you for your comment. We are pleased to refer to our recommendation that supports the sharing of the individualised care plan across the multiprofessional team responsible for the care of the person in the last days of life (recommendations

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				The two bullet points in 1.2.5. are separate issues and should be treated accordingly. Caution also needs to be taken when using different language to describe similar tools/documents, such as 'Advance Care Plan', 'Advance Decision to refuse treatment' and 'record of care'. This is especially confusing for the patient and relatives.	2.3.5 and 2.3.6). We agree that Advance Care Planning and Mental Capacity assessments are two different issues. However, the recommendation is drafted to ensure that healthcare professionals consider both issues when communicating with the dying person and those important to them during the last days of life. We have made amendments to this recommendation to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and Lasting Power of Attorney. For all NICE guidance a patient friendly version of the guideline is published in the format of 'information for the Public', this version of the guideline uses layman's terms to support the dissemination of the guideline Further discussion is provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on Mental Capacity. We have also made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental

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					capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Compassion in Dying	Short	1.3.2		Many people in the final stages of life will lack capacity. One study indicates that one third of terminally ill patients demonstrated serious impairment on at least one domain of decisional capacity at end-of-life and another that around 40% of people who have a dementia diagnosis die in hospital (although this data covers 2001-2010 and there are indications that this number is decreasing). This highlights the importance of discussing and recording care and treatment preferences before capacity is lost and the importance of shared decision-making if the person lacks capacity and has not recorded their wishes. This highlights the parallel importance of good implementation of the Mental Capacity Act at the end of life, alongside the NICE Care of the Dying Adult guidance. This requires effective understanding and application of the Act's five principles especially that any decision made on behalf of a person who lacks capacity must be made in their best interests. This requires consultation with others and consideration of the person's wishes, feelings, values and beliefs. Feedback from our	The committee agree that level of consciousness and mental capacity at end of life are important issues when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues. We have also made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. We recognize that it is important to undertake advance care planning early but as the focus of this guideline is on the last 2-3 days of life, we have only been able to address this issue within this time frame. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare

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				service users suggests that this does not always happen. It also means thorough understanding of the different tools that people have under the Mental Capacity Act for their future treatment and care, namely Advance Decisions and Lasting Powers of Attorney for Health and Welfare. It is important to note that if the patient lacks capacity and they have made an Advance Decision that meets certain requirements (is 'valid and applicable), it must be followed by the healthcare professional responsible, even if those close to the patient disagree with its content. If Advance Decisions are valid and applicable, they are not just part of the process of shared decision-making as something that must be taken into account, but are binding on healthcare professionals. It is important to note that there are additional requirements for Advance Decisions that refuse life-sustaining treatment. Life-sustaining treatment includes things like CPR and clinically assisted nutrition and hydration. If the Advance Decision does not meet the standard needed to be valid and applicable, it must be given consideration as evidence of the person's wishes for treatment as part of the best interests' process if the patient lacks capacity. We welcome the inclusion of the dying person's goals and wishes as something that must be taken	

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				into account in the shared decision-making process. We also feel that focus needs to be given to ensuring people can record their goals and wishes for end of life before the critical stage. As evidenced by recent data, work is needed to ensure that people are made aware of, and can act on, their end-of-life rights. In a 2015 YouGov poll of 2,000 people, only 20% reported that the last close relative or friend who died had their end-of-life wishes formally recorded, for example through completing an Advance Decision, or having their wishes recorded in their medical notes (29% don't know, 51% said there was no record of wishes). This poll excluded those who died suddenly. When patients' wishes were recorded, they were 41% more likely to be judged by loved ones to have died well. Where end-of-life wishes were not recorded people were 53% more likely to receive treatment they did not want. 39% of respondents said that their friend or relative was given medical treatment at the end of life intended to keep them alive, such as cardio-pulmonary resuscitation or artificial nutrition and hydration. 20% of these people felt that the dying person would not have wanted to receive this treatment. Crucially, for those people who were felt to have received treatment that they did not want, 17% had their end-of-life wishes formally recorded, whereas 26% did not.	

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				http://www.ncbi.nlm.nih.gov/pubmed/24698057 http://www.ncbi.nlm.nih.gov/pubmed/24666928 http://compassionindying.org.uk/one-in-five-dying-patients/	
Compassion in Dying	Short	1.3.5		We support this proposal but it should not replace the fact that every member of the healthcare team should be aware of the person's wishes and decisions and be able to engage in shared decision-making.	Thank you for your comment. We have amended our recommendation to encourage people providing end of life care to share the care plan with the dying person, those important to them and all members of the multiprofessional team.
Compassion in Dying	Short	1.3.6		We support the reference to recording care plan discussions and decisions in the person's medical records and sharing this information with all members of the multi-professional care team. This must also extend to sharing information across different care settings and ensuring that a robust system is in place for communicating this information. A key concern for Compassion in Dying service users is that their recorded wishes will not be known about at the time they are needed so we feel it is vital that systems are in place to make sure that this concern is addressed. We would suggest that a practical way to overcome some of these challenges would be to have a national centralised register of Advance Decisions. This would mean that they can	Thank you for your comment. How information is communicated across care settings is outside the remit of this guideline. NICE is currently developing guidance on palliative care service delivery and this topic may be included in that guidance. More details can be found at the following link: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799. The Committee agrees that ensuring that the wishes of the dying person are met at the end of life is a key element in delivering the best end of life care and have drafted recommendations that encourage healthcare professionals to consider, explore and discuss the goals, wishes and needs of the dying person and to prioritise these in the delivery of individualised care.

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				be easily accessible to any professional that requires them and the existence of them can be communicated across different care settings.	We are unable to comment on your suggestion of a national centralised register of Advance Decisions.
Compassion in Dying	Short	1.2.3.		This is potentially confusing and does not reflect realities of practice. Whilst we support having a 'champion' or expert in palliative/end-of-life care in each multidisciplinary team, we are concerned that the reality is different. In order that this aim is set out in NICE Guidance, more work is needed to ensure that care teams have an appropriate mix of expertise.	Thank you for your comment, the composition of the multidisciplinary team would vary according to patient needs, setting of care and possibly across different Trusts, and is therefore outside the remit of this guideline. The recommendation you refer to is intended to ensure that an appropriate team member explains prognosis based on a particular skill set or relationship. The committee note that this may be any member of the multi professional team providing they have the relevant experience and skill.
Countess of Chester	Full	245	3	Refers to `Advanced care planning` and `advanced care plan` instead of `advance care plan`. Advance and advanced in this context are used interchangeably throughout both long and short documents including in glossary and acronyms (section 11). My understanding is that this refers to planning of care in advance, not `advanced`.	Thank you for your comment. This has been amended throughout the document.
Countess of Chester	Short	18	21	The wording implies that people remaining ambulant, self-caring, taking oral medication and eating and drinking right up to the point of dying is common. I agree is occurs but would suggest it is uncommon (hence the indicators that a person is	Thank you for your comment. We believe that our introductory text is reflective of the broadest range of experiences as people enter the last days of life and do not feel that additional text is required here.

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				dying) and that it would be helpful if the wording reflected this. It would also be helpful to indicate that not everyone who is dying needs a syringe driver and that this is dependent on their symptoms and whether they need medication for symptom control. There can be an assumption particularly within hospitals that anyone who is in the final days and hours of life should have a syringe driver.	
Countess of Chester	Full	155	7	Should read `putting` (typo)	Thank you for your comment. This has been amended.
Countess of Chester	Full	183	13	The comment that Octreotide was more clinically effective than Hyoscine butylbromide in 1 study but less clinically effective in another – this does not seem to reflect what is written about these studies on page181, appears to contradict this	Thank you, this has been amended.
Countess of Chester	Full	210	24	Glycopyrronium also has antispasmodic effects and can be used in bowel obstruction – has the advantage over hyoscine hydrobromide that can be used in syringe driver with cyclizine	Thank you. This has been amended. These medications are listed providing licensed medications first and then other non-licensed medications are listed alphabetically, and not in order or preference. The Committee have also made recommendations linked to the use of syringe pumps (please see recommendation 59)
Countess of Chester	Short	11	12	May help to indicate that the patient`s ability to swallow safely is likely to deteriorate with their condition hence the importance of ongoing review	Thank you for your comment. We feel "tailored to the person's condition" covers your point.
Countess of	Short	11	13	May be relevant to include other routes such as topical and sublingual which may be of particular	Thank you for your comment. Detail has been added to the 'Linking evidence to recommendation' section

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Chester				importance in community and particularly care home settings	of chapter 9 (please see section 9.34).
Countess of Chester	Short	11	8	As I understand it the evidence that Cyclizine may exacerbate heart failure is theoretical and there is very little evidence of the significance of this in practice. When this was discussed in the development of our regional guidelines for palliative care in patients with heart failure there was much debate about how relevant this is in practice when a patient is in the final days of life. Wording does not reflect this	Thank you for your comment. The Committee noted that the summary of product characteristics from the manufacturer of cyclizine gives the following special warning and precaution for use: Cyclizine should be used with caution in patients with severe heart failure or acute myocardial infarction. In such patients, cyclizine may cause a fall in cardiac output associated with increases in heart rate, mean arterial pressure and pulmonary wedge pressure. The Committee discussed that it was important that clinicians were aware of this advice, but was aware of the lack of evidence regarding the efficacy and harms of cyclizine in the end of life setting and therefore was unable to make any specific recommendations in this regard. Further detail has been added to the 'Linking evidence to recommendations' section in the full guideline (Please see section 9.13).
Countess of Chester	Short	12	25	Also important to consider if oxygen when tried provides any symptomatic benefit or not – in hospital oxygen is quite frequently started and continued even when not really providing any symptomatic benefit	Thank you for your comment. The Committee chose not to make any recommendation for starting oxygen other than for those who are hypoxemic, due to the lack of evidence for its efficacy in managing breathlessness. The group felt no change was required.
Countess of Chester	Short	13	16	Would be helpful to indicate examples of non-pharmacological methods for treating nausea and vomiting here	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of

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					consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Countess of Chester	Short	15	11	I appreciate from the full version of the guidance that atropine is used more in other countries but it may be helpful to indicate here the more limited use and experience in the UK and if this is principally referring to use of the eye drops sublingually (as indicated in table 6 on p 22 of full guidance. Presumably the patient would need to be able to tolerate sublingual medication so eg level of consciousness and lucidity may affect use in practice	Thank you for your comment. The drugs listed here are in alphabetical order rather than order of preference. Further detail is given in the full guideline 'Linking evidence to recommendations section of chapter 9 (section 9.30).
Countess of Chester	Short	28	16	Wording `consider increasing dose up to the maximum dose of the medication if the dying person is still breathless` is misleading – what is maximum dose? Also need to be sure that if it is not helping other options are considered rather than dose just increased further	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Countess of Chester	Short	28	27	`4` next to Diazepam needs to be superscript otherwise may look to be part of dose recommendation	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Countess of Chester	Short	30		This section does not seem to consider addition of Haloperidol to Cyclizine which is a frequently used combination in this region and would often be used if cylizine is helping to some extent rather than a switch to levomepromazine	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Countess of Chester	Short	30	10	Prochlorperazine is rarely used in palliative care teams I have worked in	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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					being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Countess of Chester	Short	30	Note b	Cyclizine is commonly used in this area as first line antiemetic without significant problems in syringe drivers (although not used in combination with hyoscine butylbromide) and the phrase `not readily mixable in syringe driver with other drugs` suggests more problems than we experience in clinical practice. Levomepromazine also causes site inflammation and can be associated with unpredictable sedation	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Countess of Chester	Short	31 32		Need to adjust `6` by Clonazepam and Midazolam and `7`by Olanzepine and Risperidone to superscript otherwise looks as if is part of dose recommendation	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain

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					targeted at the non-specialist prescriber and will be made available on the NICE website.
Countess of Chester	Short	33	8	Hyoscine hydrobromide can be used in higher doses over 24hours than 1200mg over 24hours	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Department of Health	Full	general		Thank you for the opportunity to comment on the draft for the above clinical guideline. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment.
Douglas Macmillan Hospice	Full	21	1	I am surprised that the issue of benefits/risks of clinically assisted hydration is not identified as a key research question	Thank you for your comment. As we have made recommendations in this area, the Committee felt that these will guide practice sufficiently to ensure that high quality care is offered. Given that there is evidence in this area, although limited, and that there is a recent Cochrane review, the Committee

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					wanted to prioritise other areas in which less research has been conducted.
Douglas Macmillan Hospice	Full	21	15-44	No suggested research methodology is described for question 3. All the other questions include a suggested approach to research.	Thank you for your comment. This section has been reworded and detail added to this section. Further methodology for research recommendations can be found in Appendix O.
Douglas Macmillan Hospice	Full	General	General	Most of the document is reasonable.	Thank you for your comment.
Douglas Macmillan Hospice	Full	150	Recommendation 27	The statement "giving clinically assisted hydration may relieve distressing signs or symptoms related to hydration" sounds stronger than the evidence quoted supports. Given the high media interest in this topic, I think this recommendation, worded like this, may be interpreted to mean that hydration will often relieve distress. I realise this is not what is being said, but I wonder whether the recommendation needs to be reworded to more clearly describe the lack of evidence of meaningful benefit for most patients at this time (although clearly it is desirable to try to improve the evidence base)	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and have amended the work 'unlikely' to 'uncertain' whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given.
Douglas Macmillan Hospice	Full	217	1	Opioids needs mention/clarification when on regular opioid needs to be converted to syringe driver when patient unable to swallow po meds. Prn dose will be 1/6th of total opioid dose in previous 24 hrs Remove titration up in opioids to maximum dose as	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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				this is not true for most opioids use or really applies to buprenorphine Better to add titrate up as patient tolerates monitoring for side effects . Clarify if opioid naive or not on regular dose of morphine sulphate or diamorphine 2.5-5mg prn In section on continuous opioid infusion –would not put dose suggestion in Suggest instead comment like This needs to be reviewed after 24 hrs and if 2 or doses have been given the a syringe driver with diamorphine or morphine sulphate should be commenced with reference to the total amount of diamorphine or morphine sulphate required over previous 24 hours	implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Douglas Macmillan Hospice	Full	218	3	**Table 2: Prescribing for management of breathlessness in adults in the last days of life On opioids for breathlessness** Remove titration up in opioids to maximum dose as this is not true for most opioids use or really applies to buprenorphine Better to add titrate up as patient tolerates monitoring for side effects Consider syringe driver when patient unable to tolerate po meds for ongoing breathlessness management Again needs mention of diamorphine as morphine not widely used across uk Again would not specify dose in syringe driver whether diamorphine or morhine sulphate as this	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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				needs to be calculated whether opioid naive or on reg opioids on how much patient received in previous 24 hours Clonazpeam for injection going out of stock nationally so would remove	
Douglas Macmillan Hospice	Full	219	3	**Table 3: Prescribing for the management of nausea and vomiting in adults in** 1 **the last days of life** Would remove Prochlorperazine 5 mg up to 3 times a day from first line choices Continuous subcutaneous infusion haloperidol 1.5-5mg Second line levomepromazine never used prn dose 2.5-5mg suggest 6.25mg-12.5mg 4-6hrly	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Douglas Macmillan Hospice	Full	220	3	**Table 4: Prescribing for management of anxiety (with or without agitation) in adults in the last days of life** Not sure clonazepam s/c or via syringe driver should be included due to national shortage	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Douglas Macmillan Hospice	Full	221	3	**Table 5: Prescribing for management of delirium (with or without agitation) in adults in the last days of life** If unable to swallow meds would remove respiridone/olanzepine as never used in reality in this circumstance Subcutaneous dose of haloperidol 1-3mg prn s/c three times a day	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Douglas Macmillan Hospice	Full	222	2	**Table 6: Prescribing for the management of noisy respiratory secretions in** 1 **adults in the last days of life** Would not use transdermal hyoscine hydrobromide route or atropine drops ever in last days of life Reduce prn rates to 4hrly	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Douglas Macmillan Hospice	Full	General	General	I have some concerns about the section on pharmacological guidance for non specialist prescribers. Although the text at the beginning of this section explains the limitations of this guidance, a	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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				table containing specific drugs and doses in a NICE guideline is likely to be viewed as best practice rather than just suggestions. For example, the inclusion of only morphine under opioid medication may be interpreted as a recommendation that this should be the preferred opioids medication in this setting. Other guidance relating to prescribing exists, and given that the evidence does not support the use of specific medication for these symptoms, I think it would be better for this section to be omitted altogether.	being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short		2	Consider adding "particularly where there is concurrent anxiety" (this is a licensed indication for benzodiazepines; further there's little evidence that benzodiazepines have a direct anti-dyspnoeic effect – they may be addressing concurrent anxiety symptoms and thus be best used where these are prominent)	Thank you for your comment. We are unable to identify the text to which you refer, and so are unable to assist.
Earl Mountbatten	Short		general	GDG – Guidance Development Group. Not all of our team knew this acronym.	Thank you for your comment. This has now been amended

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Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)					
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short		general	The group felt strongly that the document would be more useful and relevant if reformatted to fit into the 'Five Priorities of Care'.	Thank you for your comment. The Committee considered the policy documents that outline the five priorities of care at all times but drafted their recommendations after due consideration of the evidence. Reference is made throughout the guideline to the current policy documents relevant to this area.
Earl Mountbat	Short	19	3	Suggest comment includes: '… should help healthcare systems to provide seamless healthcare	Thank you for your comment. We are content with the current structure of this paragraph and have not

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ten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)				across all professions'	made any further amendments.
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from	Short	22	3-7	The overwhelming majority of palliative care specialists would disagree with this paragraph. You overstate the adverse effects (such patients have almost always lost consciousness so blurred vision isn't relevant; dry mouth for multiple reasons is already present and requiring mouth care; catheters are commonly needed to protect skin integrity and as micturition becomes ever more exhausting); The patients we've raised this with in advance have, to date, universally stated that if secretions distress their family they would very much want us to treat it.	Thank you for your comment. This text has been amended.

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our end of life care strategy group)					
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	3	9	Suggest inclusion of 'Medical treatment is no longer producing a benefit or improvement in symptoms'	Thank you. The Committee feel that your concern is addressed by the existing bullet points on current clinical signs and symptoms and the person's medical history and the clinical context.
Earl Mountbatten Hospice and Isle of Wight	Short	4	14	point relates to patient deterioration, not the dying phase	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of

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NHS Trust (joint feedback from our end of life care strategy group)					the full guideline (Please see section 5.8). The issue of progressive weight loss reflects the evidence considered for our review.
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	4	15	point relates to patient deterioration, not the dying phase.	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (5.8). The issue of social withdrawal reflects the evidence considered for our review.
Earl Mountbatten Hospice and Isle	Short	4	22	Our care plans state 4 hourly for inpatients. In the community, monitoring and review may consist of telephone contacts rather than physical review.	Thank you for your comment. The recommendation provides a minimum of 'at least every 24 hours' so does not preclude more frequent monitoring.

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of Wight NHS Trust (joint feedback from our end of life care strategy group)					
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	5	13	Suggested inclusion of recognising that discussions will evolve over time and decisions will need to be updated and documented.	Thank you for your comment. The Committee agrees that this is important and is happy to refer to recommendations that encourage healthcare workers to continue to explore the understanding and wishes of the dying person and those important to them and to update the care plan as required.
Earl Mountbatten Hospice	Short	5	22	Include accurate information about how to contacts family / next of kin	Thank you for your comment. The committee believe that this information is routinely captured as part of individualized patient records and this level of detail is not required within the body of a recommendation.

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and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)					
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	6	10	This is a really important point, but you could perhaps point out that details of the patients care plan should be available to all clinicians caring for them; for patients in the community, this will need to include all healthcare services, including ambulance control and out of hours services.	Thank you for your comment. The Committee thinks this recommendation is clear as currently edited. The Committee has also recommended that the healthcare team record individualised care plan discussions and decisions in the dying person's medical records and share the care plan with the dying person, those important to them and all members of the multiprofessional care team. The guideline is for all multiprofessional teams in all settings where NHS care is provided.
Earl Mountbatten	Short	6	19	Establish capacity as per MCA so that best interest decision support is available.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate

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Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)					and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	7	4	Suggested inclusion of documenting changes to key worker as patient moves through their journey.	Thank you for your comment. Our shared decision making recommendations have been amended to ensure that the care plan is shared with the dying person, those important to them and all members of the multiprofessional care team. We do not wish to specify this issue within the recommendation but local arrangements may consider this appropriate.

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Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	8	9	The group reiterated the great importance of this point.	Thank you for your comment.
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy	Short	9	15	The group felt this addressed an important issue, effectively combating the criticism of the Liverpool Care Pathway where patients were denied hydration.	Thank you for your comment.

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group)					
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	9	8-14	The first bullet needs to be modified to acknowledge that mouth care may be equally, or more, effective The second bullet to include that fluids can sometimes worsen other symptoms (e.g. breathlessness or chest secretions)	Thank you for your comment. We agree, please see the recommendations on mouth and lip care for this detail. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given.
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care	Short	10	14 onwards	"There should be a set of locally agreed guidelines to manage common symptoms" (or this could sit with appendix 1)	Thank you for your comment/ We agree that this guideline may inform local policy and decision making and note that NICE implementation tools will be published alongside this guideline.

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strategy group)					
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	12	4-17 overall	In general, the group felt that the section on pain was very brief, though recognise there is other relevant guidance. However, perhaps should mention non-pharmacological management of pain, as you have for other symptoms further down	Thank you. We agree and have added a new recommendation.
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life	Short	13	1	Consider adding "particularly where breathless at rest (because the evidence is clearest for breathlessness at rest; there's little evidence that opioids are effective for exertional breathlessness)	Thank you for your comment. We do not have evidence from our review to support this change.

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care strategy group)					
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	14	3	The "hyoscine 1st / octreotide 2nd" aspect is very sensible (hyoscine being similarly effective and significantly cheaper). However, an antiemetic is usually required alongside these anti-secretory drugs to control the nausea. We would suggest either haloperidol or levomepromazine (because cyclizine often crystallised when combined with hyoscine butylbromide)	Thank you for your comment. The recommendations as drafted reflect the limited evidence available for this issue and we are therefore unable to provide any more detailed recommendations.
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our	Short	15	10	Atropine and hyoscine hydrobromide both cross the blood brain barrier and can thus worsen agitation by causing a cholinergic delirium – their inclusion is thus surprising (despite line 16 – just don't use them in the first place); prescribers should be encouraged to use antimuscarinics that do not cross the blood brain barrier. Of the latter you could then add "use the peripherally acting antimuscarinic *with lowest acquisition costs*" (i.e. hyoscine butylbromide).	The Committee discussed acquisition costs related to these drugs and concluded that costs are similar with the exception of octreotide. This is also reported in the 'Linking evidence to recommendations' of this section.

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end of life care strategy group)					
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	27	Footnote c	Perfectly sensible – we absolutely support that	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint	Short	27	Non-opioids	Ibuprofen cannot be given via a continuous subcut infusion – no UK parenteral preparation exists. Suggest you give diclofenac as the only SC infusion option (the other parenteral NSAIDs [e.g. ketorolac] have additional risks and thus should not be mentioned because their specialist initiated only)	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain

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feedback from our end of life care strategy group)					targeted at the non-specialist prescriber and will be made available on the NICE website.
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	27	Opioids	We very much support your decision to advocate morphine sulphate SC rather than diamorphine. We've reduced the overall cost of our pre-emptive prescribing scheme by switching. Diamorphine is more expensive and without additional advantages (specialists are [or should] be involved in the rare instances where doses are high enough to cause volume problems with morphine)	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Earl Mountbatten Hospice and Isle of Wight	Short	28	Bottom row	Buccal midazolam is extremely expensive relative to lorazepam and diazepam – cannot see how you can justify its inclusion here	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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NHS Trust (joint feedback from our end of life care strategy group)					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	28	Bottom row	Subcutaneous clonazepam should not be included. It's non-UK; importing it is expensive and cumbersome relative to midazolam; it has no advantage over midazolam.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Earl Mountbatten	Short	30	2nd line row	It's difficult to justify including unlicensed 6mg tablets. It's important to recognise that, as unlicensed drugs, a month's supply can cost	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)				hundreds of pounds in the community – 25mg tablets are very much cheaper and easily quartered with a tablet cutter.	symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	31	Right hand column	Again, subcutaneous clonazepam should not be included. It's non-UK; importing it is expensive and cumbersome relative to midazolam; it has no advantage over midazolam.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Earl Mountbatten Hospice and Isle of Wight NHS Trust (joint feedback from our end of life care strategy group)	Short	33	1st row	The inclusion of SC hyoscine hydrobromide is not justified (though the absence of transdermal alternatives may justify its inclusion in that column) – it crosses the blood brain barrier, risking a cholinergic delirium, and is more expensive than hyoscine butylbromide The inclusion of glycopyronium is also questionable – there is no evidence of superiority over (the less expensive) hyoscine butylbromide	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
East & North Herts NHS Trust	Short	19	21	Add 'if appropriate'	Thank you for your comment. Given your page and line reference, we are uncertain where it would be appropriate to add your suggestion and therefore have made no amendment.
East & North Herts NHS Trust	Short	19	19	May be give examples i.e fan therapy etc	Thank you for your comment. We assume you are referring to examples of non-pharmacological management although the reference you provide does not correspond to text. We are unable to comment specifically on non-pharmacological measures for managing symptoms as we did not undertake an evidence review in these areas as it

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					was beyond the scope and remit of this guideline. The Committee recognize their importance and value as part of care and have made a number of consensus recommendations. Examples, however, are provided in the relevant 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
East & North Herts NHS Trust	Short	4	15	In our experience it is recognised that people towards EOL have an increased risk of falls- could this be added. . It may be useful to bullet point these in a chronological order as much as possible ie; Cheyne-Stokes breathing is high on the order list.	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8). The issue of falls did not appear in our evidence review and the committee on consideration of this issue, do not feel it necessary to include this in the list of issues of relevance to the last 2-3 days of life.
East & North Herts NHS Trust	Short	6	13	We are concerned that this recommendation may not be explicit enough & think this requires more explanation. For e.g. some staff would what know what to say in this situation? It needs to state that this may not be possible and if asked, relevant information would be given sensitively.	Thank you for your comment. The Committee appreciates the challenges of communication in end of life care but believes that communication instructions would be best managed at the Trust level. . The committee relied on guidance provided in the NICE guidance entitled, Patient Experience in the adult NHS services to support effective communciation. A cross reference to this guideline has been included. More information on

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					this guideline can be found at: https://www.nice.org.uk/guidance/cg138.
East & North Herts NHS Trust	Short	8	13	We are concerned that this recommendation (check for difficulties) may not explicit enough and may expose the dying person to unnecessary examinations by SALT etc.	Thank you for your comment. We are unable to make a detailed recommendation on checking for swallowing difficulties as we have not prioritised this topic for review. Further detail has however been added to the 'Linking evidence to recommendations' section of the guideline.
East & North Herts NHS Trust	Short	14	1	We are concerned this this is too complex to be addressed in bullet points. May be better to state 'contact palliative care team'.	Thank you for your comment. This recommendation has been drafted to reflect the evidence base considered.
East & North Herts NHS Trust	Short	14	13	Add 'if appropriate'	Thank you. We are aware that reversible causes may not be possible to treat, but expect healthcare professionals to use clinical judgment to explore these.
East & North Herts NHS Trust	Short	15	11	In our experience Atropine would not be the first line choice and has some side effects that we would be concerned about i.e. . agitation, especially in Parkinson's disease. We would recommend Glypyrronium as the 1st line drug.	Thank you for your comment. The drugs listed here are in alphabetical order rather than order of preference. Further detail is given in the full guideline 'Linking evidence to recommendations' section of chapter 9 (section 9.30).
East & North Herts NHS				Col 4 in our experience we would start a lower dose of morphine (5mg/SC/24 hr) for frail elderly.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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Trust					implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
East & North Herts NHS Trust				Col 3 in our experience it can be difficult to roll a breathless patient to administer PR diazepam therefore could we add this to the notes at bottom of table, rather than in table?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
East & North Herts NHS Trust				Col CSCI- in our experience Clonazepam is not used as 1st line in generic practice as staff are not familiar with it. We would recommend Midazolam.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be

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					made available on the NICE website.
East & North Herts NHS Trust	Short	27	Table 1	We are concerned that the table is too complex for generic use and would not be used. A preferred option would be to identify fewer drugs and then contact the palliative care team. This applies to tables 1-5.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
East & North Herts NHS Trust	Short	27	Table 1	We are concerned that the dying person may be disturbed unnecessarily to administer PR drugs when the SC route is preferable and should be 1st line management for those unable to swallow.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
East & North	Short	27	Table 1	Opioids, col 2. Remove 'up to max dose' as we are concerned that this may result in under dosing.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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Herts NHS Trust					symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
East & North Herts NHS Trust	Short	27	Table 1 notes	Consider adding conversion of oral to SC dose. Also add seek SPCT advice for patient with renal failure.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
East & North Herts NHS Trust	Short	28	notes	Consider adding 'seek advice of SPCT in renal failure'?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This

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					important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
East & North Herts NHS Trust	Short	28	Table 2	Col 3 In our experience we would commence a lower dose morphine (1-2mg) for non malignant respiratory patients.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
East & North Herts NHS Trust	Short	30	Notes b	Would suggest 'substitute not 'add in' antipsychotic in this situation	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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East & North Herts NHS Trust	Short	30	Table 4	As for 16. Consider contacting SPCT.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
East & North Herts NHS Trust	Short	32	Table 6	Col 2 In our experience we would prefer Glycopyrronium as 1st line as we feel it works better & has less side effects. Atropine- as for 8.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Faculty of Pain Medicine	Full	General		• The prescribing advice on the management of pain in the dying adult was quite cautious, in particular the recommended dose of 2.5 - 5mg of oramorph 2-4 hourly. This would be a suitable starting dose for an opioid-naive	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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				patient. • Diagnosis of a dying patient can be difficult as several other conditions can lead to agitation e.g. constipation, pain, distress etc. • My personal experience with Liverpool Care Pathway (LCP) was that often inexperienced people made the decision to put people on LCP and often communication with both the person and their family was poor. How is the situation going to be different this time? It would seem to be more formalised, but training for ward staff and time for that training will be needed. Will this be given? Who will do this on a busy ward? Will a Palliative Care team need to be involved in all decision making? Probably not at 3am on a surgical ward, so, who will have seniority to do this? • Are the suggestions for medication evidence based? Who will prescribe as some of these suggestions are not common e.g. sub-cut diclofenac.	implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
FaithActi	Full	13	21-22	We would like to stress the importance of health	Thank you for your comment. Further detail has

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on			& 26-28	care professionals having an awareness of the faith groups that are present in their local communities before the situation arises in which they are caring for a dying person (we liken this to knowing where the fire extinguisher is in your building and how to operate it, rather than running around trying to locate it in the moment of crisis). Many local areas have a 'faiths forum' which will be able to help – but the best thing to do is to talk to patients about what is important to them.	been added to the 'Linking evidence to recommendations' section, using your suggested text.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	3	19	1.1.2: Many of these indicators are not specific to the last days of life and may be reversible. We appreciate the difficulty in diagnosing dying, but for instance fatigue, loss of appetite, progressive weight loss and social withdrawal could all be symptoms of depression or potentially treatable physical illness, rather than an indication that death is a few days away. It could be helpful to note that several of these indicators often co-exist in the last days of life (for example, mottled skin indicated poor perfusion in association with decreased consciousness and noisy respiratory secretions). Use of radiological investigations is not generally recommended in palliative care settings as a necessary part of the diagnostic process of dying.	Thank you for our comment. Reversible causes are discussed in the 'Linking evidence to recommendations' section of the full guideline. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8). The Committee agree that unnecessary investigations should be avoided, but that, if available, they may provide useful information. Available investigation results have been moved to the stem of the recommendation to avoid confusion with other signs or symptoms of recognising dying.

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Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	3	9	1.1.1: It could be argued that much of this information should have been sought well before the person's last days of life. The public may feel that we are being encouraged to leave things too late.	Thank you. We agree that in ideal situations this may be done much earlier. However, the remit of the guideline, seeks to ensure that these matters are not neglected in the last days of life.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	4	16	1.1.3: Many people with advanced illness will be gradually deteriorating (over weeks or months) or broadly stable rather than either of these two categories. It is unhelpful to present these alternatives ("nearing death" or "recovering") as the only two possible outcomes.	Thank you for your comment. The Committee discussed the bullet points in the recommendation and decided to amend these to state: nearing death, deteriorating, stable or improving.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	5	13	1.2.2: I often feel that the person who is dying knows before anyone else that they are dying. I am concerned about the recommendation to insist that all people who are dying **must** have a discussion about this unless there is clear indication that they do not wish to be informed. Sometimes communication can be far more subtle and nuanced than a formal discussion of prognosis, and encouraging sensitive communication (which may include a look of peaceful resignation from the person who is dying, gentle touch, what is left unsaid rather than what is said) seems far more patient-centred than insisting that everyone has this spelt	Thank you for your comment. The Committee agrees that communication when delivering end of life care is an important and sensitive topic. The Committee believes that the guideline, encourages healthcare professionals to prioritise the needs, wishes and goals of the dying person in the delivery of individualised care and have provided a framework for communication that assists the multiprofessional team navigating this difficult area.

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				out to them.	
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	6	8	1.2.5: I am concerned about the implications for this recommendation. Having explained that the person is likely to be dying, are we expected to ask them if they can remember this? Bearing in mind that many people who are in their last days of life have altered cognition, this seems an odd approach. If people cannot remember or verbalise what has been said, are we expected to repeat it? This guidance could be interpreted to mean that people should be told they are dying each time they are reviewed, which could lead to significant unnecessary and potentially harmful distress.	Thank you for your comment. We have amended the recommendation. Healthcare professionals are asked to explore with the dying person and those important to them, 'whether the dying person has understood and can retain the information given about their prognosis'.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	11	14	1.5.5: I think this would be clearer as two sentences, i.e. "Avoid giving intramuscular injections. Use subcutaneous or intravenous injections as appropriate for the setting."	Thank you for your comment. After careful consideration the Committee feel that no change is required.
Forest Holme Hospice Poole Hospital	Short	11	17	1.5.6: We avoid the use of the word "syringe pump" as it can be misinterpreted. It can lead to the distressing perception that the person who is dying is being "pumped full of drugs", leading to sedation. We prefer the term "syringe driver" to give a	Thank you for your comment. The Committee discussed the terminology of pump versus driver and reached a consensus decision to use pump. This has been detailed in the full guideline glossary.

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NHS Foundation Trust				continuous subcutaneous infusion; this seems to be commonly accepted.	
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	14	1	1.5.22: There is no guidance provided in this section for other types of antiemetic, although for most people who are in the last days of life, bowel obstruction will not be present. This section may therefore be confusing for staff who are not experienced in palliative care. I would recommend that other medication, such as levomepromazine or haloperidol, is available for nausea or vomiting in the last days of life.	Thank you for your comment. The Committee were unable to give specific recommendations in this area due to equivocal evidence.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	15	11	1.5.30: Atropine is not routinely used in UK palliative care settings to manage respiratory secretions, as far as I am aware.	Thank you for your comment. The drugs listed here are in alphabetical order rather than order of preference. Further detail is given in the full guideline 'Linking evidence to recommendations' section of chapter 9 (9.30).
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	general	general	The Palliative Care Formulary (5th edition, available at palliativedrugs.com) is an authoritative and internationally recognised reference for prescribing in palliative care, with no serious rivals. It would be appropriate to signpost staff to this publication. It should be widely available to NHS staff and organisations to support high standards of safe and effective prescribing for people who are dying.	Thank you for your comment. We are aware of the Palliative Care Formulary, however this guideline is based on systematic evidence reviews to provide evidence based guidance. Other guidance is also available and we are only able to cross refer to existing NICE guidance. We believe that this is not available free of charge to England and that our recommendations reflect the evidence considered

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				It is available free of charge (centrally funded) to staff in Scotland and I strongly recommend that it is similarly made available to staff elsewhere in the UK.	for an English audience.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	27	1	Table 1: For people who have been taking non-opioids but are now unable to swallow, a low dose opioid continuous subcutaneous infusion is appropriate and is likely to be better tolerated than regular rectal medication and more cost-effective than paracetamol given intravenously. If a NSAID is needed, we use ketorolac 30-90mg over 24h by CSCI rather than diclofenac or ibuprofen (I am unsure if there is a parenteral form of ibuprofen available in the UK). A NSAID is often helpful for pain on movement, for example the stiffness often associated with prolonged bed rest in the last days of life.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	27	1	Table 1: The table does not make it clear what should be prescribed if a person's pain has been well controlled on oral morphine, but they are no longer able to take oral medication. There is a risk that inexperienced staff would simply use 10-20mg over 24h irrespective of the dose of morphine which the patient had been taking. This is unsafe.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	28	1	Table 2: The doses of oral benzodiazepines seem high and likely to lead to excessive sedation.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	28	1	Table 2: Clonazepam may be less widely available than midazolam.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Forest Holme Hospice	Short	30	1	Table 3: I would avoid cyclizine by CSCI as it often leads to site irritation.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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Poole Hospital NHS Foundation Trust					implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	30	1	Table 3: No maximum dose for levomepromazine is given (sc or iv route). It is commonly used as an antiemetic in palliative care but is associated with sedation at higher doses so it would seem particularly pertinent to include an upper limit recommended for generalist use (e.g. 12.5mg over 24h sc)	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	30	1	Table 3: One study shows that metoclopramide is not significantly better than placebo for nausea. It seems likely that antipsychotics are more effective than metoclopramide for nausea associated with advanced disease. I appreciate the evidence base from RCTs is limited, but broad estimations of effectiveness from available research: levomepromazine 85%, haloperidol 65%, metoclopramide 30%, placebo 25-30%.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be

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					made available on the NICE website.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	31	1	Table 4: Reliance on benzodiazepines seems inappropriate - for anxiety associated with delirium, an antipsychotic is preferable.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	31	1	Table 4: Doses of benzodiazepines seem relatively high and may lead to oversedation.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	32	1	Table 5: Levomepromazine csci starting dose 12.5-50mg seems high. Inexperienced staff may start with 50mg over 24h which is highly likely to lead to sedation.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Forest Holme Hospice Poole Hospital NHS Foundation Trust	Short	32	1	Table 5: Several citation numbers are given in regular font rather than superscript. This typo could lead to significant overdosing by inexperienced staff.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
General Medical Council	Full version	110		a) The draft guideline mentions that 'The Guideline Development Group (GDC) felt that health and care professionals sometimes do not have, or may lose, their skills and confidence in delivering difficult	Thank you for your comment. The purpose of the guideline is to provide a framework for and reinforce best practice across all settings where NHS services are provided, for the dying person. We have added further information about the GMC regulations into

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				news. Training programmes are available and health and care professionals should be encouraged to keep their skills updated'. Of course, as the professional regulator, we have set out general duties on doctors to keep their knowledge and skills up to date (paragraph 8 of our core guidance Good medical practice). There is also an obligation on doctors, through our revalidation process, to reflect on their practice; identify areas where they can improve; and ensure they have the necessary skills and competence to provide a good standard of care to their particular population of patients (see the revalidation guidance here). You might want to consider whether a reference to these professional obligations would strengthen the guideline.	the 'Linking evidence to recommendations' section in section 6.6 of the full guideline
General Medical Council	Full version	108		We would like to make an observation about recommendations 7 and 9. The introductory comments set the context for these recommendations, with the following opening statement: recognising and communicating that a person is in the last few days of life is essential for good end of life care. Ensuring good communication about this with the person and those important to them is a vital part of shared decisionmaking (lines 3-5). The draft guideline currently lays out the following recommendations in relation to patients not	Thank you for your comment. We have made reference to the document you refer to in section 6.6 of the full guideline.

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				wishing to be informed about their prognosis: • Recommendation 7: Discuss the dying person's prognosis with them (unless they do not wish to be informed) as soon as it is recognised that they may be entering the last days of life and include those important to them in the discussion if the dying person wishes. • Recommendation 9: Provide the dying person, and those important to them, with accurate information about their prognosis (unless they do not wish to be informed). We would like to bring to your attention our guidance on Treatment and care towards the end of life: good practice in decisionmaking. This makes it clear that we expect doctors to take a series of steps when faced with these circumstances and highlights a doctor's responsibility to attempt to discuss a patient's prognosis with them if the patient has capacity, unless this will cause the patient harm. However, we also recognise the value of and sensitivity surrounding the last days of a patient's life and the importance of doctors respecting the patient's choice about how much they wish to know about their prognosis during this time period. The steps that we expect doctors to take are set out in paragraphs 56-59 of our guidance and you may wish	

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				to consider if there's value in including a link to this guidance.	
General Medical Council	Full version	110		The draft guideline states that the 'GDC noted in the evidence review that those important to the dying person may wish to try and withhold information regarding prognosis from the dying person. The GDC recognised this was a problem in their clinical experience and recommended that any requests be dealt with sensitively and respectfully, but clinicians should always act in the dying person's best interest'. We suggest that the final guideline document should include a link to paragraph 59 of our guidance on Treatment and care towards the end of life: good practice in decisionmaking. In this, we state that 'apart from circumstances in which a patient refuses information, you should not withhold information necessary for making decisions (including when asked by someone close to the patient), unless you believe that giving it would cause the patient serious harm. In this context 'serious harm' means more than that the patient might become upset or decide to refuse treatment'. It might also be helpful for the above section of the draft guideline to include a link to the Priorities of Care for the Dying Person resources (available at NHSIQ), since this framework has national support and underpins CQC inspections of end of life care	Thank you for your comment. We have added reference to this document in the 'Linking evidence to recommendations' section of section 6.6 of the full guideline.

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				provision in health and care services.	
General Medical Council	Full version	111	12-15	The draft guideline states that one particular issue that the GDG recognised is 'when a dying person had expressed specific preferences or wishes regarding their care, but circumstances in their final illness indicate that their interests might be better served if these were not observed'. We note the scenario included in lines 15 to 24 of this section and would like to recommend that the following aspects of this are made clearer: • Whether there was any discussion with the patient, while competent to make decisions, about the possible future course of her condition and the circumstances in which the question of whether to use a syringe driver might arise. • Whether the patient and/or those close to the patient were/or could have been informed in advance about the consequences of opting not to have treatment by syringe driver and how it would impact on the patient's death. • Whether the patient made a competent decision against using a syringe driver or simply expressed a preference which left room for others to decide at the time	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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				whether complying with her wish was still in her best interests. In the absence of the clarifications set out above, we believe you would need to provide a clearer explanation of the legal justification for not adhering to the patient's wishes in relation to treatment, taking account of the requirements of the Mental Capacity Act (2005).	
General Medical Council	Full version	General		We are pleased to note that the broad principles underpinning the draft guideline are in line with our guidance on Treatment and care towards the end of life: good practice in decision making, particularly the sections relating to communication and shared decision-making.	Thank you for your comment
George Eliot Hospital	Full	13	18	"Identify a named lead healthcare professional, who is responsible for encouraging shared decision-making in the person's last days of life." This requires further explanation.	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform who the most appropriate person is to encourage shared decision making. The Committee feel that this person may be a clinician or nurse or any relevant person delivering NHS care. Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section.
George Eliot Hospital	Full	General	General	There needs to be acknowledgement that specialist palliative care services need to be staffed better to support this area of care.	i. Thank you for your comment. Service Delivery, including staffing of palliative care services, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative

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					care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
George Eliot Hospital	Full	General	General	Education and training in EOLC needs to be mandatory.	Thank you for your comment. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
George Eliot Hospital	Full	217	General	Mouthcare needs to be identified as a common symptom management issue.	Thank you for your comment. The Committee agreed that mouth care is an important element in care of the dying adult and have made a specific recommendation covering this that states: Offer frequent care of the mouth and lips to the dying person, and ensure that their care plan includes the management of dry mouth in their care plan, if needed. Offer the person, as needed: • help with cleaning their teeth or dentures, if they wish to • frequent sips of fluid. Thank you for your comment on the prescribing tables. Because of the recognised importance of

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					supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
George Eliot Hospital	Full	217	General	There is little or no reference to non-drug interventions in managing symptoms in the medication guidance, although there is the odd reference within the main section and an acknowledgement at the start of the tables!	Thank you for your comment. The Committee recognises that non-pharmacological interventions are important in the care of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas were considered more likely, during scope development, to have a wider impact on clinical practice. As such no specific evidence reviews on non-pharmacological methods of symptom management were undertaken and specific recommendations on these were not made as the evidence base for them was not evaluated.
George Eliot Hospital	Full	217	General	Anticipatory prescribing may not have a firm evidence base but it is particularly pertinent in community settings. It feels like this is not being wholly supported and risks a lot of distress if practice veers away from ensuring appropriate medications are available.	Thank you for your comment. The Committee agrees that despite limited evidence, anticipatory prescribing is important in clinical practice, and chose to make several recommendations based on consensus in this review area. The Committee consider these recommendations to apply to all settings, including the community.

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George Eliot Hospital	Full	217	General	I realise there is more in the main text but I can see doctors just printing out these charts which I think is not going to promote an individualised approach to care.	Thank you for your comment. The text precluding the tables advises that standard prescribing principles should be followed, and the medications listed are suggestions reflecting the combined experience and consensus of the Committee and that the preferences of the dying person should be respected. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, the prescribing tables are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Full	217	General	I am concerned about the prescribing guidance in the main and in the appendix:		Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Full	217	General		There is too much reference to oral medications and PR medication when we know the oral route is something which quickly fails.	Thank you for your comment. The Committee appreciates that some adults in the last days of life may not be able to take or tolerate oral medication. Our recommendation states: Consider prescribing different routes of administering medication if the person in the last days of life is unable to take or tolerate oral medication. Avoid giving intramuscular injections (use subcutaneous instead or intravenous if the setting allows).
Full	217	General		PR medication in the dying isn't impossible but it can be quite difficult and traumatic. I have problems with staff not wanting to give glycerin supps because of consent issues in patients with dementia for example. If this is a dying patient, there is no point having a drug prescribed that no one is prepared to administer.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Full	217	General		I am concerned about the list of options for nausea and vomiting, cyclizine first line when it can cause anticholinergic side effects in the elderly in particular- confusion being the biggest issue but also	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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				dry mouth.	being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Full	217	General		I realise hyoscine hydrobromide is the only licensed drug for secretions but it crosses the BBB, leading to confusion and agitation in some and necessitating further drugs to manage this. I would advocate glyco or butylbromide if we need something.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Full	217	General		Worried about advocating clonazepam as access to this drug in hospital and community has been a MASSIVE issue over recent months. There is also limited experience using this drug for non-specialist staff.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain

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					targeted at the non-specialist prescriber and will be made available on the NICE website.
Full	217	General		Hyoscine patches for terminal secretions? Most patients die quite soon after the onset of this symptom so I would worry this is not going to work. There is very limited acknowledgement of the support and explanation needed around this particular symptom and the fact that treatment does not influence the secretions already present.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Gerald Morgans North Staffa				I note your draft guidance suggests Morphine as the Opioid of Choice for syringe driver use. I would comment that Diamorphine may be a better choice in the community as it is more soluble and allows a smaller volume of diluent and leaves more volume in the 24 hr syringe driver for additional drugs eg Hyoscine butylbromide. I would be grateful if you could consider the implications in your final guidance. There may also need to be some thoughts or advice about anticipatory guidance in the community where travel time for both Doctors and Community nurses may impact on the dosing and doses of End of Life drugs. I have often tried to teach colleagues to look	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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				at the underlying disease process and its rate of deterioration to guide them in the prescription and use of anticipatory medication	
Full	General		Within tables of evidence, variation over superscript lettering, some n brackets, some not.		Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	21	46	A comma is needed after the word residence.	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	21	50	We are concerned that there is no mention here of medications to manage secretions. We appreciate there is a need for more evidence but at present, they should be prescribed.	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	22	15	Expected NOT expecte	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	23	13	Professionals NOT professions	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	23	28	Sentence should read 'in THE care of the elderly'	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	23	31	Sentence should read 'for THE clinical care'	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	23	37	Sentence should read 'a person is dying AND how to communicate'	Thank you for your comment. This has been amended.
Gloucest	Full	23	46	Sentence should read 'in THE care of dying people'	Thank you for your comment. This has been

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ershire Hospitals					amended.
Gloucestershire Hospitals	Full	24	3	Sentence should read 'such as THOSE with'	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	245	Acronym	Should read ALZHEIMER'S disease not Alzheimer disease	Thank you for your comment. This has been amended. .
Gloucestershire Hospitals	Full	246	Acronym	Assisted hydration – this has been defined as fluids administered via a drip or gastric tube but would this not specifically relate to clinically assisted hydration whereas the term assisted hydration could include, holding a cup to help someone drink.	Thank you for your comment. This has been amended, assisted hydration has been removed throughout the document
Gloucestershire Hospitals	Full	247	Acronym	There should only be one full-stop after the definition	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	FULL	31	9.3	Should state OPIOIDS and not opiates – this is in several placed within this section.	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	35	15	Sentence requires a SPACE between or and markers	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	35	17	Sentence requires a COMMA between recovery and then	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	35	34	Sentence requires a FULLSTOP between protocols and For	Thank you for your comment. This has been amended.

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Gloucestershire Hospitals	Full	85	13	Sentence should read ADVANCE care planning not advanced	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	General		Section 1.1 is repetitive and should be structured, themes grouped, better ordered in terms of likely chronological order of events/need to address issue.	Thank you for your comment. The relevant chapter headings have been added to this list for clarity.
Gloucestershire Hospitals	Full	245	Acronym	Should read ADVANCE care plan not advanced care plan	Thank you for your comment. This has been amended throughout the document.
Gloucestershire Hospitals	Full	244	Acronym	Should read ADVANCE care planning not advanced care planning	Thank you for your comment. This has been amended throughout the document.
Gloucestershire Hospitals	Full	20	17	This should be advance not advanced	Thank you for your comment. This has been amended throughout the document.
Full	21	13		We are concerned that this statement does not make sense and will be confusing to clinicians/practitioners in terms of what is expected of them.	That you for your comment. Further detail has been added. Please note that the appendix contains additional information about the design of the proposed trial.
Full	20	38		We are concerned that this statement may lead to poorly communicated information. I am unaware of any evidence to corroborate the statement that patients become dehydrated at the end of life and that altered renal function/skin turgor is not part of the dying process.	Thank you for your comment. This has been amended to state "may develop sepsis, dehydration and various biochemical disorders which may predispose lead to the development of delirium"
Gloucest	Short	4	21	Suggest this should state potential for recovery	Thank you for your comment. This recommendation

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ershire Hospitals				rather than recovering with comment to then initiate discussion over whether a patient wishes to continue pursuing that recovery. We feel that it is important that general physicians remember to acknowledge patients may wish to stop treatments even if they could on paper 'recover'.	is about the health care professional assessing the patient to be in the last days of life, and does not refer to treatment decisions. We have drafted a recommendation which discusses shared decision making and highlights patients' goals and wishes as an important factor to consider when creating an individualised plan of care.
Gloucestershire Hospitals	Full	59-60	Within table	Within column 4 section mortality at 2 days, the b after bias should be superscript throughout section.	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	63	8-9	Sentence should read 'approach TO care'	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	82	Last section of table	Sentence should read ' they will receive DIFFERENT' not differentiate	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	55	Table 12	Within prognostic or diagnostic factors – sentence 'signs and symptoms including in at least 1 of the following categories' does not make sense.	Thank you for your comment. This has been amended and now reads: 'signs and symptoms including at least 1 of the following categories'.
Gloucestershire Hospitals	Short	7	27	We have experience of a countywide document for communicating individuals care wishes/needs and would be happy to share this.	Thank you for your comment. Our colleagues at NICE may be able to use the document you refer to as part of their implementation support. We will forward your comment to them.
Gloucest	Short	5	10	With emphasis in the literature recently we would	Thank you for your comment. The Committee felt

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ershire Hospitals				suggest that assessing cognition and information needs should be the first step here.	that an important part of attempting to meet the communication needs of the dying person would involve first establishing who they would like to have access to information related to their last days of life. As a guide the committee relied on guidance provided in the NICE guidance entitled, Patient Experience in the adult NHS services. More information on this guideline can be found at: https://www.nice.org.uk/guidance/cg138
Gloucestershire Hospitals	Short	7	15	Delivery of meals seems less relevant to the last days of life and may be confusing. Again, this may be an appropriate place to highlight out-of-hours alerts/arrangements.	Thank you for your comment. The Committee disagrees, and felt that this was a good example of one area that would need to be considered when planning care in the last days of life. This information should help guide appropriate shared decision making with the dying person.
Gloucestershire Hospitals	Full	111	15	Sentence should read - For example a PERSON not persons	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	111	19	Sentences should read HOURS not ours	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	111	34	This should state Lasting Power of Attorney for Health and Welfare which has superseded the previous enduring power of attorney.	Thank you for your comment. This has been amended to read as follows: They may have appointed someone to have an Enduring Power of Attorney (which would only be valid if made before 1st October 2007), or a Lasting Power of Attorney for personal welfare which came into effect after the introduction of the Mental

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					capacity act in 2005. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Gloucestershire Hospitals	Full	113	Table	Almack 2012 column 4 – Should read ADVANCE care planning not advanced	Thank you for your comment. This has been amended throughout the guideline. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Gloucestershire Hospitals	Full	115	Table	Boot 2014 column 4 – Should read ADVANCE care planning not advanced	Thank you for your comment. This has been amended throughout the guideline. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Gloucest	Full	131	Table	Column 3 – Should read ADVANCE care planning	Thank you for your comment. This has been

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ershire Hospitals				not advanced	amended throughout the guideline. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Gloucestershire Hospitals	Full	136	Table	para 2, line 6 – should read ADVANCE care planning not advanced	Thank you for your comment. This has been amended throughout the guideline. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Gloucestershire Hospitals	Full	87	Table 23	Review strategy last line – a SPACE is needed between information and on	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Short	5	1	We are concerned that there will be an impact upon training needs around communication for clinicians and also a need for clinical supervision/debrief where in depth discussions are frequently taking place.	Thank you for your comment. Service delivery, including training of staff is outside the scope of this guideline. There is a service delivery guideline in production that may address this issue.
Gloucestershire Hospitals	Short	7	27	We are concerned that there will be difficulties communicating decisions across numerous IT systems to ensure all services ranging from acute to community to voluntary to emergency services have appropriate information.	Thank you for your comment. Service delivery, including the coordination and standardising the use of IT systems, is outside the scope of this guideline. There is a service delivery guideline in production that may address this issue. Please note that more detail about the development of this guideline can be found at the following link:

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					http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Gloucestershire Hospitals	Short	general		Where comments are made to seek specialist advice, there will be a huge impact upon specialist palliative care services both in and out of hours.	Thank you for your comment. The committee believed that generally, specialist palliative care advice is currently available to health care professionals delivering end of life care to dying persons either face to face or by phone, so it is the view of the Committee that their recommendations will not put additional strain on existing resources. However, the committee is aware that there is intention to review the optimal organisation of current resources and that this issue may be addressed by the palliative care service delivery guideline currently being produced by NICE. More detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Gloucestershire Hospitals	Full	136	Table	Para 7 – second sentence does not make sense.	Thank you for your comment. This has been amended and now states: They also acknowledged that in some situations shared decision making can be complex and difficult to formulate, and if so additional support from specialist palliative care services should be sought.
Gloucestershire	Short	7	20	DNACPR has not been mentioned, this may be an appropriate section.	Thank you for your comment. We recognise that CPR and DNAR decisions are an important area in

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Hospitals					care of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas are more likely to have a wider impact on clinical practice. DNAR discussions will not be included in this guideline.
Gloucestershire Hospitals	Short	7	7	We are concerned that there needs to be a realistic expectation over access to a named clinician. This should be made explicit for hospital/community settings. This may also be an appropriate place to highlight out-of-hours alerts/arrangements.	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section.
Gloucestershire Hospitals	Short	6	16	We are concerned that there will be an impact upon training needs around communication for clinicians and also a need for clinical supervision/debrief where in depth discussions are frequently taking place.	Thank you for your comment. Service delivery, including training of staff is outside the scope of this guideline. There is a service delivery guideline in production that may address this issue. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Gloucestershire Hospitals	Full	149	7	Should read DEHYDRATED not dehydrate	Thank you for your comment. This has been amended.
Gloucestershire	Full	151	Table	Column 2, para 1, line 9 – should this read HYPERcalcaemia and not hypocalcaemia	Thank you for your comment. This has been amended.

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Hospitals					
Gloucestershire Hospitals	Short	9	1	We are concerned that this would be difficult to fully implement in all care settings especially community settings due to lack of training/skills/resources to support artificial hydration. We would be concerned that this may impact on patients achieving care in their preferred setting if clinicians do not have further training to understand the issues around artificial hydration.	Thank you for your comment. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Gloucestershire Hospitals	Short	9	13	Were the experiences of two people within the UK who chose to stop eating and drinking recently considered within this section? Their experiences were reported in the media.	Thank you for your comment. The Committee drew on both clinical evidence identified through the systematic review and from their clinical experience to formulate this guidance.
Gloucestershire Hospitals	Short	8	26	We are concerned that an alert was placed over use of oral hygiene sponges – may have been withdrawn in some areas.	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.
Gloucestershire Hospitals	Full	150	8.6 no.24	I believe oral hygiene sponges have been removed from clinical practice.	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.
Gloucestershire Hospitals	Full	153	Para 2, last line	We are concerned that an alert was placed over use of oral hygiene sponges – may have been withdrawn in some areas.	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full

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					guideline.
Gloucestershire Hospitals	Short	15	15	We are concerned that assessment at least every 12hours will be difficult to achieve in every care setting, especially community settings due to limited resources.	Thank for your comment. The Committee note that this may present some challenge but feel that where medicines are being used to manage symptoms it is not unreasonable to expect that the prescribing clinician would want to measure benefit within this time frame and the Committee felt it important to formalize this in a recommendation. Service Delivery is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Gloucestershire Hospitals	Short	15	3	We would suggest giving examples of non-pharmacological management such as regular repositioning, postural drainage and on occasion, gentle suctioning.	Thank you. The Committee acknowledges the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.

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Gloucestershire Hospitals	Short	16	12	We are concerned that this will impact upon clinical teams both within the hospital and community settings. This is due to time constraints and also clinical knowledge in making decisions over choice of medications. This is turn will impact upon specialist palliative care due to increased need for advice and education.	Thank you for your comment. The Committee note that this may present some challenge but feel that where clinicians are prescribing medicines it is not unreasonable to expect that they would want to individualize and tailor that prescription to need rather than provide a blanket set of options. the Committee felt it important to move towards this approach in light of the findings of the Neuberger review and wished to formalise this in a recommendation. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Gloucestershire Hospitals	Short	11	16	We feel that intravenous administration of medications/fluids needs to be given more context. Subcutaneous route is the most commonly used at the end of life as it is often difficult and distressing to try and cannulate patients who are dying. Where a line is in situ, this can be made use of but it would be very rare to suggest siting an IV line in the dying phase.	Thank you for your comment. The Committee recognises that the subcutaneous route is widely used because gaining IV access in dying adults may be difficult and distressing. We have added additional context in the 'Linking evidence to recommendations' section to clarify this.
Gloucestershire Hospitals	Full	162	Para 7, last line	Should read ADVANCE not advanced	Thank you. This has been amended.

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Gloucestershire Hospitals	Full	163		First sentence of paragraph – we are concerned that this is incorrect statement. 'renal patients with chronic pain who would usually be given a package of fentanyl and opioids such as diamorphine for pain'. Diamorphine is contra-indicated in patients with advanced renal failure and not routinely used within chronic pain anyway.	Thank you for your comment. The Committee discussed patients with chronic pain and renal impairment and this has been captured in the 'Linking evidence to recommendations' statement for this chapter. The group is aware that caution was advised in the use of opioids in renal impairment, especially where a drug or its active metabolites have significant renal elimination, and thus the potential for accumulation. The group is also aware of the advice given by the British National Formulary in this area. The 'Linking evidence to recommendations' edits state: The Committee wanted to highlight the importance of taking into consideration other comorbidities and other medications the dying person is taking when making prescribing decisions. They chose not to make any specific recommendations about pain management in different patient groups, and suggested that clinicians should follow their normal prescribing practices as at any other time of life.
Gloucestershire Hospitals	Full	189	26	We are concerned that this statement may lead to poorly communicated information. I am unaware of any evidence to corroborate the statement that patients become dehydrated at the end of life and that altered renal function/skin turgor is not part of the dying process.	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	Section 9.3	General	Consider addition of corticosteroids – altered blood glucose may be a useful measurable outcome	Thank you for your comment. Blood glucose was not prioritised as an outcome for this review. No evidence was identified for corticosteroids.

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Gloucestershire Hospitals	Full	190	10	This does not make sense.	Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	210	7	Should this read 23 – 92% (we think hyphen missing)	Thank you for your comment. This has been amended. .
Gloucestershire Hospitals	Short	12	21	This infers that clinical situations such as pulmonary oedema must be treated but in some situations, they can only be managed, for example a patient who is dying may become anuric and if they then develop pulmonary oedema, diuretics could in fact cause harm and not give benefit so in such a situation, a clinician can only manage the symptoms. We are concerned this statement may lead to inappropriate aggressive management.	Thank you for your comment. The Committee wished to make this recommendation to identify those circumstance where symptoms may be improved by treating reversible causes. They believe this would always be supported by appropriate clinical judgement. Please see the 'Linking evidence to recommendations' section of chapter 9 (9.9)for further detail.

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Gloucestershire Hospitals	Full	217	Table re pain relief	There is no mention to consider renal function to assist with choice of opioid	Thank you for your comment. An evidence review undertaken during this guideline did not identify any evidence for choice of opioids in patients with renal failure in the last days of life. The Committee agreed that this is a difficult clinical issue but felt unable to make a specific recommendation given the paucity of evidence. In the introduction to this section it is suggested that specialist advice should be sought if there are uncertainties including renal impairment. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, the prescribing tables are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Full	222	Table 6	Column 2, row 3- should be a SPACE between up to and every		Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Full	213	Point 59 in table	Refers to syringe pump – previously referred to as syringe driver within the rest of the document – I believe syringe pump is in fact the correct term.		Thank you for your comment. This has been amended.
Gloucestershire Hospitals	Full	218, 220	Table 2 and table 4	Clonazepam is now no longer available in parenteral form	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Great Western Hospitals NHS Foundation Trust	Short version	General	General	The diagrams used are good and clear	Thank you for your comment and for participating in the consultation process.
Great Western	Full versio	Gen eral	Gener al	Overall the Guideline is helpful and clear	Thank you for your comment and for participating in the consultation process.

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Hospitals NHS Foundation Trust	n				
Great Western Hospitals NHS Foundation Trust	Short version	General	General	Whilst the guideline is not intended to be setting specific, there are variations is appropriate practice between settings such as demonstrated by comment number 3 above. It may be helpful to provide separate guidance for inpatient and community settings and for particular professional groups eg GPs	Thank you for your comment. This guideline is aimed at all health care professionals who might be involved in the care of a person who is nearing death, and so attempts to address the variations you mention by setting standards for practice across a wide range of settings. For most recommendations the Committee (made up of professionals from a variety of primary and secondary care settings) believe that they can be applied regardless of settings.
Great Western Hospitals NHS Foundation Trust	Short version	Section 1.1.1		Refers to having conversations with patients in the last days/hours of life- Would like it to suggest that these conversations should in many instances have been had a long time before the last few days/hours. Should not be left to the last moment.	Thank you for your comment. The remit of this guideline is last days of life, however the guideline Committee acknowledge that this may occur earlier and have discussed this in the full guideline 'Linking evidence to recommendations' section (please see section 5.8).
Great Western Hospitals NHS Foundation Trust	Short version	Section 1.1.4		Guidance states patients should be reviewed daily. However if the patient is not receiving symptom control via a syringe driver then the frequency of visits (when people are being cared for at home) should be discussed with the patient and family as not everyone wants to be ' medicalised' with daily visits/ phone calls. Review should be a mixture of	Thank you for your comment. The Committee consider the recommendations equally applicable to hospital and community settings. The recommendations are intended to be patient focussed and to adopt an individualised approach. The Committee consider monitoring for further changes when the person may be entering the last

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				clinical and social need and be very much patient specific. This should clearly be in the context that the patient and family know who to contact between arranged visits.	days of life. Additional information is provided in the 'Linking evidence to recommendations' section in the full guideline (please see section 5.8).
Great Western Hospitals NHS Foundation Trust	Short version	Section 1.4		Reference Clinically assisted hydration in the community - The efficacy of the S/C route is unclear At home the patient's family/carer should be supported to encourage oral hydration and mouth care.	Thank you for your comment. The Committee considered that setting was not a barrier to providing clinically assisted hydration. Text has been added to the 'Linking evidence to recommendations' statement in section 8.6 in the full guideline.
Great Western Hospitals NHS Foundation Trust	Short version	Section 4		It is helpful the guidance was very specific about anticipatory drug being prescribed with an authorisation to administer , It is not good enough to use pre-printed proforma as prescribing should be patient specific	Thank you for your comment.
Great Western Hospitals NHS Foundation Trust	Short version	General	General	For anticipatory prescribing- Where possible this can be progressed by GPs prior to the last days/hours of life for all patients irrespective of diagnosis. There is a really good breakdown of costs of drugs and wastage (not a huge amount of cost)	Thank you for your comment the content of which is noted.
Great Western Hospitals NHS Foundati	Short version	General	General	It is helpful that the guideline makes clear the benefit of the professional/patient relationship over a longer period than days/hours in anticipatory prescribing and in ensuring patient specific treatment.	Thank you for your comment the content of which is noted.

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on Trust					
Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks	Full	Page 135/136		Specialist Palliative Care support • There are a number of occasions within the guidance, where it refers to difficulty for inexperienced physicians to manage and that increased specialist support is needed in these areas - it is acknowledged that this has implications for specialist palliative care services, but then goes on elsewhere to say that it has not made any recommendations of how services should be delivered although recognises work to be undertaken in 2016 to update 2004 Supportive and Palliative Care Guidance - it would be helpful to describe how the implications of this work and the associated capacity and education and training issues will be linked between this guidance and the guidance work next year. • The guidance describes that it is targeted towards generalists but it needs to recognise that it is also care supported by Specialists and that the education and training and implementation and support for this guidance will be support by specialist services as well. The economic sections within the document make little acknowledgement of costs of specialists time and capacity and also the education and training required across the whole workforce around the key recommendations in question.	Thank you for your comment. **NICE is currently developing guidance in palliative care service delivery and access to specialist palliative care services may covered by that work. Please note that more detail about the development of this guideline (including dates of the opportunities to comment on the draft scope for this work) can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799** Regarding the cost implications of specialist advice, in the Linking Evidence to Recommendations section we do explain that "There could be some economic implications associated with shared decision making in terms of healthcare professional time and with the availability of support out of normal working hours. However, it was the Committee's opinion that this should already be in place". We recognize that there is variability on out of hours specialist palliative care advice but the Committee felt that generally, support would always be available over the telephone which although an impact on time may not create additional costs.

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				• Suggestion that the GDG opinion is that out of hours support should already be in place - and that this includes specialist support - although the reality is these services may not already be in place in some areas and have a cost associated to this.	
Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks	Full	Page 88 Page e110 Page e 186 Page e191		Research Recommendations • The document currently highlights research needed re: uncertainty of recognition of dying and its impact on communication and ACP/ Management of Delirium/ Anti-secretory medications/ anticipatory prescribing/ but not on other areas highlighted throughout the literature reviews as LOW evidence such as: ○ Lack of Studies focused on communication of likelihood of entering the last days of life ○ Lack of Studies focused on training in difficult conversations and benefits on outcomes ○ Lack of Studies focused on clinical assisted hydration ○ Lack of Moderate or higher evidenced studies around other symptom management aside from anti-secretory medications ○ No evidence found with regards to anxiety and agitation ○ Lack of evidence of harm with no anticipatory prescribing vs harm and evidence in anticipatory prescribing – this could also include the benefits vs harms of anticipatory prescribing as	Thank you for your comment. We agree that there are additional areas within the guideline where the evidence base is limited and no research recommendation has been made. However, the Committee have prioritised areas and selected key research recommendations that are likely to inform future decision-making (based on a systematic assessment of gaps in the current evidence base) for inclusion in the guideline. Criteria were used to help the Committee decide what to recommend for research, including the importance to patients or the population, relevance to NICE guidance and the NHS, national priorities, economic considerations, feasibility and equalities consideration. Further details can be found in the appendix of the full guideline.

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				required medications related to specific symptoms rather than the anticipatory prescribing of regular medications such as the future use of a syringe pump with s/c medications	
Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks	Full	General	General	General Overall Comments • There are many good sound principles within the guidance and the literature reviews in each area covered are useful. • However, there are a number of elements within the guidance and recommendations where there is noted to be limited evidence within the research/ literature reviews. It is important that it is clear and transparent around which recommendations are based on research evidence (and what level of evidence), experience, best or common practice, consensus or are anecdotal. • There are 67 key recommendations highlighted within this document plus a further research recommendations - although these all cover important areas within the care of the last days of life, the numbers of recommendations within this document need to be reduced to allow all areas to focus on key priorities - otherwise there is a	Thank you for your comment. • Discussion is provided within the 'Linking evidence to recommendations' sections of each of the evidence review chapters that indicate the level of evidence upon which recommendations were made or where they have been made by consensus. • It is no longer NICE policy to identify key priorities for implementation. We assume that these may be different for each different service depending upon current practice and priorities. • Noted • We have made reference throughout the document to 'One Chance to get it right'. We do not believe it is helpful to organize our recommendations in this way. For some it would be obvious (communication and care planning), for others less so (e.g. clinically assisted hydration and pharmacological management. • The guideline has not been able to address all issues relevant to the care of the dying adult. This issue is beyond the remit and scope of this

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				risk that the high number of recommendations may make this a difficult document to deliver operationally in practice. • These recommendations are in addition to the last days of life recommendations within 'More Care, Less Pathway' and 'One Chance to Get it Right' as well as likely recommendations from current national RCP hospital audit for care of dying. • It would be helpful for the recommendations to be collated under the headings around the 'Five Priorities for Care' that is already national guidance in this area and that more reference is made to 'One Chance to Get it Right' as a response to 'More Care, Less Pathway' – reflecting the positive examples as well as negatives - particularly in the one year review post 'One Chance'. • It is unclear why it was decided not to provide guidance around care after death and in to bereavement? • Theme maps (e.g. Figure 4, 5 and 6) are helpful and should be highlighted within the short version of the document.	guideline. We are not able to include theme maps in the standard format of the NICE guideline. We are glad you found these helpful.
Greater	Short	Pag	Gener	**Recognition of Last Days of Life**	Thank you for your comment. Further detail is given

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Manchester, Lancashire and South Cumbria Strategic Clinical Networks		e 3.	al	• It is unclear why prognostic tools were excluded from the evidence review but at the same time a conclusion has been made that 'these tools are not sensitive enough for use in our remit ..... to recognise when a person is shifting in to the last days or hours..' • Is there evidence that changes in communication (for example talking about the nearness of death) is a sign of last days of life – if so it would be helpful to include this specific evidence? • Laboratory Tests for Prognostication- GDG chose only to include these in recommendations if they were available - it would be clearer to say whether the evidence supports these tests in helping with the uncertainty of the recognition of dying or not - this means that the place of care doesn't dictate the investigation but rather the evidence of the potential benefit or not dictates their use.	in the full guideline, which explains that we focussed on individual prognostic factors. Detail of functional observations are given in the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8). After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Details of the qualitative review underpinning this recommendation are in the full guideline. The Committee consider that unnecessary investigations should be avoided, but that if available may provide useful information. Available investigation results have been moved to the stem of the recommendation to avoid confusion with other signs or symptoms of recognising dying.
Greater Manchester, Lancashire and South Cumbria Strategic	Short	Page 7	General	**Individual Plans of Care** • Any individual plan of care needs to specifically include nutrition and hydration needs and the lead healthcare professional should be competent to facilitate communication and shared decision making with patient and those close to them.	Thank you for your comment. Nutrition is outside the scope of this guideline. The Committee consider that hydration needs are covered under preferences for symptom management and anticipated care needs in recommendation 1.3.5 of shared decision making.

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Clinical Networks					
Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks	Full	Page 152		**Clinically Assisted Hydration** • The document notes that 'there is a clear lack of evidence based guidance on whether clinical assisted is beneficial' and this is then reinforced within the evidence review with evidence regarded as LOW or VERY LOW. Section 8.3.2 and Section 5 then highlight evidence which reports no statistical evidence of benefit in the studies quoted - however, the recommendations then suggests discussion and a therapeutic trial of clinical assisted hydration - this may be appropriate - but it is not clear at all how these recommendations have been formulated - if it is consensus or current practice guidance then this needs to be clear. • It is unclear where the evidence is around the symptoms of dehydration and that this can cause 'considerable' distress - given the studies that have been quoted.	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and have changed 'unlikely' to uncertain' whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given. The full guideline does discuss the evidence and its limitations. It also states that: The experience of the Committee was that there is benefit in some circumstances, such as in the case of managing thirst or managing delirium caused by dehydration, but this was not captured by the evidence. As such a weak recommendation was made "consider a therapeutic trial of…" Further details have been added to the full version of the guideline under 'Linking evidence to recommendations' statement in section 8.6.
Greater Manchest	Full	Page	Line 6-8	**Symptom Management** • It is helpful that treatment of underlying potential	Thank you for your comment. We agree that communication with dying person and those

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er, Lancashire and South Cumbria Strategic Clinical Networks		155 Page 161 Page183		causes for symptoms is highlighted within the symptom section particularly as well as careful discussion and communication with patient and those close to them? • It should be added that the assessment of each symptom should be clearly documented including the level and all possible causes as well as linked prescribing and administration decisions. • The guidance around specific medication prescribing via different routes in last days of life (Tables 1 – 6) are useful and would be help to be supported by cross reference to any specific literature re: doses etc. • Should the doses of subcutaneous or IV medications in the tables be recorded as separate lines in the table – is there evidence of different doses or side effects when giving medications IV or S/C. • It would be helpful to quantify the evidence that supports the statement 'Many of the medications used to manage these symptoms cause a degree of sedation, or other side-effects, that could lead to development of new signs and symptoms or a more rapid deterioration in the dying person.' This is particularly because the	important to them is important - please also see the chapters on communication and shared decision making. Thank you for your comments on the prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website. The introduction section and 'Linking evidence to recommendations' sections in the full guideline on nausea and vomiting have been amended to state "may cause a degree of sedation". No evidence was found regarding the efficacy of cyclizine in the last days of life, but the Committee state their consensus opinion, that this drug had lower efficacy compared with others. This has been clarified in the 'Linking evidence to recommendations' section. The Committee recommend trialling treatment for

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				evidence review states 'no evidence was found for the quality of life or time-to-death outcomes'. • The side-effect and sedative effects of anti-emetics are highlighted but not evidenced within this section - which would be helpful if literature evidence available - the only information evidenced is two of the studies, using surrogate measures of drowsiness and fatigue. - there is contradiction between statements on this page, which suggest '...inconsistent and therefore not directly supporting one over another recommendation' followed by 'GDG ...were particularly surprised...that cyclizine was most commonly prescribed antiemetic given. In the GDG's opinion, this drug has lower efficacy compared with others' and then 'no evidence was identified for cyclizine and no recommendations were made'. • The literature review for respiratory secretions helpful in highlighting the considerable rate of improvement in secretions in some studies with no evidence to suggest one treatment was more effective than another – the recommendations are useful and practical – however, it is difficult to judge whether the advice of changing or stopping medication, in the event of on-going respiratory	respiratory secretions for 12 hours and then switching based on the evidence review that indicated that these drugs may be clinically effective at 12 hours. The group did not want symptoms to remain unresolved for a longer time period as the prognosis in these people is very short. The group note that clinical judgement should be used to consider a longer trial of the existing medication for those who may not be dying imminently.

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				secretions or side effects, is better than continuing with the original medication as there is no trial data re: this clinical practice.	
Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks	Full	Page 240/241		**Anticipatory Prescribing** With regard to anticipatory prescribing, an individualised approach is correct and appropriate but we do not the evidence as yet to say whether there is a benefit or harm form this type of prescribing or 'just in case' boxes – the guidance needs to be clear around this – and ask professionals to weigh up the risks and benefits for an individual in prescribing and administering medications in this way. It would also be useful in these recommendations to highlight that 'on the whole the GDG recognised that anticipatory prescribing was likely cost effective ……..ensuring that wastage and adverse effects were kept to a minimum', but that also 'written clinical justification would be required as part of anticipatory prescribing'. The clinical justification may be part of good prescribing practice but still is needed to be highlighted within the recommendations here.	Thank you for your comment. We have provided an in-depth discussion in the 'Linking evidence to recommendations' section of the full guideline on this issue (see 10.8). The Committee has also made a research recommendation in this area (see 10.9) to help guide practice in the future
Guy's & St. Thomas'	Full	21	21	Typographical error "23 – 92%"	Thank you for your comment. This has been amended.

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NHS Foundation Trust					
Guy's & St. Thomas' NHS Foundation Trust	Full	22	15	Typographical error "expected"	Thank you for your comment, this has been amended.
Guy's & St. Thomas' NHS Foundation Trust	Full	14	25	This overstates the evidence of benefit (which is mixed) from evidence cited. It may well be interpreted as likelihood that CAH will relieve symptoms/ signs. Suggest "may or may not relieve distressing symptoms or signs" would be more balanced.	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given.
Guy's & St. Thomas' NHS Foundation Trust	Full	14	30	Second statement within recommendation 27 more balanced and recommendation 28 is useful to guide teams when a trial of CAH would be useful.	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around

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					survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given.
Guy's & St. Thomas' NHS Foundation Trust	Full	17	24	The problem with stopping some medications may not be immediately obvious as a potential cause of worsening symptom control, for example anti-Parkinsonian medications. Consider re-wording this section or add another section to highlight this.	Thank you for your comment. The group consider sufficient detail is given in the 'Linking evidence to recommendations' of the full guideline (section 9.34). In addition the group also recommend regular reassessment of symptom management in recommendation 61.
Guy's & St. Thomas' NHS Foundation Trust	Full	General	General	Consider recommending/ or making more clear the switch to a quaternary Antimuscarinic where CNS side effects becomes a problem with hyoscine hydrobromide or atropine, in other words rather than ruling out a therapeutic trial of this class of drug all together. In light of limited evidence between any of these agents we avoid using agents that are known to cross the BB barrier.	Thank you for your comment. We do not believe we have reviewed any evidence that would allow us to provide a recommendation with this level of detail.
Guy's & St. Thomas' NHS Foundation Trust	Full	General	General	When making arrangements for anticipatory prescribing it is preferable to make contact with the dying person's usual community pharmacy to offer them advance warning of the prescription. Also, to establish the process for disposal of any unwanted medications, including controlled drugs should the become necessary.	Thank you for your comment. The Committee were unable to comment further on service delivery issues or waste disposal as this is outside the remit of this guideline. NICE is currently developing guidance in palliative care service delivery and the issue of training and education may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.

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Guy's & St. Thomas' NHS Foundation Trust	Full	217	Table 1	Some services prescribe a lower dose of morphine for breathlessness than for pain – however, given the recommended dose is small, a pragmatic approach seems reasonable to minimise error.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Guy's & St. Thomas' NHS Foundation Trust	Full	217	Table 1	Consider recommendations that manage people who present with an opioid transdermal patch in situ.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Guy's & St. Thomas' NHS	Full	218	Table 2	We would question the routine use of clonazepam without first seeking specialist advice given lack of familiarity, including compatibility restrictions when mixed in syringe. Supply may also pose a problem as this remains a specials manufactured product in	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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Foundation Trust				the UK.	implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Guy's & St. Thomas' NHS Foundation Trust	Full	219	Table 3	Multiple options with respect to anti-emetics are likely to lead to confusion and errors. Most organisations are likely to make pragmatic choices, for example based on likely cause of the nausea and/ or vomiting, from a smaller number of options in their formulary. Consider identifying logical choice of anti-emetic based on underlying cause if this is known, or suggested by the clinical picture. Typo in the notes section – metoclopramide.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Guy's & St. Thomas' NHS Foundation Trust	Full	220	Table 4	We would question the routine use of clonazepam without first seeking specialist advice given lack of familiarity, including compatibility restrictions when mixed in syringe. Supply may also pose a problem as this remains a specials manufactured product in the UK.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be

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					made available on the NICE website.
Guy's & St. Thomas' NHS Foundation Trust	Full	222	Table 5	Question whether the inclusion of hyoscine hydrobromide and atropine reflect specialist palliative care practice?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Guy's & St. Thomas' NHS Foundation Trust	Full	General	General	Where choices from options are offered between drugs in any of the symptom categories consider guiding the reader in making this choice wherever possible, for example (and where there is lack of guiding evidence) this may be based on local formularies and therefore familiarity in clinical practice.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Guy's & St. Thomas' NHS Foundation Trust	Full	General	General	We appreciate the drive for safe and appropriate prescribing. However, 2-4hrly frequency for morphine and midazolam; tds for haloperidol; 12hrly for levomepromazine; 6-8hrly for glycopyrrolate and hyoscine butylbromide: these are all relatively infrequent compared to our practice. This leaves frontline staff with a difficulty when attempting to gain initial control of a difficult symptom and risks poor symptom control. Consider raising awareness of where more rapid initial dose titration may be appropriate, for example every 1-2hrs with a cut off (for example 2 x PRN) after which further repeats are not made until a specialist is contacted for advice. This may require a change in medication or a switch to a syringe pump. We have built this process into our treatment algorithms to balance effective initial titration against risk of overzealous administration. We would suggest a higher permitted frequency (e.g. 1-2hrly for morphine / midazolam with a maximum dose / interval specified). We would suggest recognition of the potential need for more frequent dosing in initial use with Antimuscarinic.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Healthwatch Bracknell Forest	Full	11	17	The person wanted to die at home and it was only because of the persistence of his wife and carer that this happened.	Thank you for contributing to the consultation process.

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Healthwatch Bracknell Forest	Full	13	8	There is concern that the persons wishes can be ignored when they want to let things run there course. "The process feels like a tick box exercise which resulted in my husband being refused the one thing he wanted". His Wife and Carer could have been more involved in these discussions to enable this.	Thank you for your comment. The recommendations made in this guideline are aimed to move away from a "tick box" approach towards individualised care.
Healthwatch Bracknell Forest	Full	13	26	Establish as early as possible the resources needed for the dying person. "Discharge was made difficult due to a lack of joined up hospital services". Hospital Pharmacy was unable to provide the necessary medication prior to discharge and the individual was taken home in an ambulance without pain medication fortunately shortly after arrival at home a GP prescribed medication. Medication was made available later that evening which the Family had to return to hospital to collect. "The palliative care team were brilliant and liaised with Community Care and GP".	Thank you for your comment. The recommendations in this guideline aim to prevent the situation you detail.
Healthwatch Bracknell Forest	Full	13	29	Care plans are not always in the interest of the individuals wishes "He was desperate to have the catheter removed". This was refused in hospital due to risk of infection and told would have to stay in for a further 24 hours. Once home District Nurse allowed this request. "Removing this made such a difference to his psychological wellbeing".	Thank you for your comment. The recommendations in this guideline aim to prevent the situation you detail. The committee acknowledge there are certain circumstances where it may not always be appropriate to meet the dying person's wishes but have made a recommendation to describe appropriate action in this case (see recommendation 20).

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Healthwatch Bracknell Forest	Full	15	31	Management of Pain – *"Reactive prescribing was not swift enough in hospital as busy Nurses could not deal promptly to changing needs".* There is further concern that if medical staff erred on the side of keeping a dying person lucid but uncomfortable rather than favour a pain free state which might result in sedation.	Thank you for participating in the consultation process. The Committee considered this issue and this is discussed in detail in the 'Linking evidence to recommendations' table within this section.
Healthwatch Bracknell Forest	Full	15	31	Management of Pain Out of Hours - Things get worse out of hours, the District Nurse was urgently required but was the other side of the county. Hospital suggested readmission. Having just in case medication avoided readmission whilst they waited for the Nurse to arrive. (In this instance it wasn't used).	Thank you for participating in the consultation process. The Committee considered this issue and this is discussed in detail in the 'Linking evidence to recommendations' section 9.5 of the full guideline.
Healthwatch Bracknell Forest	Full	15	31	The GP also went to the Pharmacy at one point to collect medication to ease agitation. *"If just in case medication was available at home this could have been avoided."*	Thank you for participating in the consultation process. The Committee considered this issue and this is discussed in detail in the 'Linking evidence to recommendations' section of the full guideline. (please see 9.5)
Helen and Douglas Hospice	General		General	Otherwise I would like to congratulate you all on what I sincerely believe to be an excellent piece of work, which ought to help to improve the life (and death) of patients in receipt of palliative care.	Thank you for your comment and for participating in the consultation process.
Helen and Douglas Hospice	Full 10.2	217		The prescribing tables are a very useful additional resource. I work in a hospice setting for children and younger adults with palliative care needs (Helen & Douglas House). Many of the young adults that we	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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				treat are very much smaller than 'average adults' (as I imagine are very many frail elderly patients). I wonder if it would be prudent to more clearly indicate that smaller starting doses, or indeed doses based on body weight may be appropriate?	being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Herts Community NHS Trust	short	4	16	Defining multidisciplinary team, specifically the role of Doctors, would be very helpful as GPs may otherwise defer to non-medical professionals to decide when last few days of life starts. Our trust has struggled to implement One Chance to get it Right due to uncertainty of the role of GPs.	Thank you for your comment. Multiprofessional team structure was not in the scope of this guideline. NICE is currently developing guidance in palliative care service delivery and the issue of defining the multidisciplinary team may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Hospice UK (previously Help the Hospices)	Short	18	12-19	This could simply say these guidelines are aimed at supporting all health care professionals, particularly generalists, in all settings, acute and community, where people die.	Thank you for your comment. We have made some amendments to this section to incorporate other settings.
Hospice UK (previously Help	Short	17	21-25	It is for these reasons (as in earlier sections) it should be stressed that senior clinicians need to be leading on discussions with and about dying people. It is also for this reason that symptom tables should	Thank you for your comment. We have made a number of recommendations about access to senior specialist advice.

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the Hospices)				not be so brief (omitting relevant caveats and prompts) that medication is used injudiciously and the LCP debacle is repeated.	It's not possible for the guideline to outline all clinical actions to be undertaken, especially as part of prescribing practice. This guideline assumes that prescribers, regardless of setting or specialism, will follow standardised prescribing principles and relevant professional guidance, for example as outlined in the British National Formulary or by the General Medical Council. Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	19	27	'Advance' not 'advanced'. This mistake is made frequently throughout the short and full guideline.	Thank you for your comment. This has been amended throughout the guideline.

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Hospice UK (previously Help the Hospices)	Full	245	Glossary	Advance, not advanced care plan – needs a re-write to include a more contemporary explanation of the ACP process together with definitions of Advance Statement and Advance Decisions to Refuse Treatment and Lasting Power of Attorney	We have amended the guideline to refer to Advance Care plans and Advance care planning and have also now included reference to lasting powers of attorney where relevant.
Hospice UK (previously Help the Hospices)	Full	244	Acronyms	PPC = Preferred Place of Care ACP = Advance Care Planning	Thank you for your comment. This has been amended
Hospice UK (previously Help the Hospices)	Full	247	Glossary	End of life - ? last days or ? last year of life – needs definition appropriate to this document	Thank you for your comment. This has now been amended in line with definition used in 'One Chance to get it Right'.
Hospice UK (previously Help the Hospices)	Full	General	General	Many aspects of the draft Guidelines are valuable pointers to better practice, particularly for generalists caring for people at the end of life, but there are also many areas of fundamental concern, which have been gathered as feedback from hospice/palliative clinicians, social workers and palliative educators, the Association of Palliative Medicine and the RCP Committee on Ethical Issues in Medicine.	Thank you for your comment.

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Hospice UK (previously Help the Hospices)	Full	General	General	The approach to evidence gathering and grading is enormously thorough – however some of the really relevant omissions which concerns us in the Short Guideline are actually addressed in 'other considerations' in the Full Guideline, but fail to be translated into what is likely to become the main useable document	Thank you for your comment.
Hospice UK (previously Help the Hospices)	Short	18	10	The term 'end of life' is now very ambiguous in NHS parlance. For the public, and for these guidelines, end of life means the last days. It is awkward to have other documents focussing on 'end of life' which talk about a year of care. It would be easier to talk about care in the last years of life or last days. We would all understand this.	Thank you for your comment. We have been keen to refer to the last days of life to minimize confusion with the term 'end of life' which, in other documents, refers to the last year of life.
Hospice UK (previously Help the Hospices)	Short	18	19	This should say 'NHS and non-NHS palliative care units and hospices'	Thank you for your comment. We prefer our wording and have not made any change to this section. NHS settings are referred to earlier in the text.
Hospice UK (previously Help the Hospices)	Short	19	2	This is a strange statement – re conscious or unconscious, with no mention of capacity. Note previous comments about the lack of reference to decision making and the MCA	Thank you for your comment. This text has been amended and now reads: The guideline recommendations apply to people at the end of life across all levels of consciousness.
1.				5. It seems odd to actually suggest a	Thank you for your comment. Suggesting

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				research protocol/method in this guideline. This needs more consideration.	recommendation for research is a standard approach within all NICE guidance as detailed within the NICE methods manual: https://www.nice.org.uk/media/default/about/what-we-do/our-programmes/developing-nice-guidelines-the-manual.pdf.

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Hospice UK (previously Help the Hospices)	Short	21	3-7	It is unlikely that research will elucidate exact doses to manage delirium which is multifactorial in the last days of life.. Guidance will always be based on the lowest doses, with pointers about safe titration and review.	Thank you for your comment. The GDG consider that research in this area will have benefit and add to the evidence base on how to control delirium.
Hospice UK (previously Help the Hospi	Short	22	26	A cluster RCT would be difficult to do ethically. It is embedded teaching now to think ahead and prescribe for those at home and in care homes to avoid the chasing of medications in a crisis. However a large scale follow-back survey to look at home deaths and what medications were used in the last days and whether these were prescribed in advance would be valuable.	Thank you for your comment. The GDG recognise that research at end of life is difficult and understand than gaining ethical approval can be a challenge, however consider that people should be able to participate in research if prior permission has been given. Further detail is given in the appendix around feasibility of these research recommendations.

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Hospice UK (previously Help the Hospices)	Short	22	5	This is a strong statement – 'hard to justify their continued use' and yet there are recommendations in the guidelines to do so?	Thank you, this text has been amended.
Hospice UK (previously Help the Hospices)	Full	General	General	**Recognising the 'dying' phase –** this is obviously crucial but complex, and will always rely on a constellation of functional and biomedical parameters, as well as the wisdom and experience of clinicians who understand the context of the person and the illness. This needs seniority in clinical leadership to manage interdisciplinary discussions as to whether someone is dying or recovering –*seniority* needs to be identified in the Guidelines, whatever the setting – ie the appropriate level of doctor or nurse in hospital or primary care.	Thank you for your comment. We agree that recognising dying is difficult and have discussed this in the NICE version and full version of the guideline. We do recommend seeking advice from colleagues with more experience of providing end of life care if there is uncertainty and have detailed challenges in the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8). We believe that experience is as valuable as seniority. NICE is currently developing guidance in palliative care service delivery and the issue of seniority and team structure may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Hospice UK (previousl	Short	3	9-18	These bullet points don't follow normal clinical practice i.e. history and context come before signs and symptoms. The other bullet points could come	Thank you for your comment. These points are in alphabetical order as each point is considered to have equal status.

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y Help the Hospices)				after 1.1.2 i.e. once it is established that the patient is dying.	
Hospice UK (previously Help the Hospices)	Short	4	1-15	This seems to be a random disordered list ?– it would be better to group functional changes, behaviours, symptoms, and physical signs into groups. ECOG also needs explanation.	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (Please see section 5.8).
Hospice UK (previously Help the Hospices)	Full	General	General	**Ethics and capacity and communication** – There are general concerns about lack of focus on capacity assessment in the last days, explanations of 'best interest' decision making and the role of 'those important to the patient'. It seems as though in an attempt to involve the family/carers, equal weight has been given throughout this guidance to the patient and their family. The family need support and have communication needs, but their role in decision making needs much more clarity in terms of legal status. There are also several references to out-dated terms in relation to advance care planning. Details below.	Thank you for your comment. The committee agree that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. We wished to understand how the dying person, their loved ones and their multiprofessional team could best work together to ensure that decisions made considered and met (where possible) the dying person's wishes (see 7.1 for further information behind the intention of the evidence review that informed these recommendations. We have not undertaken a review of capacity or 'best interests' as these issues are defined in law. However, we have added further detail to the guideline to provide further context on this issue. We would expect health and care providers to be aware of and cognisant of the

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					implications of the act when providing care to patients but always to act in the best interests of the dying person. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Hospice UK (previously Help the Hospices)	Full	91	Fig 4	Valuable thematic maps – this one is related to 'communication' not 'shared decision making'?	Thank you for your comment. The map you referred to is related to shared decision making which makes strong reference to principles and elements of communication.
Hospice UK (previously Help the Hospices)	Short	6	4	Advance Care Plan needs clarity. The recognised terms are Advance Statement and Advance Decision to Refuse Treatment – both to be considered in the event of loss of capacity. However if the person has capacity at the time of this conversation, then the exploration is whether they have thought about preferences for this stage of their life and what their goals, hopes and wishes are now, bearing in mind the current context. If the person does not have capacity at this stage, then it should be established whether a formal	Thank you for your comment. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare Advance Care Planning and Advance Decision to Refuse Treatment have been discussed in the 'Linking evidence to recommendations' section of the full version of the guideline. Definitions of both items have also been included in the glossary and the introductory text of

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				Advance Statement, any informal recording of wishes or an ADRT is available to guide further decision making. It should also be established whether anyone has ben granted Lasting Power of Attorney. A 'best interest' meeting would then take place.	the guideline. Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Hospice UK (previously Help the Hospices)	Short	5	10	The bullet point on cognition is crucial and needs to be at the start of 1.2.1 as cognitive status will affect subsequent discussions, decisions and questioning about information needs. Cognition is often affected in the final days, and efforts should be made to communicate at time when the dying patient is at their most alert. An explanation of capacity assessment regarding specific decisions, together with an outline of how 'best interest' decisions are made is an essential	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this

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				part of these communication guidelines – it was this lack of understanding that led to some of the communications failures around the LCP.	area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Hospice UK (previously Help the Hospices)	Short	5	13	Seems to repeat bullet points of 1.2.1? It might be better phrased as exploring the dying persons wish (or not) to understand their prognosis, and if they are keen to know, establish what they themselves think. Give examples of possible conversation openers – these are the most difficult conversations that doctors ever have.	Thank you for your comment. Recommendation 1.2.1 (currently 2.2.1 in the final guideline) establishes the parameters for communication with the dying person, how much they want to know, who they would like present and their capacity and cognitive status. Recommendation 2.2.2 urges healthcare professionals to initiate discussions around prognosis, using the patient's articulated communication needs and capacity as a guide. We agree and as a guide to support difficult conversations, the committee relied on guidance provided in the NICE guidance entitled, Patient Experience in the adult NHS services. A cross reference to this guideline has been included. More information on this guideline can be found at: https://www.nice.org.uk/guidance/cg138.
Hospice UK (previously Help the	Short	6	8	This bullet point is strange – you can't keep asking someone if they remember they are going to die!! Assessment of capacity should be at the start of this communication section.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking

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Hospices)					evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009
Hospice UK (previously Help the Hospices)	Short	7	1	"Those important to them' do not have decision making powers if the person has capacity	Thank you for your comment. The committee feels that this recommendation provides an opportunity if the dying person wants those important to them to be involved in decision making or conversations about their care. It does not intend that they have decision making powers. It is intended as a reminder to care givers to be cognisant of the needs of those supporting the dying person.
Hospice UK (previously Help the Hospices)	Short	5	17	Identifying the best person to communicate should come before Section 1.2.2	Thank you for your comment. This has been amended.
Hospice UK	Short	5	23	Repeats 1.2.2	Thank you for your comment. The Committee's intention is to first ensure that a discussion takes

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(previously Help the Hospices)					place with the dying person, recommendation 1.2.4 that you refer to covers the provision of information and opportunities for further discussion. The committee sees all the elements described in each recommendation as a key to the communication process.
Hospice UK (previously Help the Hospices)	Short	6	13	Again – this is difficult for junior staff to handle – some communication guidance would be useful at this point.	Thank you for your comment. The Committee appreciates the challenges of communication in end of life care but believes that communication instructions would be best managed at the Trust level. We agree and as a guide the committee relied on guidance provided in the NICE guidance entitled, Patient Experience in the adult NHS services. A cross reference to this guideline has been included. More information on this guideline can be found at: https://www.nice.org.uk/guidance/cg138.
Hospice UK (previously Help the Hospices)	Short	6	19	Shared decision making is a specific concept that needs explanation – Sections 1.31 and 1.3.2 seem to repeat much of what has been said in the Communication section? Again capacity needs to be considered.	Thank you for your comment. The shared decision making definition in the glossary has been amended and now reads: A process in which patients, when they reach a decision crossroads in their health care, can review all the treatment options available to them and participate actively with their healthcare professional in making that decision. Further details related to what is expected to be included in shared decision making is discussed in the 'Linking evidence to recommendations' section in the full guideline (7.6)

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					We believe that the two sections provide recommendations pertinent to each topic as we feel one set describes a process (Communication) and the other the content of an activity(Shared decision making) . Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Hospice UK (previously Help the Hospices	Short	6	24	See previous need for clarity around advance care planning terminology	Thank you for your comment. We agree and have recommended that the ACP be part of the shared decision making process. We are unable to make include addition detail in the short version of the guideline, but do expand on this in the full version 'Linking evidence to recommendations' section. We

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)					have also added ACP to the list of acronyms and glossary of the guideline and made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare.
Hospice UK (previously Help the Hospices)	Short	7	21-26	These feel a bit future-focussed? – if the patient is dying now, then current symptoms, resources and care needs are more relevant – i.e. a plan for today	Thank you for your comment. The Committee agrees, that ideally, the needs of patients would be best established during an earlier point in care. However, the Committee also felt strongly that this recommendation was very key to delivering an individualised care plan to the dying person. The list now includes 'current and anticipated care needs and preferences for symptom management'
Hospice UK (previously Help the Hospices)	Short	7	4	A single name at this stage may be unworkable – several options should be given plus emergency contact numbers of the team, rather than one person.	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. The Committee recognises that there may be challenges to its implementation, but that is an aspirational recommendation.
Hospice UK (previously Help the Hospices	Short	7	7	Equally, the healthcare team should establish contact details of who to contact should there be deterioration ie a two way sharing of contact details.	Thank you for your comment. The Committee agree and that next of kin contact details should be obtained, but considered this to be standard practice and applicable prior to the last days of life. They therefore chose not to specifically state this in the recommendation.

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Hospice UK (previously Help the Hospices)	Short	8	10	Perhaps it would be better to say 'Seek specialist advice if decision making is complex or if there is significant conflict within the team, or with the patient and those close to them'	Thank you for your comment. This has been acknowledged within the full version of the guideline in the 'Linking evidence to recommendations' section.
Hospice UK (previously Help the Hospices)	Short	8	13	'Support the dying person to drink' – encouragement with a straw, a teaspoon, the right beaker, thickened fluids etc. – i.e. real encouragement and patience to support drinking. A Speech and Language therapist can advise on the best positioning to avoid aspiration, but this is often inevitable to some extent in the final days, as swallowing weakens.	Thank you for your comment. Your examples have been added to the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
Hospice UK (previously Help the Hospices)	Short	8	1-5	Needs some guidance about how decisions are updated in the absence of capacity eg about sedation, withdrawal of treatment etc.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available

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					at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Hospice UK (previously Help the Hospices)	Short	9	12	Hydration may well prolong the dying process by some hours or days – so not sure this line is accurate.	Thank you for your comment. This statement is based on the clinical evidence review of clinically assisted hydration, which (despite being of limited quality) showed that survival did not increase or shorten compared to placebo/usual care. Further detail is available in the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
Hospice UK (previously Help the Hospices)	Short	9	14	Add 'in the final days'	Thank you for your comment. We have carefully considered your suggestion and feel that no change is required.
Hospice UK (previously Help the Hospices)	Short	9	15-25	1.4.6 and 1.4.7 should be at the start of the 'hydration' section	Thank you for your comment. We have carefully considered this suggestion and feel that no change is required. We prefer our ordering of recommendations which advocate oral hydration and mouth care at the beginning of this section.
Hospice UK (previously Help	Short	9	1-7	The suggestion of daily review of clinically assisted hydration and 'respecting wishes and preferences' is difficult guidance and implies an obligation to put up a drip, even when it would be harmful or ineffective.	Thank you for your comment. The recommendations are intended to first explore maintaining hydration via drinking or supporting the dying person to drink then to consider the risks and benefits of clinically

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the Hospices)				There is also the issue that IV hydration would require transfer from a community setting to hospital or hospice – this needs to be clarified in the guidance. Obviously if it is appropriate to rehydrate to reverse a treatable complication, then the net benefit of transfer and treatment should be discussed.	assisted hydration. Rec 2.4.4 highlights that when reviewing the need for clinically assisted hydration the dying person's wishes and preferences should be respected. This is further detailed in the 'Linking evidence to recommendations' statement in section 8.6 of the full version of the guideline. The Committee intends that the recommendation for a clinical trial of assisted hydration would apply to all settings and are aware that clinically assisted hydration may take place in the community, but note that there may be challenges to its implementation.
Hospice UK (previously Help the Hospices)	Short	9	26	This is not so easy in all settings e.g. home or care home and needs clarification and discussion of net benefit.	Thank you for your comment. Text has been added to the full guideline that states: The Committee discussed whether a person dying at home would require a move to hospital for clinically assisted hydration, but agreed that this was not necessary and that it is possible to provide clinically assisted hydration at home. The Committee discussed that setting was not a barrier to providing clinically assisted hydration, but that this may require additional resources for implementation and is an aspirational recommendation.
Hospice UK (previously Help the Hospices)	Short	9	8	This advice section should come at the beginning of the 'hydration' section	Thank you for your comment. We have carefully considered the order of the recommendation and feel that no change is required.

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Hospice UK (previously Help the Hospices)	Full	183		Comment about cyclizine – its lack of efficacy compared to other antiemetics, poorly tolerated etc. – yet it appears as one of the 5 options for anti-emetics in the Prescribing Table for nausea?	Thank you for your comments on the prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website. We have made no specific recommendations for the use of cyclizine given the lack of evidence and the Committee's agreement with the issues your raise.
Hospice UK (previously Help the Hospices)	Full	General	General 217-222	**Symptom management** – the text and tables are really concerning. The literature review only included studies on populations with 30 days to live – this will have excluded significant higher grade evidence for symptom management that is probably still applicable in the final days. In the absence of high grade evidence, a new set of short symptom Tables have been drafted, which are not only unsafe in parts, but suggest medicines and routes of administration which are really not appropriate for brief generalist guidelines. The rationale for developing new prescribing Tables based on '*consensus and experience'* of the	Thank you for your comment. The remit of the guideline in last days of life and we have considered studies up to 30 days as indirect evidence. Thank you for your comments on the prescribing tables. Because of the recognised importance by many stakeholders of the need to support non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This

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			162	guideline development group is a strange decision, when there are recognised formularies of palliative prescribing in the last days, regularly edited, referenced and based on 40 years of national and international palliative practice. For instance the PCF 5 (Palliative Formulary 5 by Twycross, Willcox et al) is the basis for much end of life teaching and practice. The prescribing tables in the PCF 5 have the safety caveats that the Tables in the draft NICE guidelines have omitted. On page 162 there is a statement that pre-existing pain management frameworks should be used – but the Prescribing Tables in the draft Guidelines do not refer to any of these. We make a strong recommendation that the Prescribing Tables are significantly reviewed – see detailed comments below. It is likely that people ignore text and go straight to Tables– they therefore need to be comprehensive and safe.	important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	10	21	If the patient is capacitous, it really isn't up to 'those important to them' as to whether medication is stopped. Need clarification between discussion, information and decision-making.	Thank you for your comment. The Committee consider that including those important to the dying person is important and have made a minor amendment to this recommendation
Hospice UK (previousl	Short	10	29	Some specific guidance – (here or in the appendices) about stopping steroids, insulin, anti-coagulants etc would be helpful. These are difficult	Thank you for your comment. We are unable to comment on specific conditions or diseases as this is non-specialist guidance and was beyond the remit

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y Help the Hospices)				decisions and I have seen difficult bereavements where a person felt their loved one had died because the insulin was stopped with out discussion. There are excellent guidelines on diabetic end of life care.	of the evidence reviews conducted to inform these recommendations.
Hospice UK (previously Help the Hospices)	Short	11	13-19	Intravenous medication rarely appropriate in the UK, even in ICU settings. Subcutaneous infusions via a syringe pump (previously know as syringe driver) is the recommended route in the final days for continuous symptom control and can be safely used in all settings e.g. hospital, care home or home. If this is not possible, then transdermal or rectal routes should be considered if oral route no longer possible and frequent prn doses needed.	Thank you for your comment the content of which is noted.
Hospice UK (previously Help the Hospices)	Short	11	22	Appendix A does not give any titration guidance – yet this paragraph refers to it.	Thank you for your comments on the prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance together with any reference to an appendix. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK	Short	11	26	Symptoms need more than 'daily' assessment ! If prn dose of analgesia does not give adequate pain	Thank you for your comment. "At least daily" does not preclude more frequent reassessment. As no

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(previously Help the Hospices)				relief within an hour or two, then dose needs adjusting. No symptoms in the last days of life should remain uncontrolled for a whole day – regular assessment of symptoms is the key to good care at the end of life.	evidence review was conducted in this area the Committee are unable to be more prescriptive.
Hospice UK (previously Help the Hospices)	Short	11	27	Safe guidance on titration needed – it is nor given here or in Appendix	Thank you for your comment. As no evidence review was conducted in this area the Committee are unable to be more prescriptive. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website. This issue will be raised with the group developing this work
Hospice UK (previously Help the Hospices)	Short	11	3	Seems repetitious – see Page 10 Line 29	Thank you for your comment. The Committee feel that this detail is needed in both recommendations. Recommendation 1.5.2 is about involving the dying person and those important to them and recommendation 1.5.3 focusses on the healthcare professional making the decision of what to offer.
Hospice UK (previousl	Short	11	8	The warning about cyclizine and heart failure appears several times in the guidance – a judicious dose can be chosen (e.g. less than 150mg per day)	Thank you for your comment. The Committee noted that the summary of product characteristics from the manufacturer of cyclizine gives the following special

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y Help the Hospices)				– but exacerbation of heart failure may not be of real relevance in the final days if cyclizine is the best antiemetic.	warning and precaution for use: Cyclizine should be used with caution in patients with severe heart failure or acute myocardial infarction. In such patients, cyclizine may cause a fall in cardiac output associated with increases in heart rate, mean arterial pressure and pulmonary wedge pressure. The Committee discussed that it was important that clinicians were aware of this advice, but was aware of the lack of evidence regarding the efficacy and harms of cyclizine in the end of life setting and therefore was unable to make any specific recommendations in this regard. Further detail has been added to the 'Linking evidence to recommendations' section in the full guideline (please see section 9.13).
Hospice UK (previously Help the Hospices)	Short	12	11	The management of pain in the final days is not governed by the same principles as pain at other times of life eg there are no concerns about addiction, the routes of administration are different, the frequency of review is different etc	Thank you for your comment. After careful consideration we do not feel any change to our recommendation is required. The intention of this recommendation is to outline that similar considerations should be made when managing pain in the last days of life. This does not preclude an assessment of benefits and harms but these would be considered within this specific context.
Hospice UK (previously Help the Hospices	Short	12	13	The dying persons 'preferred' route of administration may not always be effective or possible	Thank you for your comment. We agree and have added in "if appropriate"

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Hospice UK (previously Help the Hospices)	Short	12	16	It would be helpful to identify a 'validated behavioural pain assessment tool'	Thank you for your comment. An evidence review was not conducted on the use of pain assessment tools in the last few days of life, however the Committee chose to make a recommendation about their use based on their own clinical experience. Further detail has been added to the 'Linking evidence to recommendations' section of this chapter in the full guideline (please see section 9.5).
Hospice UK (previously Help the Hospices)	Short	12	19	Give examples of non-pharmacological techniques to help breathlessness eg complementary therapies, hand-held fan	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Hospice UK (previously Help the Hospices)	Short	12	21	Need to add the words 'if appropriate' – and explain that reversing causes of breathlessness (eg transfusion, drainage of effusions) may require admission from the community. Again net benefit needs to be sensitively discussed.	Thank you for your comment. The Committee consider identifying and treating reversible causes of breathlessness as very important. They considered that clinical judgement be used as to whether this was possible or not and that no further detail was needed.
Hospice UK	Short	12	3	'Specialist advice' should not only be sought if there are 'undesirable side effects' but whenever help is	Thank you for your comment. We believe that this is implied within the recommendation as currently

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(previously Help the Hospices)				needed to improve symptoms when first line medicines or doses haven't helped. It should be stated here, or at the start of the Symptom section, that staff should always be aware of who and how to get urgent symptom advice from – i.e. is there a Palliative Advice Line for 'out of hours and weekend' support and/or the local hospice number.	worded and do not feel any change is required. Service Delivery, including access to specialist palliative care out of hours, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Hospice UK (previously Help the Hospices)	Short	12	4-17	The pain section is crucial – the symptom most of us fear and the symptom that junior doctors and generalists most often struggle with – the draft guidelines are too vague. The assessment section 1.5.11 should advise on whether pain is present at rest or just on movement, previous analgesia etc. It should link to established guidelines on pain assessment if the details aren't to be included here.	Thank you for your comment. As no review was prioritised for pain assessment we are unable to provide more detail in the recommendation. We have added more detail to the 'Linking evidence to recommendations' section in the full guideline (please see chapter 9).
Hospice UK (previously Help the Hospices)	Short	13	1	The footnote re prescribing authorisations re using opioids and breathlessness will stop some people from using small relevant does to palliate breathlessness and should appear as a single overarching proviso in the breathlessness section – perhaps as 1.5.18 – with the added comment that there is emerging evidence of value and that it is established palliative practice and again point to guidelines developed by experts which suggest low starting doses, and careful titration depending on the	Thank you for your comment. The footnotes are standard NICE text when a drug is recommended outside its licensed indication.

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				underlying cause – ie the level and type of respiratory failure.	
Hospice UK (previously Help the Hospices)	Short	13	14	At this point it should be suggested that buccal, subcutaneous or transdermal routes may be best – as nausea suggests retro-peristalsis and poor absorption via the oral route	Thank you for your comment. Recommendation on appropriate route are made in the general pharmacological intervention section - see recommendation 1.5.4 and 1.5.5
Hospice UK (previously Help the Hospices)	Short	13	16	It would be helpful to suggest some non-pharmacological treatments	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Hospice UK (previously Help the Hospices)	Short	13	5-13	It is usual to distinguish between nausea and vomiting. It would be helpful to categorise the list eg Consider bowel causes, medication, metabolic or intra-cranial – as this will help identify first line choices of treatment	Thank you for your comment. After careful consideration, the Committee felt it was helpful to outline the detail as currently drafted. We believe that this list may support the relevant action based on the likely cause or distinction between nausea and/or vomiting.
Hospice UK	Short	14	1	Not sure why you have picked out this particular scenario (bowel obstruction) when there are	Thank you for your comment. This reflects the evidence considered for the specific use of

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(previously Help the Hospices)				numerous other scenarios. In bowel obstruction it is important to assess whether functional (in which case a laxative or prokinetic agent might help) or a mechanical blockage.	Octreotide.
Hospice UK (previously Help the Hospices)	Short	14	13	'Treat any reversible causes' – again the net benefit has to be considered. If the delirium is due to hypercalcaemia or sepsis or uraemia, there needs to be a 'best interest' discussion about treatment and potential transfer if not in an acute setting.	Thank you. We agree that clinical judgement should be used here, but expect this recommendation to apply to all settings.
Hospice UK (previously Help the Hospices)	Short	14	16	If agitation is due to an underlying delirium, then a benzodiazepine may well worsen the agitation.	Thank you for your comment. This is further explored within the 'Linking evidence to recommendations' section of the full guideline (please see section 9.17).
Hospice UK (previously Help the Hospices)	Short	14	3	Unclear – it says 'first line pharmacological treatment'. Does this mean for the nausea and vomiting of bowel obstruction? Cyclizine and haloperidol are the standard approach for nausea although hyoscine butylbromide may work. Though it is usually added for colic and reduction of bowel secretions.	Thank you for your comment. This recommendation is for people with obstructive bowel disorders who have nausea and vomiting. As stated in the full guideline: As there was no clear evidence that octreotide was the more clinically effective option, yet it was considerably more expensive, the Committee decided to recommend its use only for when hyoscine butylbromide produced ineffective results. Recommendation 1.5.21 covers nausea and vomiting in the last days of life, however the

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					Committee chose not to state specific medications here due to the lack of evidence identified.
Hospice UK (previously Help the Hospices)	Short	14	7-20	Unhelpful grouping of key symptoms – anxiety, delirium and agitation. They need definition, different approaches and medication choices. If somebody is very agitated or delirious – then 'exploring the causes' with them is a strange suggestion. There is an additional syndrome of 'restlessness' in the final hours of life which hasn't been mentioned. Again (as with nausea) a simple categorisation of common causes of delirium in the last days would be useful. Generally there needs to be more succinct but helpful guidance on the use of sedation at the end of life – it is something people are fearful of, has ethical challenges and yet is critical to bring about a peaceful ending in many situations.	Thank you for your comment. We recognize the very individual nature of these issues. The recommendations drafted reflect the evidence considered and the Committee expert opinion. Further discussion can be found in Chapter 9 of the full guideline. The Committee did not wish to provide a separate list of common causes as they felt it an area that may require specialist input. The Committee have been keen throughout this guideline to make recommendations which support an individualized approach to symptom management which incorporate the dying person's preferences, consider drug interactions and the need for frequents assessment and review to avid unwanted sedation.
Hospice UK (previously Help the Hospices)	Short	15	19	If antisecretory drugs are tried but have unacceptable side effects, then the medication should be stopped rather than treat the side effects. Treating the side effects is likely to increase sedation and compound the problem.	Thank you for your comment. We have provided a series of recommendations which address this area. We feel that recommendation 1.5.32 which suggests stopping medication if unacceptable side effects persist is helpful in this regard. We feel that advice should be available in terms of what to do if side effects persist and the symptom remains troubling to the individual. Recommendations 1.5.3 and .1.5.8 provide an additional context for prescribing that

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					help avoid the situation you describe.
Hospice UK (previously Help the Hospices)	Short	15	7	Medication cannot be given to the dying person (especially when it has been established that antisecretory medication often doesn't work and has side effects) just to ease the comfort of 'those important to them'! This is not in line with the MCA	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We have also made amendments to the recommendation to clarify that the intention of treatment should be to treat the dying person. We would also note that despite the limited evidence in this area, the Committee felt that it may remain a valid treatment option and so chose to make the recommendations as weak as possible but with some clear advice to review and stop medication if there was no benefit to the dying person.
Hospice UK	Short	16	10	Repeats Line 8	Thank you for your comment. The wording of this recommendation has been amended.

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(previously Help the Hospices)					
Hospice UK (previously Help the Hospices)	Short	16	1-26	This is very wordy! The simple message is – anticipate what symptoms are likely to happen in the remaining days of life and prescribe appropriately, on an individual basis. The prescription should be based on previous dosage history, likely worsening or occurrence of specific symptoms and the most likely successful route of administration.	Thank you for your comment. The wording of this recommendation has been amended.
Hospice UK (previously Help the Hospices)	Short	16	28	Symptoms need to be monitored much more frequently than daily. This would not be good care at this stage of life.	Thank you for your comment. "At least daily" does not preclude more frequent reassessment. As no evidence review was conducted in this area the Committee are unable to be more prescriptive.
Hospice UK (previously Help the Hospices)	Short			Guidance needed on when to use subcutaneous furosemide in end stage heart failure	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be

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					made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	24	19-25	There are rarely people with 'authority to give consent' on behalf of patients (ie very few LPA's at present). Also patients in the last days are unlikely to be concerned with issues around 'licencing' and 'off-label' use. If prescribing is done safely in line with established formularies, and documented well – then this should be satisfactory to protect the doctor!	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	24	4	If there is little evidence, but much experience for current practice, then surely the guidelines should signpost to the best UK guidelines endorsed by experts and wait until further research is completed, rather than develop new unsupported guidelines/tables in the interim?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previou	Short	25	5	With respect to the Committee – the tables proposed are incomplete and therefore limited and potentially dangerous. It is stated that the choice of medicines	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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sly Help the Hospices)				has been limited by the evidence reviews and the experience of the Committee – but this is not a standard approach to developing new symptom guidelines. A simple example is that dexamethasone has been omitted from the nausea and vomiting guideline – this is a standard approach to the initial treatment of mechanical bowel obstruction and other causes of nausea such as raised intracranial pressure. Even if everything included in the tables were safe, they become unsafe if there are key omissions.	symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	25	8	'Preferences of the dying person should be respected'. The sentiment is understood but it needs clarification as doctors prescribe to minimise distress and cause least harm – they cannot simply prescribe what the patient requests?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospice	Short	26	1	This is a huge weakness and make the tables unsafe. They exclude medications we would expect generalists to use, not just specialists in palliative care e.g. dexamethasone as above for the nausea of raised intracranial pressure.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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s)					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	27		Opioids – comment on 'maximum' dose is highly dangerous – what is it? This table could lead to dangerous escalation of doses leading to unwanted sedation and possibly hastened death Opioids – IV morphine unlikely to be used in any setting outside hospital	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	27		Opioids - Guidance needed on conversion from oral to subcutaneous prn and 24 hour dose (otherwise some one on 400mg oral morphine will be put on 10mg morphine in a syringe pump according to these guidelines) Opioids - Guidance needed on safe increments for titration Opioids - Guidance needed on possible other opioids if morphine not tolerated Opioids - Guidance need on how to manage transdermal fentanyl in final days	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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				Opioids – guidance needed if unable to take neuropathic agents (that have previously helped) in last days	
Hospice UK (previously Help the Hospices)	Short	27	Table 1	Non-opioids – oral doses may be better in syrup form as swallowing declines Non-opioids – rectal route often not a dignified option in the final days Non-opioids – intravenous paracetamol not an option outside acute setting Non-opioids – subcutaneous NSAIDs are irritant, and can cause severe nausea if patient no longer eating	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	27-33	All Tables 1-6	All tables have unsafe comments about increasing to maximum doses, without advice about titration increments or exactly when to seek specialist help The intravenous route is unlikely to be used by generalists in the last days of life Clonazepam injection often has a supply issue in the community and is more commonly used in specialist settings All table need to identify if there are conversion factors when switching from oral to subcutaneous routes All tables need to indicate what the various causes of symptoms might be All tables need to include all medications that are in	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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				common use for specific symptoms All tables need to include some simple reminders about non- pharmacological interventions	
Hospice UK (previously Help the Hospices)	Short	28		The suggested diazepam dose ranges are huge – 10mg tds rectally is potentially dangerous in respiratory failure. PRN does of intravenous midazolam 5mg 2hourly is also not useful on a generalist guideline The ranges suggested for subcutaneous infusion of midazolam and clonazepam also seem very high with no guidance on titration Clonazepam is not widely used outside specialist settings, has a very long half life and can be surprisingly sedative in low doses	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	28	Table 2	The dose of opioid in breathlessness absolutely depends on the cause and type of respiratory failure and drive. Often the starting dose may be even lower than 2.5 mg morphine – e.g. in pulmonary fibrosis. IV morphine not useful on a generalist guideline 20mg morphine over 24 hours would be a high starting dose for breathlessness in a generalist setting Switching to another opioid – example and conversions need to be given	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice	Short	30		Second line anti-emetics – a warning about the	Thank you for your comment on the prescribing

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UK (previously Help the Hospices)				sedative side effects of levomepromazine is needed at doses greater than 12.5mg per 24 hours	tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	30		Guidance should include a mention of the value of ondansetron and dexamethasone	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospice	Short	30	Table 3	First line anti-emetics – a choice of 5 is unhelpful without any guidance on what to try for different causes Subcutaneous cyclizine is painful and often lower doses than 50mg tds are effective Meotoclopramide is a 2ml injection subcutaneously,	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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s)				is unlikely to be given intravenously (procyclidine should be available to cover a dystonic reaction)	members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	31	Table 4	Comment on maximum dosages need qualifying Guidance needed if previously on an antidepressant	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Hospice UK (previously Help the Hospices)	Short	32	Table 5	The 'as required' parenteral doses are very high and likely to sedate – e.g. 12.5mg Levomepromazine every 2 hours will be extremely sedative. 50mg of levomepromazine over 24 hours is much more sedative than 5mg haloperidol – the way the guidance is written suggests equivalence.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Hospice UK (previously Help the Hospices)	Full	General	Question 2	What would help overcome challenges? Much boils down to education, mentoring and role modelling at all levels of learning, rather than knowledge resources. More palliative care hours in the undergraduate curricula of nurses and doctors, systematic hospice placements, post-graduate rotations in geriatrics and primary care all to include some time with palliative teams, all palliative consults to include a nurse or doctor shadowing etc. Obvious signposting to multimedia resources to support communications skills. Obvious signposting to where and how to get urgent palliative support day, night and weekends – e.g. Advice lines and hospice numbers must be obvious in A&E, all wards, care homes etc. So – if dying is to improve everywhere, the most important change will be at the interface between specialists and generalists i.e. faciliatatory and enabling resources. The answer	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.

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				isn't thousands more palliative staff. Relevant respected formularies, as previously mentioned, accessible free online for the NHS would be great – Scotland has done this nationally with PCF5	
Hospice UK (previously Help the Hospices)	Full	General	Question 1	Recognising Dying and communicating more confidently These areas are likely to have a big impact on practice – if more patients are recognised to be in the last days of life, then the right conversations might take place, burdensome treatments stopped and a focus on good symptom control will ensue. However it will be a challenge to implement as the culture of medicine, certainly in the acute sector, is to 'fix' what can be fixed.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Hywel Dda University Health Board	Full	General	General	The document does not allude to the support required by patients/ families/ carers in managing expectation with respect to absent nutrition nearing death, i.e appetite is often severely reduced in terminal disease and the sensation of hunger and thirst is suppressed.	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult. This issue is beyond the remit and scope of this guideline.

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Hywel Dda University Health Board	Full	General	General	Concerns are that there are no recommendations in the guidance for DNACPR discussions with patients and those important to them.	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult. This issue is beyond the remit and scope of this guideline.
Hywel Dda University Health Board	Full	15	22	The document does not discuss capacity to make decisions /Best Interest meetings and impact of Lasting Power of attorney with respect to supportive decision making.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We have also made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare

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Hywel Dda University Health Board	Full	14	10-14	My usual advice re mouth care is to give sips of ice water or chips of ice for the usual reasons of it being a small volume ie easy to cope with by a debilitated patient & their carers, it is ice cold and therefore more refreshing than warm water, being ice cold also dramatically reduces the risk of this fluid being aspirated causing distressing choking or coughing as the patient cannot forget it is there and inhale it as they often do with warm fluids. I also usually advise the use of small volumes ie 5ml teaspoons/soft plastic baby feeding or oral medicine syringes/spoonsful of honey/golden syrup/honey and glycerine cough mixture as these fluids are easily held within the mouth, are sweet and pleasant to take & easily coat all of the oral mucous membranes (with one or two tongue movements) reducing the unpleasant dehydration/drying out of the mucous membranes. These liquids also stop the sore tongue of thrush etc being as painful/distressing as it can be or at least ameliorate it. These fluids can also be absorbed onto oral sponges for improved mouth care. Patients who are heavily mouth-breathing, as they often are towards the end, will suffer desiccation of their mucous membranes out of all proportion to the rehydration effects of a 'drip' on their mucous membranes so drips in this situation are of no value whereas good quality mouthcare is far more beneficial and paramount to the patient's needs.	Thank you for your comment. We have added some of your suggested detail to the 'Linking evidence to recommendations' section in the full guideline. We have made further amendments to this recommendation and it now states: Offer frequent care of the mouth and lips to the dying person and ensure that their care plan includes the management of dry mouth if needed.

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Hywel Dda University Health Board	Full	14	32	The document is not explicit regarding the risks associated with clinically assisted hydration e.g cellulitis, pulmonary oedema.	Thank you for your comment. This is discussed in the full version of the guideline in the 'Linking evidence to recommendations' in section 8.6.
Hywel Dda University Health Board	Full	14-15	18 (p14) to 12 (p15)	Concerns revolve around the issue of the perceived need for IV fluids as patients will suffer distressing dehydration. This to me is a completely incorrect assumption for the vast majority of palliative patients and its use in these patients will lead to an increased workload for the community nurses and the daytime/out of hours GPs. Clinically assisted hydration may well be needed, but rarely still, in young palliative care patients as they are far more likely to suffer the unpleasant effects of dehydration with increased sensation of thirst which could become distressing. I personally have never seen this in the many young palliative patients that I have seen but it could be an issue as they would still have some sense of thirst and this might not be mitigated by good quality mouth care. A drip in this rare situation could therefore be beneficial for this individual patient but I have never seen the clinical need for it myself.	Thank you for your comment. The 'Linking evidence to recommendations' section in 8.6 gives further details on the issues you mention, especially around support for oral hydration. Please note that the Committee have amended the recommendations for clarity to emphasize that their preference is for hydration by oral means and then to consider a trial of clinically assisted hydration based on an individualised approach taking into account the risks and benefits. The Committee discussed whether a person dying at home would require a move to hospital for clinically assisted hydration, but agreed that this was not necessary and that it is possible to provide clinically assisted hydration home if there were appropriate available resources. The Committee discussed that setting was not a barrier to providing clinically assisted hydration, but that this may require additional resources for implementation.

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				Elderly palliative patients in my experience are very unlikely to have issues with thirst and be in need of clinically assisted hydration. In actual fact, I have never known any elderly palliative patient (and I have looked after thousands of them in my 30 years as a hospital doctor and GP) ever complain of thirst that is distressing and/or is not resolved by sips of ice cold water or the other suggestions that I usually give. I also specifically find it difficult to understand the concept of thirsty palliative patients as most elderly patients have a greatly reduced sense of thirst anyway as this sense naturally declines with age in my experience so I feel this is an overstated concern. Also, most patients with chronic renal failure or acute on chronic renal failure already have raised urea and creatinine levels and even these patients never complain of thirst in my experience and this is presumably an adaptation of the body to reduce what could be a distressing symptom. As most palliative patients are this elderly group then the use of 'drips' is completely pointless in my experience. I am also concerned regarding 'putting up drips' in patients' homes where there is no guarantee that this will be clinically beneficial. In this circumstance,	

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				the families of these patients often cling to the 'drip' being a magical thing that is keeping their loved one alive which of course it does not and most often will only prolong their inevitable death. I do not feel keeping somebody alive in a comatose state is prolonging a life but is only prolonging a death. Therefore, is this not more a prolongation of the agony of a patient and their family going through the terminal phase of their condition, often with them being comatose/barely rousable when hopefully all of the last words and good-byes etc will already have been said when the person was still able to hear/respond back to them. We all know the sense of hearing is still present until death but exhausted patients and exhausted families clustered around a bed for even longer than the natural time for death to occur often have very little left to say when I have been present at those times. It is also sometimes an issue that prolonging an unpleasant death by any means actually fails to achieve the 'good death' that GPs try to achieve for their patients and more often than not, results in increased misery and despair at what the patient and their family are going through. With regard to the effect upon the workload of already pressed community nurses/ARTeams and GMS/OOH GPs, the imposition of even a few drips across a county regularly will lead to a noticeable increase in workload and this could be a significant	

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				concern by day and definitely overnight. Poorly managed 'drips' in this situation could actually result in increased distress for the patients or their families and rarely in them suffering from severe but avoidable harm.	
Hywel Dda University Health Board	Full	15	8	This comment refers to reviewing the risks/benefits of clinically assisted hydration. Many patients are also in receipt of clinically assisted nutrition. Clinically assisted nutrition and its appropriateness in the end of life needs to be discussed as per reference to the Royal College of Physicians /BSG document 2012 (oral feeding difficulties and dilemmas) Decisions regarding Clinically assisted nutrition/hydration need to be supported by the MDT including Dieticians who are experts in clinically assisted nutrition/hydration.	Thank you for your comment. Nutrition is beyond the remit and scope of this guideline.
Intensive Care Society	Full		8.6	There is a paragraph repeated within the text	Thank you for your comment. We are unable to locate the item you are referring to and so, we are unable to assist.
Intensive Care Society	Full		1.1	Unclear why guideline would not also apply to those dying after trauma provided timeframes allow guidance to be implemented, principles apply the same (eg location of death, persons present, symptom control etc all key)	Thank you for your comment. This text has been removed. We believe that many of our recommendations do apply to this group, given sufficient timeframes. Thank you for alerting us to this.

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Intensive Care Society	Full	General		In general terms a very good document which is primarily aimed at the non-specialist managing death in the community. As such many parts are of limited relevance within ICU, and there is limited or no guidance on management of ICU specific issues during the EOL (e.g airway management). This is wholly appropriate and we would expect to offer this guidance from within the FICM (GPICS etc). We would support the aims and the broad principles and conclusions of the document. There has clearly been an extremely detailed, methodical and robust appraisial of the evidence which in addition has been discussed and distilled	Thank you for your comment and for participating in the consultation process.
Intensive Care Society	Full		7.3	Much of the limited data on barriers to shared decision making comes from outside the UK. These barriers are likely to be specific to particular countries and their unique cultural, ethical and legal codes.	Thank you for your comment. The committee considered the evidence identified and commented on the applicability and quality. Evidence was also supplemented with the consensus opinion of the UK committee.
Intensive Care Society	Short		1.2.5	Assessment of capacity needs to occur prior to discussions over treatment course. Should in addition be recognized that capacity in such circumstances is likely to be context sensitive and partial	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this

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					area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Intensive Care Society	Short		1.3.3	named professional laudable aim, however not clear that resources are available to ensure this can happen in all settings	Thank you for your comment. Resourcing is beyond the scope of the guideline, however the Committee feels that 'named professional' offers multiprofessional teams more flexibility in achieving this ideal.
Intensive Care Society	Short		1.3.2	add capacity assessment	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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Intensive Care Society	Full		6.6	Whilst we appreciate outside the scope of the guideline it's perhaps a missed opportunity to not evaluate communications training as a worthwhile intervention.	NICE is currently developing guidance in palliative care service delivery and the issue of education and training may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Intensive Care Society	Full		8.6	There is a large amount of text summarizing discussions here. This would benefit from further editing to highlight salient points. Not clear that the intended audience will be able to read a document stretching to 250 pages	Thank you for your comment. This has been revised but we believe the level of detail is required to capture the Committee's discussions in this sensitive area. The structure of this discussion is in line with the NICE standard format.
Intensive Care Society	Full		8.6	Noted that ultimately expert opinion (in the form of the GDG) was influential "considered there were potential benefits not captured by the evidence". We consider this to be absolutely appropriate within this topic area, where evidence base is very weak, and likely to remain so. The guideline should explicitly recognize this (as it does) and by reflection support the application of such expert opinion within clinical practice (which it does via the recommendation of second and / or senior opinion).	Thank you for your comment

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Intensive Care Society	Full		9	No guidance is given on management of delirium and agitation on the basis that there is no evidence specifically within the palliative care population. There is however evidence from within ICU, a significant number of whom are also dying. We could provide expert opinion statements as used above. It seems odd to offer little or no guidance in contrast to the extensive discussion of expert opinion in other topic areas, for what is a difficult to treat and distressing problem for patients and families	Thank you for your comment. No evidence was identified from ICU settings for pharmacological management of delirium or agitation in the last days of life. We are unable to cite expert opinion statements in NICE guidance, where we have conducted specific evidence reviews and included published evidence.
Intensive Care Society	Short		1.5.16	Oxygen therapy is not indicated even in the known presence of hypoxia where it will not relieve symptoms, or may prolong the dying process. Instead appropriate management of dyspnea would be medication as outlined in 1.51.7. Perhaps reword to "consider oxygen therapy if likely to reduce symptoms rather than simply to reverse hypoxia".	Thank you for your comment. The evidence review was unable to show whether oxygen was beneficial or not for the management of breathlessness in the last few days of life, however the consensus of the Committee was that oxygen may be beneficial to people who are symptomatic with known or suspected hypoxia based on their clinical experience. The recommendation has been amended to state "Only offer oxygen therapy to people known or clinically suspected to have symptomatic hypoxaemia" and additional text has been added to the 'Linking evidence to recommendations' section of the full guideline.
Intensive Care Society	Short		Table 2 –	the IV doses of opiates stated are considerably less than those often required to palliate dyspnea and distress in patients with acute respiratory failure previously supported with invasive ventilation. Critically in such circumstances doses are titrated to	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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				effect by clinicians, and the guideline needs to explicitly support the principal that there are no "maximum doses" where opiates are being used in the knowledge of their "double effect". It is recognized that in such circumstances opiates may shorten life, although the evidence base suggests that they often do not.	implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Keith Young				I am the 'lay' or one of the 'patients and relatives' representatives on a number of FICM (as well as ICS) Committees. I have over the years had quite a lot of contact with and have worked with critically ill patients and their families / carers and this includes the relatives and carers of patients who have died. As an aside, this contact is continuing post my retirement with the local adult hospice movement. Care of the dying is, therefore, of some close interest to me. I found this document very interesting and clearly a lot of thought has gone into it - mostly building on the unfortunate experiences that arose following the controversy over the 'Liverpool Care Pathway'. My view is that most of the recommendations within the Guideline are essentially common sense and logical and should be applied without delay or difficulty. However, there will be issues over training of staff to reflect and respond appropriately with compassion and patience. There is also, in many settings be	Non-registered stakeholder. No response needed

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				issues around recognising appropriately that a patient is, in fact, dying. My main concern with the Guideline, however, is with communications or rather lack of them, with family members and carers. The Guideline is well populated with phrases such as 'advising the dying person and those important to them....' etc. I would, however, have liked to see a separate section within the 'Communications' section specifically upon dealing with family members including, of course, those close to the dying person who may technically not be members of the family. This section should, I would suggest, reflect upon issues such as managing expectations, what is achievable and what is not, how the patient is likely to appear, behave or respond as their end nears and next steps. These are issues that it may not be appropriate to discuss with the patient but will, nevertheless, be of very real interest to members of the family and will be of concern to them. I am sure that many would agree that, many patients and their families are very realistic about the likely outcome and that this may be terminal but I do feel that it needs to be recognised that these topics need to be explained sensitively and separately from the patient.In my experience, this is what is sometimes lacking and I feel that this Guideline would be stronger if the need to close communications with family members was	

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				expressly described.	
Leeds Teaching Hospitals	short	23	2	We feel that it will be difficult to assess patient rated quality of life when patients are in the last hours of life. Also it would be helpful to assess stress levels of family members, to see if the potential delays in getting the right medication by the best route in place for patients in response to a change in their condition. Having anticipatory medications available ensures that changes in symptoms are able to be responded to promptly to keep the patient as comfortable as possible. It should also be recorded about what impact not having the medications available has on the family members – will they have to go out and leave the patient on their own to get medications?	Thank you for your comment. The Committee appreciates that assessing patient rated quality of life may be difficult; however they feel that this outcome is important and want to strive for research in this area. The Committee note that whilst there is limited research for any aspect of end of life care it is possible and that any research proposal in this area should sensitively address the needs of both the dying person and those important to them. Other outcomes may well be useful for this research, however the Committee has prioritised those they consider the most important in this area.
Leeds Teaching Hospitals	Full	247	Table	Definition of end of life care is described as 'people in the terminal stage of an illness'. Most national definitions refer to to patients in the last year of life - there needs to be consistency throughout	Thank you for your comment. This has now been amended in line with definition used in 'One Chance to get it Right'.
Leeds Teaching Hospitals	Short	20	23	Is there evidence that inappropriate large doses of sedatives have compromised respiration and shortened lives?'	Thank you for your comment. We have edited this text.
Leeds Teaching Hospitals	short	4	25	Add into this section – and communicate this updated plan to the patients and those important to them	Thank you for your comment. After careful consideration the Committee felt that no change was required as other recommendations later in this

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					guideline address this (1.2.4).
Leeds Teaching Hospitals	short	6	7	Should place of care be included here and also if the patient has any fears or concerns?	Thank you for your comment. The Committee agrees that this is important, but would consider advance statements to include details related to the dying person's preferred location for palliative care. We have made amendments to a number of recommendations to clarify that the important information of relevance at this time includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare and added explanations of these in the glossary of the full guideline.
Leeds Teaching Hospitals	Full	Whole		Advance care planning is not 'advanced' - referred incorrectly throu ghout the whole document	Thank you for your comments. This has been amended throughout the guideline. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Leeds Teaching Hospitals	short	8	21	Should full mouthcare be included here? To ensure the whole mouth is kept moist.	Thank you for your comment. We have amended this recommendation to state: Offer frequent care of the mouth and lips to the dying person and ensure that their care plan includes the management of dry mouth if needed.
Leeds Teac	short	9	1	We feel patients should have their care plan reviewed daily – by a suitably trained professional – either Dr or nurse	Thank you for your comment. This recommendation is for any health professional providing care.

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hing Hospitals					
Leeds Teaching Hospitals	short	9	14	Should the possible burdens of hydration also be discussed	Thank you for your comment. We agree and feel this is covered by recommendations 2.4.8 and 2.4.9 on monitoring and when to reduce or stop clinically assisted hydration.
Leeds Teaching Hospitals	short	9	27	What are the distressing symptoms being referred to here?	Thank you for your comment. Further detail is provided in the 'Linking evidence to recommendations' in section 8.6. We believe these signs to include psychological distress.
Leeds Teaching Hospitals	short	9	7	Should the word 'withholding' be added to this sentence? Patients and their families may have concerned about the withholding of artificial hydration	Thank you for your comment. We have amended the recommendation to provide greater clarity. Further detail is provided in the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
Leeds Teaching Hospitals	Full	Whole		Advance care planning is not 'advanced' - referred incorrectly throu ghout the whole document	Thank you for your comment. This has been amended throughout the guideline.
Leeds Teaching Hospitals	Full	Whole		Throughout the document 'doses' need to clearly indicate whether these are starting doses or the range from minimum to maximum to avoid patients being initiated on very high doses.	Thank you for your comment. We have made a specific recommendation on starting at the lowest effective dose and titrating up - see recommendation 60.
Leeds Teaching Hospitals	Full	Whole		The document need to clearly indicate when intravenous and rectal routes should be used over the oral and subcutaneous routes - the routes generally used in palliative care. Whilst it is	Thank you for your comment. We agree that routes of administration are an important consideration and have made a recommendation on this (recommendation 57). We do not feel it appropriate

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				appreciated that this document is about ensuring individualised care for the dying patient, for newly qualified generalists with little experience with prescribing in the dying patient, having to choose from such a range of routes may be rather daunting and could potentially lead to suboptimal therapy or inappropriate prescribing.	to be prescriptive about a particular route as this should always be based on individual need.
Leeds Teaching Hospitals	short	10	19	There should be some reference in this section about what to do if the patient is unconscious and whether capacity assessments need to be undertaken	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Leeds Teaching Hospitals	short	11	10	We are concerned if medications are only prescribed orally, there may be a delay in administering medications if the patients condition deteriorates and they are unable to take oral medications	Thank you for your comment. This recommendation is aimed to highlight "the most effective route for administering medications", which may not be orally, but by other means such as IV or subcutaneously.
Leeds	short	12	13	There should be guidance here to remind people to	Thank you for your comment/ We are unable to

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Teaching Hospitals				convert existing analgesia (total dose required) to the sc route if patients are unable to take oral medications	provide that level of detail within the guideline.
Leeds Teaching Hospitals	short	13	17	Examples of non pharmacological methods would be helpful here	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Leeds Teaching Hospitals	short	13	25	This sentence sounds like it is referring to someone in the last weeks of life as opposed to the last days of life	Thank you for your comment. We do not agree. This is particularly relevant in the last days of life when medications may be being administered by a syringe pump.
Leeds Teaching Hospitals	short	14	25	Replace 'them' with those important to them	Thank you for your comment. After careful consideration, the Committee did not feel any amendment was necessary.
Leeds Teaching Hospitals	short	15	21	Add in here – stopping medications if 'they have been given regularly and'	Thank you for your comment. After careful consideration, the Committee decided no changes to the recommendation were required.
Leeds Teaching Hospitals	short	15	3	Examples of non pharmacological measures would be helpful here	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are

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					unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Leeds Teaching Hospitals	short	16	30	It would be helpful here if there was guidance about using prn medications initially in response to symptoms and then administering regularly if more than a certain amount of doses have been required within 24 hours – we suggest is more than 3 doses have been required to consider and 24hour continual sc infusion	Thank you for your comment. We agree. Please see recommendation 1.5.6
Leeds Teaching Hospitals	Short		Table 2	'if still breathless with opioid (despite dose increases and switching), consider adding benzodiazepine' - Benzodiazepines are generally considered for anxiety/panic associated with breathlessness and this needs to be stated. Additionally if BNZ are to be recommended then the sedative side effect needs to be discussed with the patient and those that are important to them. General practice is to avoid the sedating BNZs such as clonazepam and use midazolam instead.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospital	short	24	21	Documenting consent from others is rarely documented currently.	Thank you for your comment on the prescribing tables and the additional introductory text. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the

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s					last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	short	26	4	Palliative sedation – this should be defined?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	short	27	Table 1	Opioids: In leeds we recommend in our guidance 2 hourly prn with a maximum of 4 doses within 24 hours, prior to medical review. We are concerned that limiting to dose intervals of 2 – 4 hourly, patients may not have their changing symptoms managed promptly.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This

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					important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	short	27	Table 1	There is no guidance about maximum dose or maximum number of doses.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	short	27	Table 1	We do not recommend ranges for prescriptions.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds	short	27	Table	There is no mention of considering renal function	Thank you for your comment on the prescribing

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Teaching Hospitals			1	prior to prescribing opioids	tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	short	27	Table 1	There is no mention of dose considerations for frail elderly patients	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	short	27	Table 1	There is no guidance about how to convert to another route for opioids and prescribing another route pre-emptively to ensure prompt symptom management - generalists needs help and guidance about this	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	27	Table 1	We are concerned that there are too many drug choices for generalists to consider particularly for patients in the last few days or hours of life	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	27	Table 1	We are concerned that there is no recommendation about when to start an continual sub cutaneous infusion in opioid naïve patients - we advocate the use of prn medication and if 2 or more doses have been required to consider using a continuous subcutaneous infusion	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Leeds Teaching Hospitals	Short	27	Table 1	There is no guidance to help generalists decide what is the best analgesic to use - opioids and non opioids	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	27	Table 1	In our experience rectal medications are rarely indicated for dying patients - we are concerned that including them as a recommendation in this table will encourage generalists to start prescribing these drugs inappropriately	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospital	Short	27	Table 1	The starting dose for sc morphine is low for patients who have normal renal function and are no frail elderly patients	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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s					being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	27	Table 1	'consider increasing dose up to the maximum dose of the medication if the dying person is still in pain' - there needs to be clearer guidance about safe titration for the generalists	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	27	Table 1	Consideration needs to be taken into account of tablet burden in the last days of life and therefore starting new non opioids orally (paracetamol) might not be appropriate.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain

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					targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	28	Table 2	'consider increasing dose up to the maximum dose of the medication if the dying person is still breathless' - there needs to be clearer guidance about safe titration for the generalists	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	30	Table 3	There is no recommendation about the maximum number of prn doses to be given in 24 hours	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teachin	Short	30	Table 3	There is no reference to EMAs warning re domperidone and metoclopramide - why not include	Thank you for your comment on the prescribing tables. Because of the recognised importance of

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g Hospitals				domperidone orally.	supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	30	Table 3	Sub cut doses of levomepromazine are low and there is a typing error	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	30	Table 3	Dosing interval of 12 hourly is long - it would be better to recommend a maximum dose in 24 hours - there is not currently one stated	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently,

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					they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	30	Table 3	There are a lot of considerations for the generalists to consider and this may lead to confusion. Levomepromazine gives a good coverage for all causes of nausea and vomiting and if a maximum dose in 24 hours is recommended this should guard against over sedation.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	30	Table 3	It would be helpful to add into the boxed to consider adjuvants in bowel obstruction: Hyoscine butylbromide and octroetide	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Leeds Teaching Hospitals	Short	31	Table 4	Midazolam - it would be preferable to have a definite 2 hourly as opposed to 4 hours - 4 hours is a long time to wait if the patient is agitated and you would like to consider administering another dose. In leeds we say that the dose has not to be repeated within 30 minutes and prescribe a maximum dose in 24 hours prior to medical review, which enables staff to response to symptoms promptly and safely and seek advice if the maximum dose has been administered, highlighting the need to support	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	31	Table 4	Again it would be helpful to offer guidance for the generalists about starting with prn sc doses and when it would be indicated to start a continual infusion	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	31	Table 4	Clonazepam is more sedative than other options such as midazolam and not a drug routinely recommended at the end of life for that very reason. Not an appropriate option for generalist to have to consider.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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					implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	32	Table 5	As above it would be helpful to offer guidance for the generalists about starting with prn sc doses and when it would be indicated to start a continual infusion	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	32	Table 5	As above it would be helpful to have a maximum number of doses in 24 hours which enables staff to response to symptoms promptly and safely and seek advice if the maximum dose has been administered, highlighting the need to support	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be

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					made available on the NICE website.
Leeds Teaching Hospitals	Short	32	Table 5	Frequency of medications suggests TDS - we recommend a minimum of 1 hour between doses with a maximum number of doses in 24 hours	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	32	Table 5	The starting dose range for levomperomazine 12.5 mg to 50mg. We feel 50mg is a large starting dose.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching	Short	33	Table 6	Our local policy is to use Hyoscine Butylbromide first line as less sedating	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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Hospitals					symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Leeds Teaching Hospitals	Short	17	8	Undertaking research about anticipatory medications - not prescribing anticipatory medications for patients at home will have a big impact on practice and will be challenging to implement - there is a concern that if medications are not available for when symptoms change, this can cause undue distress to not only the patient but will also have implications for the family who may have to source the medications themselves - taking them away from the patients side	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Living Well Dying Well	Full	135		In the section 'Trade off between clinical benefits and harm' – ' the need for the dying person and those important to them to be provided with the information needed to make decisions regarding end of life matters' is crucial to improve the quality of care. We would like to see a clearer recommendation about the training required to conduct open conversation and to instil the awareness of true person-centred, whole person	Thank you for your comment. Service delivery, including staff training and mentoring support is outside the remit of this guideline. NICE is currently developing guidance on palliative care service delivery and this topic may be included in that guideline. More details can be found at the following link: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799

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				approach. In addition that staff support through mentoring and supervision be embedded to develop it. The NHS culture needs to change and that begins with individual change and personal development.	
Living Well Dying Well	Full	20	1-32	The Dying Person and their family and friends may not know what questions can be asked about prognosis. They are therefore reliant on the quality of the communication from the medical professional.	Thank you for your comment. The process of Shared Decision Making supports effective communication at end of life and the Committee have made a number of recommendations in this regard to enable the dying person and those important to them to engage in effective communication.
Living Well Dying Well	Full	23	37	We agree that a significant factor in downfall of the LCP was related to poor communication. We are happy to see concerns that impede communication have been highlighted in the Full report.	Thank you for your comment.
Living Well Dying Well	Full	24	21	It is good to read that that the focus will be extended beyond Cancer. End of Life Care appears to be comparatively under developed in other life limiting illnesses	Thank you for your comment. Further details can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Living Well Dying Well	Full	85	19- 20	We would like to further highlight the need for a coherent approach and openness in sharing information between everyone involved, the person who is dying, family, important others and across members of the multi-disciplinary team. Family and friends may have an entirely different view of the situation because professionals will only have short	Thank you for your comment. We have made a number of recommendations in this regard in chapter 6 on communication.

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				periods of contact over different periods of time and the 'snap shots' will differ. We also suggest there could be one responsible person to co-ordinate and liaise on the person's behalf.	
Living Well Dying Well	Full	9		The Guideline Development Group members who have direct patient contact mainly work within a hospital, hospice or an NHS framework. We are concerned there may be insufficient representation of persons working outside the NHS and/or within the home or community environment e.g. McMillan, Marie Cure, other significant organisations in the private or voluntary sector.	Thank you for your comment. The Committee have been recruited to represent the broadest range of care settings at end of life. This includes providing care at home and within hospices where NHS care is provided. The guideline is targeted at professionals providing care in NHS settings as is the remit of NICE guidance. We believe that our recommendations are also of direct relevance to professionals providing end of life care outside of NHS settings.
Living Well Dying Well	General	General		It is noted that the document concentrates mostly on institutional care and little reference is made for the provision of end of life care in the home or community environment. As demands on the NHS increase and statistics show the majority of people would prefer to die in their home, then attention should be given to how this can be facilitated.	Thank you for your comment. The Committee feels that all of its recommendations should be relevant to the care of people in the last days of life regardless of setting.
Living Well Dying Well	General	General		There is increasing concern by leading commentators in the field of death and dying, that it has become over medicalised and separated from society, communities, families. The focus of the recommendations is inward looking in this respect.	Thank you for your comment. The focus of this guideline has been to address the clinical care of the dying adult in the last days of life. We recognize that this is a very specific element of the dying process. It is not possible for this guideline to be able to

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					address all issues relevant to the care of the dying adult.
Living Well Dying Well	General	General		While we appreciate the work of the GDG is not to redefine the members of the multi-disciplinary team we would like to see reference to the role of end of life Doulas, as non-clinical supporters who are closely involved as facilitators of the wishes of the dying person.	Thank you for your comment. We are aware of the role of end of life Doulas. One of our Committee members is an end of life doula and has been very helpful in contributing the broad experience of this function to other members of the Committee. We do not feel it necessary to make specific comment to this role as we do not highlight and other roles by name. We would consider this role as part of the multiprofessional team alluded to in a number of our recommendations.
Living Well Dying Well	Short	22	9-11	As the trend is moving towards home death, we would like to see the system of anticipatory prescribing be streamlined and available to all. It is never acceptable for families to be left struggling to cope without adequate access medication. In this instance cost effectiveness should not be a consideration. However we would like the question of unused medication be considered a key factor in relation to cost effectiveness. In our experience there is an unacceptable level of waste of unused, in-date, unopened boxes of medication, following a death at home.	Thank you for your comment. We agree and have made recommendation around access to anticipatory prescribing and medications. In addition we have made a research recommendation in this area to explore further the clinical and cost effectiveness of anticipatory prescribing on symptom control.
Living	Short	5	13	We do not see adequate emphasis regarding to	Thank you for your comment. We agree and as a

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Well Dying Well			20-23	communications training of doctors, nurses, care staff and other professionals involved with families at the end of life, to address these concerns. We are worried that all the hard work of the GDG will be lost if this fundamental issues is not dealt with. We would like to urge within the report, a strong recommendation be made to address training in: 1 compassionate communication 2 courageous conversations 3 establishing trusting relationships 4 overcoming barriers to communication 5 acknowledging the whole person 6 recognising everyone involved is entering unknown territory and possibly the most profound experience of their lives **Training of this kind needs to be recognised to as fundamental to the success of the report so that the flaws in the practice of LCP are not repeated.** Any such training should be provided by people and organisations who have hands-on experience of working with death and dying.	guide the committee relied on guidance provided in the NICE guidance entitled, Patient Experience in the adult NHS services. A cross reference to this guideline has been included. More information on this guideline can be found at: https://www.nice.org.uk/guidance/cg138 Thank you for your comment. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Living Well Dying Well	Short	7	14-17	We would like to see reference made to the social/family network of the person being included as a support system, including the use of a coordinator/volunteer/doula/advocate/amicus mortis	Thank you for your comment. The Committee believes that 'those important to the dying person' includes the social/family network of the dying person. 'Volunteer support or assistance from an organisation' is mentioned in this recommendation.
Living	Gener	Gen		We are pleased to see such strong reference made	Thank you for your comment.

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Well Dying Well	al	eral		to shared decision-making throughout.	
Living Well Dying Well	Short	7	3	Suggest the word considered should be replaced by respected	Thank you for your comment we may consider but however, may not be able to respect all wishes of the dying person.
Living Well Dying Well	Short	9 10	15-29 1-13	We understand the scope of the report is to look at the last days and hours of life, and are therefore especially concerned at the emphasis on clinical hydration. It appears the GDG have over-considered this issue as a consequence of concerns with LCP, and lost sight of the fact that people who are dying need less intervention not more. The recommendations give the impression that clinical hydration is acceptable at this stage and that there may by benefits. We are not clear what benefits are likely. We would like to see more emphasis in **BRINGING COMFORT** at this stage and not medical intervention.	Thank you for your comment. The recommendation is intended to explore the risks and benefits of clinically assisted hydration as well as providing mouth care to ensure comfort and encouraging oral fluids as required. As you state the Committee did not want to provide unnecessary medical intervention if it is inappropriate. Further detail is provided in the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
London Borough of Redbridge, Adult	Short	General	General	The guidelines say it is for "healthcare professionals caring for people who are dying, in particular those working in primary care, care homes, hospices and hospitals". As large numbers of people die in social care settings such as residential/nursing homes, extra	Thank you for your comment. As the guideline's focus is on the clinical care of the dying person in the last days of life, addressing some recommendations to social care providers is considered to be inappropriate although we recognize that many of the guideline

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Social Services, Health and Wellbeing				care sheltered housing and their own homes; should this guidance specifically refer to its implementation in those settings and also acknowledge the role of social care professionals such as home managers during this stage. The recommendations need to more explicit about recognising the communication and other specific needs of people with learning disabilities. There is also the need to consider mental capacity to ensure appropriate support and advocacy can be sought if needed. Please refer to the information on the following website: http://www.pcpld.org/	recommendations such as those linked to recognizing dying, communication and shared decision making will be of key importance to this group of care providers. The full guideline makes comment where relevant to people with learning disabilities in the 'Linking evidence to recommendations' sections together with comments and discussions linked to mental capacity and advocacy. Further detail has been added to the guideline linked to issues about capacity. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
London Borough of Redbridge, Adult Social Services, Health and	Short	Sections 1.2 Communication and 1.3	Sections 1.2 Communication and 1.3 Shared	These are specific areas where a social care professional may be the person that is most appropriate to take the lead in those areas, depending on their relationship with the person and their family. There is no mention of social care professionals other than in the context of "multi-professional team". To overcome the fear and mistrust that happened with the LCP, the quality of staff training in all	Thank you for your committee. The committee acknowledge the importance of social care, and as you state, they are included within the multi-professional team. The 'Linking evidence to recommendations' section of the full guideline (6.6 and 7.6) state "health and care professionals". We agree that there should be a culture of openness at this difficult time for many.

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Wellbeing		Shared decision-making	decision-making	sectors will be vital. The examples of good practice and expertise within specialist palliative care and hospice settings could help achieve this by those staff reaching into other settings to train and promote champions in the use of the guidelines. There needs to be a culture of openness and transparency with the person and their family and the support that allied health professionals and social care can bring to this area should not be underestimated. The public perceptions around the LCP have been focused on its implementation by health staff. If other professionals are familiar with and understand the guidelines enough to talk to people and their families this should help to demystify and help allay fears.	Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Louise Boole University of Derby				I am not in a position to join one of the stakeholder groups but I just had a couple of comments to make on the guidelines for Care of the dying adult: 1. If working in the community setting (e.g. patients own homes, residential care homes) not all areas are now allowed to supply "oral hygiene sponges" due to choking issues. We have to get the family/carers to buy baby tooth brushes or anything similar. This is not new, it's been the case in our area for about 8 years.	Non-registered stakeholder. No response needed.

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				2. In the community setting a greater emphasis needs to be on the need for DNACPR to be in place and that out-of-hours medical providers receive a handover, so these deaths can be treated as an expected death, especially for verification purposes and removal of bodies to undertakers.	
Macmillan Cancer Support	short	general	general	The language of these guidelines does not reflect integration with social care staff.	Thank you for your comment. It is recognized that many of the guideline recommendations such as those linked to recognizing dying, communication and shared decision making will be of key importance to this group of care providers however, we do not always distinguish between health or social care providers as many of the recommendations are of relevance to both groups.
Macmillan Cancer Support	short	general	general	The language of these guidelines currently reflects a parental relationship with the patient – this needs to be changed to a partnership relationship.	Thank you for your comment. We disagree with your observation. The recommendations encourage health care professionals in all settings to communicate with the dying person to ensure that the individual's needs and assessed and considered in the last days of life. This is highlighted in the shared decision making section of the guideline.
Macmillan Cancer Support	short	general	general	The guideline does not cover "care after death" – this is a neglected area of care and inclusion will highlight its importance.	Thank you for your comment. This is beyond the remit and scope of the guideline. NICE is currently developing service delivery guidance on palliative

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					care that may address the issue you highlight. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Macmillan Cancer Support	short	general	general	It is unclear whether these guidelines are consistent with the Ambitions for Palliative and End of Life Care – it is important to ensure they have this consistency.	Thank you for your comment. We believe we've made a start toward fulfilling these ambitions. The forthcoming NICE guidance on Service Delivery in Palliative care may provide further context linked to the document you refer to. http://www.ncpc.org.uk/sites/default/files/End%20of%20Life%20Care%20Strategy%20New%20Ambitions%20Report_WEB.pdf.
Macmillan Cancer Support	short	general	general	Overall, the guidance is generally well structured bringing out recurrent themes of clear communication, shared decision making, involvement of those significant to the patient and the need for senior clinician involvement. It is a useful framework for care particularly for generalists. When reading the short guidance some things are unclear but once you go into the full text they become clear. As many generalists will only read the short guidance it is important that it is clear and succinct.	Thank you for your comment. The full guideline is intended to provide details of the evidence and the Committee's thinking in the development of the recommendations in the shorter NICE guideline.
Macmillan Cancer Support	full	general		Some recommendations where there are lists seem to be in alphabetical order - this brings an odd emphasis to the reading.	Thank you for your comment. We have chosen to apply an alphabetical ordering to minimise the risk of prioritizing one issue over any other in the absence

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					of evidence. Further detail can be found in section 4.4.
Macmillan Cancer Support	full	general		Many of the recommendations seem more relevant to the last few weeks of life rather than the last days of life. Would it help to divide up the recommendations into categories ie death in the next few weeks and death in the last few days of life?	Thank you for your comment. Our recommendations are targeted at clinical care in the last 2-3 days of life. We recognize that some may also be applicable in a broader time frame, especially those related to communication and shared decision-making. We think it would be ultimately unhelpful to make the distinction you suggest. We would wish to avoid the chance that people would think it optional not to implement the recommendations in either one or other time frame.
Macmillan Cancer Support	short	1	5	Is there a need to be more specific about who the guideline is for? – on page 18 line 13/14 it says it is for non- specialists. However there is no mention of this on page 1 line 5. There is also no mention of social care professionals or volunteers – might it also be appropriate for these groups too?	Thank you for your comment. The guideline is for all health and social care providers caring for people at the end of life as outlined on page 1 but we do believe it may be of particular relevance to non-specialists hence the additional reference on page 18.
Macmillan Cancer Support	short	4	26, 27,28	Although this paragraph is clear in the short guidance in the full guidance it is followed by a list on page 82 that does not seem helpful.	Thank you for your comment. We assume that the list of items you refer to on page 82 are the outcomes considered important by the Committee when looking for evidence on symptoms. This guided the literature search for this question. The evidence retrieved informed all the recommendations in this section not just the recommendation you allude to in the NICE

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					guideline(1.1.5 in the consultation VERSION)
Macmillan Cancer Support		11	19,20	Point 2 – could be read as suggesting bloods or x-rays are needed to fully assess that the person is entering their last days of life. This would result in investigations at a time when clinicians would normally avoid unnecessary interventions.	Thank you for your comment. The Committee agree that unnecessary investigations should be avoided, but that, if available, they may provide useful information. Available investigation results have been moved to the stem of the recommendation to avoid confusion with other signs or symptoms of recognising dying.
Macmillan Cancer Support	18. full	19		20. Points 1, 2, 3 are about assessing deterioration but they do not mention looking for reversible causes of deterioration – could this be added.	Thank you for your comment. Reversible causes are detailed in the full guideline's 'Linking evidence to recommendations' section and the Committee also feel this is captured under the introduction statement: "The recommendations supplement the individual clinical judgement that is required when making decisions about the certainty of prognosis and how to manage any uncertainty."
Macmillan Cancer Support	short	4	11	Under signs and symptoms that a person is entering their last days of life there is no mention of decreased food and fluid intake – just loss of appetite. Could this be added together with becoming increasingly bed bound.	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Some examples based on the evidence review are included here, but we acknowledge that these are examples only and clinical judgement should be used. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (Please see section 5.8). We are unable to further

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					comment on nutrition as it is outside the scope of this guideline.
Macmillan Cancer Support	short	4	2	Investigations should only be carried out ***if appropriate***. The way this is currently written might lead to staff having multiple attempts at venepuncture in a dying person	Thank you for your comment. The Committee agree that unnecessary investigations should be avoided, but that, if available, they may provide useful information. Available investigation results have been moved to the stem of the recommendation to avoid confusion with other signs or symptoms of recognising dying.
Macmillan Cancer Support	short	4	21	The term recovering is a stark statement – suggest changing to "has a potentially reversible condition with the possibility of recovering".	Thank you for your comment. The Committee discussed the bullet points in the recommendation and decided to amend these to state: nearing death, deteriorating, stable or improving.
Macmillan Cancer Support	short	4	22-25	Section 1.1.4 We need to stress here that regular review of the patient by a Healthcare Professionals is needed at the end of life as symptoms can change quickly.	Thank you for your comment. We agree and feel the recommendation covers this. More detail is also found in the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8).
Macmillan Cancer Support	short	4	4	The example under changes in communication is the patient talking about nearness to death - however there are many other changes that occur in the amount of communication that may be recognised first. Patients do talk about dying or being near death but this can also occur with reversible causes as patients feel so ill! It may be helpful if another example could be used here.	Thank you for your comment. This is an example and the introduction text states that these recommendations supplement the individual clinical judgement that is required when making decisions about the certainty of prognosis and how to manage any uncertainty. Thank you for your comment. Reversible causes are discussed in the 'Linking evidence to recommendations' section of the full

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					guideline (please see section 5.8).
Macmillan Cancer Support		5	22 to line 2 on page 6	Section 1.2.4 Suggest adding in about "discussing sensitively the dying patient's potential modes of death with the patient and there family and carers". Reason is that some patients may have an unpleasant end (eg catastrophic haemorrhage or severe vomiting (bowel obstruction" and we need to pre-warn the relatives and carers about this, to try and minimise the sudden distress (which relatives have to live with for the rest of their life). It may also help prevent any panic calls to Paramedics at the time of death.	Thank you for your comment. We agree and have added further detail on this into the 'Linking evidence to recommendations' section of the full guideline (please see section 6.6).
Macmillan Cancer Support	short	3	1	"People have the right to be involved in discussions and make informed decisions about their care". This is very tokenistic language. Consider changing to "People have the right to be treated as equal partners in discussions and be supported to make informed decisions about their care".	Thank you for your comment. This is standard NICE text and as such we do not have the ability to amend along the lines you suggest.
Macmillan Cancer Support	short	6	26	Add in checking whether the person has a nominated LPA for health and welfare.	Thank you for your comment. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare Further discussion on the Mental Capacity Act is already provided in the 'Linking evidence to

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					recommendations' section of the relevant chapters in the full guideline on these issues. We have also made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area and this includes reference to Lasting Powers of Attorney. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Macmillan Cancer Support	short	6	3-9	Section 1.2.5 Suggest adding that we should establish if the patient has a Lasting Power of Attorney in place, and also to identify and clarify who the attorney(s) is/are.	Thank you for your comment. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare. Further discussion on the Mental Capacity Act is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues. We have also made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area and this includes reference to Lasting Powers of Attorney.

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					Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Macmillan Cancer Support	short	6	4	Even if a person has already developed an ACP, it will need reviewing with the person to ensure that their wishes and preferences have not changed and it is still fit for purpose. This needs to be mentioned in the text.	Thank you for your comment. The recommendations encourage healthcare professionals to explore the person's care needs as early as possible in the delivery of end of life care and advises that the team 'continue to explore the understanding and wishes of the dying person and those important to them, and update the care plan as required.' We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare and that these are reviewed in light of the dying person's current preferences
Macmillan Cancer Support	short	5	13	Section 1.2.2 Add "sensitively" after "discuss the dying person's prognosis with them…"	Thank you for your comment. The Committee believes the recommendation, as edited, is clear and does not require further amendment.
Macmillan Cancer Support	short	general	general	This guidance is supposed to relate to people in the last few days of life. However, at times there appears to be confusion about what timescale the guidance is referring to. For example, some of the	1.3.5 and 1.3.6 refer to individualised plans of care not Advance Care Planning. Individualised plans of care will no doubt be developed prior to last days of life, but the Committee considered them very

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				guidance is far more pertinent to care f the dying eg around Advance Care Planning ie 1.3.5 and 1.3.6.	relevant to this guideline as circumstance and needs change.
Macmillan Cancer Support	short	5	4 & 5	Section 1.2.1 Rather than "Establish the communication needs and expectations…." It should add in that we need to EXPLORE the patient's communication needs and expectations in a SENSITIVE manner, as we know that some conversations can be difficult, especially when there may be conflict or collusion from family members.	Thank you for your comment. The Committee agrees that communication during end of life care is a sensitive matter. However, they believe that this recommendation is clear as currently edited.
Macmillan Cancer Support	short	5	Communication	The section on communication does not cover guidance on how to manage opposing views between the patient and the family (or others important to the patient). It is also not included on the Theme map on page 91 of the full guidance.	Thank you for your comment. The recommendations encourage health care professionals to prioritise the needs, goals and wishes of the dying person. How much those important to the dying person are included in communication and shared decision making related to end of life care is led by the dying person. In the event of the difficult circumstances raised in your comment, it has been recommended that the multiprofessional team has access to experienced staff at all times and are also encouraged to seek the support of specialist staff where required. The thematic review represents the evidence identified and as such this issue did not appear in the evidence although the committee recognize the situation describe and have drafted recommendation 2.2.7.
Macmillan Cancer Support	short	6	10 11 12	Although guidance is given in 1.2.6 to share information regarding prognosis with the MDT and document this in the care plan greater emphasis	Thank you for your comment. In addition to the recommendations on discussing and documenting discussions on the dying person's prognosis among

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				could be placed on this. It is crucial to good care at the end of life particularly with changes in care setting or service providers eg transfer from in hours care of GPs to Out of Hours Care. Suggest adding in that Out of Hours Providers should also be informed of the patient's poor prognosis.	members of the multiprofessional care team, the Committee has also recommended that the dying person's individualised care plan also be shared with all members of the multiprofessional team (see recommendation 2.3.6). However, service delivery, including out of office hours implementation matters, are outside the remit of the guideline. NICE is currently developing guidance on palliative care service delivery and this topic may be included in that guidance. More details can be found at the following link: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Macmillan Cancer Support	short	6	23 to line 3 page 7	Section 1.3.2 Suggest adding in that shared decision making should also include discussions about DNACPR, and also if the dying person lacks capacity and they have an LPA in place, that that Attorney(s) should be involved in the shared decision making.	Thank you for your comment. We recognise that CPR and DNAR decisions are an important area in care of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas are more likely to have a wider impact on clinical practice.
Macmillan Cancer Support	short	7	14-17	Section 1.3.4 In addition to "establishing as early as possible the resources…." Suggest adding that those resources need tobe accessed and implemented promptly and timely. Worst thing is to have a hospital bed./equipment delivered just as the patient dies!	Thank you for your comment. Further detail has been added to the 'Linking evidence to recommendations' section for this chapter in this regard (see section 7.6).
Macmilla	short	7	27-29	Section 1.3.6: In addition to "sharing the care plan	Thank you for your comment. We have amended

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n Cancer Support				with all members of the multiprofessional team", suggest adding that this should also be shared with the dying patient and their family & carers.	the recommendation to encourage people providing end of life care to share the care plan with the dying person, those important to them and all members of the multiprofessional team.
Macmillan Cancer Support	Full	12		If points 6, 7 and 10 are left to the **last few days of life** there will be a lot of unnecessary and difficult communications with patients which could lead to complaints that doctors and nurses are uncaring.	Thank you for your comment. Although the remit of the guideline is last days of life, the Committee do consider these recommendations valid prior to this time point and would hope they are implemented as early as possible, as discussed in the full version 'Linking evidence to recommendations' section.
Macmillan Cancer Support	Full	12		Point 8 could lead to everyone passing on responsibility to each other? All professionals should be able to manage communication at the end of life.	Thank you for your comment. We agree that all healthcare professionals should be able to manage communication at the end of life, but this recommendation is intended to identify one person to avoid any confusion in messages from multiple individuals and also identify the most appropriate person.
Macmillan Cancer Support	short	8	3	Section 1.3.7 Suggest adding after "recognise that the dying person's ….their care may change as their condition deteriorates" that we should also take into account the family and carers' physical and psychological ability to manage looking after the dying patient as their condition changes. This can have an impact on where the patient dies, and if we support the family and carers we can prevent an unnecessary admission for a hospital death.	Thank you for your comment. Additional text has been added to the full version of the guideline to capture this.
Macmilla	Full	14		Point 26-30 there are so many recommendations on	This is a complex area and we feel this level of detail

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n Cancer Support				hydration they may not all be read and followed.	is needed. Some of wording has been edited for clarity and headings inserted to guide the reader.
Macmillan Cancer Support	short	8	26	The guideline mentions oral hygiene sponges – are these available everywhere?- please check as some areas seem to have problems accessing them. At least two of our GP's have mentioned they cannot be obtained in Primary care!	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.
Macmillan Cancer Support	short	9	10-14	Need to stress the importance of the pooling effects of clinically assisted hydration in the community (fluid pooling under the skin) as hydration will most likely be given subcutaneously.	Thank you for your comment. We agree that both the harms and benefits of clinically assisted hydration should be discussed with the dying person and those important to them, as stated in recommendation 2.4.5. Also, recommendation 2.4.9 advises clinicians to reduce or to stop in the event of harm. Further detail has been added to the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
Macmillan Cancer Support	short	9	15-25	Section 1.4.7 Perhaps add in here that patients at the end of life are not usually thirsty even though they have a poor fluid intake, and often relatives worry that they will be.	Thank you for your comment. We agree that this detail is important and have captured it within the full version, 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
Macmillan Cancer Support	full	general		There are a significant number of recommendations which seem repetitive for example pages 16 and 17 – the topic noisy respiratory secretions is covered in 5 points (points 49-53) but it would be helpful if some of these could be combined.	–Thank you for your comment. We have carefully reviewed all our recommendations in light of stakeholder comments and made amendments where necessary.
Macmillan Cancer Support	full	general		It is unclear why some of the symptoms that are mentioned in the guidelines include specific medication recommendations and others do not. For	Thank you for your comment. This reflects the limited evidence identified in the last days of life. The Committee were unable to be more specific as

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				example, noisy respiratory secretions, includes 4 recommended drugs but pain and vomiting (except bowel obstruction) have none.	evidence was not found to warrant any further detail other than drug class for management of pain. The Committee have made general recommendations on nausea and vomiting, but do not recommend specific drugs as there was no evidence to recommend one anti-emetic over another.
Macmillan Cancer Support	short	10	19-23	Section 1.5.1: Suggest adding in that we should consider Anticipatory Prescribing and ensure the correct 4 core drugs (and safe quantity (then refer to Section 1.6) are in the dying patient's place of care - this is to minimise any difficulties in accessing medication in the put of Hours Period, which can be very distressing for both the patient and the carers and family.	Thank you for your comment. The Committee have recommended an individualised approach to anticipatory prescribing and feel no change is required.
Macmillan Cancer Support	short	11	19	Include that it is important to ensure anticipatory medicines are prescribed and in place in a timely fashion and that they are prescribed on the treatment sheets ready for any professional to administer.	Thank you for your comment. We agree and have detailed in the anticipatory prescribing section that they should be prescribed "as early as possible" (please see recommendation 1.6.3)
Macmillan Cancer Support	short	14	3-6	The guidance to use hyoscine butylbromide in bowel obstruction without the use of any other anti-emetic is surprising. The recommendation to use octreotide after 24 hours is also surprising. It would be very unusual to use octreotide in the community setting after such a short period of time – this could generate a lot of anxiety, cost and possible admissions to hospital to give a drug that many GPs will not be familiar with. This recommendation seems to stem from the 3	Thank you for your comment. This recommendation is for people with obstructive bowel disorders who have nausea and vomiting. As stated in the full guideline: As there was no clear evidence that octreotide was the more clinically effective option, yet it was considerably more expensive, the Committee decided to recommend its use only for when hyoscine butylbromide produced ineffective results. We do not feel it necessary to make recommendation about the use of Stents in the

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				RCT's used to supply the evidence for this guidance. These studies excluded patients suitable for a stent so the first statement should say that this guidance assumes the patient is not suitable for a stent. The trials also did not seem to use any other anti-emetic. Is this a case of the evidence not being available for other regimes rather than this being the best regime in clinical experience?	context of this guideline which covers the last 2 -3 days of life,
Macmillan Cancer Support	short	15	13	Scopoderm patches should be avoided in those patients with a history of Parkinson's as this can cause agitation and distress	Thank you for your comment the content of which is noted. Please see the footnote that accompanies this recommendation for guidance for prescribers when using these medications
Macmillan Cancer Support	short	16	2	The introduction of anticipatory prescribing should be advocated before the last days of life. Use of proactive prescribing may skew the value of the research question in the full guideline page 156 point 9.1	Thank you for your comment. The Committee agree that anticipatory prescribing should be done as early as possible, however the remit of this guideline is last days of life and we are unable to comment outside of this timeframe. We see anticipatory prescribing to be one arm of the proposed research
Macmillan Cancer Support		27-29	General comment on tables	The detail in these tables is confusing and in some cases unusual for primary care. The suggestion is that these should be re-written OR the tables could be omitted altogether and the GP referred to locally approved guidelines– • For example it is unheard of for GPs to initiate IV Paracetamol!! • Also with regards to "Switching Opioids" it seems to imply that this is easily done – in practice it is NOT, and we advise our GPs (under the recommendation of our Specialist	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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				Palliative Care Colleagues locally) to consult Specialist Palliative Care before undertaking any switch – unless of course that GP is specialised in Palliative care, but most are not.	
Macmillan Cancer Support	short	24	10,11, 12	Suggest the text includes recommendations for reduced opiate use for those with known renal impairment and that generalists look out for and know the signs of opiate toxicity such as myoclonus, hallucinations etc and seek help accordingly.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Macmillan Cancer Support	short	17	10 - 11	Question 2. How to help users overcome challenges Nationally there should be money freed up for each CCG or locality within that CCG to have a bespoke EOL service. Care could then be truly integrated with all those involved in the care from having the patients on an EPaCCS system that talks to other systems (with the patients permission) to a one telephone number support network that all can dial in to. For instance, a	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.

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				local hospice could take the lead by having a dedicated telephone number for all health care professionals to call in addition to ensuring all dying patients are put on the EPaCCS system. This would safeguard the patient, ensuring all medications are rationalized and care plans are in place for OOH and ambulance services. Empowering more senior community nurses to prescribe for dying patients. Appropriate funding of EoLC to provide effective services – such as DN cover, resourcing drugs access and Communications such as EPaCCS. Adequate Healthcare resource : including manpower, equipment access, including syringe driver provision.	

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				Development of Community Specialist Palliative Care – including Hospice at Home and models along the lines of the Macmillan Midhurst Project.	
Macmillan Cancer Support	short	17	8-9	Question 1. The areas that will have the biggest impact on practice and be challenging to implement Seeing dying patients daily – need to nominate a second healthcare professional to share this task as dr's time is increasingly being taken up by extra busy surgeries (high expectations of patients to be seen when they wish to be seen), increasing home visits – especially in more rural areas and with older populations. Access to opiate medication OOH Pharmacies having the anticipatory medicines in stock rather than taking a day or so to order them. Actually ensuring that those other health care professionals visiting the patient actively read	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.

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				the care plan – such as adult social care staff who may just call 999 or the 999 staff who are called due to difficult noisy breathing and then transfer the patient to hospital which may be inappropriate. Effective cross sector communication systems – EPaCCS - Havng a better system for OOH rather than 111's adastra system that cannot read any other system records. How can an effective EPaCCS system be run when the systems don't talk to each other? Provision of 24/7 District Nursing care	
Marie Curie	Full	25	34-38	To clarify the comment above: Marie Curie realise that training, workforce planning and service delivery fall outside the scope of this guideline; however, we would like to emphasise that high quality care for all cannot become a reality without them. We look forward to working with NICE and sharing our experiences of best practice in the future to make sure the second guideline on improving supportive	Thank you for your comment. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799

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				and palliative care, including service delivery, is as robust as possible and has wider applicability to the needs of people living with terminal conditions other than cancer.	
Marie Curie	Full	General	General	Marie Curie is the UK's leading provider of care and support for people affected by terminal illness. We welcome the publication of the draft guidelines on the care of the dying adult as a resource to help healthcare professionals identify when someone is dying and improve care in the final days and hours of life. Research has shown that 110,000 people across the UK miss out on the palliative care they need [Dixon J et al. (2015) Equity in the Provision of Palliative Care in the UK]. Failing to identify that a person is approaching the end of their life and ineffective communication between healthcare professionals and dying people and their families at this time are clear barriers to appropriate care and support. The draft guidelines provide a good baseline for the skills that all healthcare professionals involved in the care of dying people should have. We welcome that the guidelines are aimed at healthcare professionals in primary care and care homes. This reflects the importance of strengthening care in the community to meet people's wishes to be cared for in their usual place of residence at the end of life and support the	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799

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				transfer of care out of hospitals where appropriate. However, guidelines will achieve little without sufficient community resources and effective implementation through training and embedding in continuing professional development. Results from an RCN (2014) survey of over 7,700 nurses found that almost half said they do not always have a chance to discuss with patients how they would like to be cared for in their final days, with problems with resources, time or training cited as the main reasons for this failure. We believe that investment in resources and effective workforce training across all relevant settings so professionals are empowered to deliver care in accordance with the guideline will significantly impact on practice. Not addressing these issues poses major challenges to implementation. This point is clearly made in the Leadership Alliance for the Care of Dying People's Five Priorities for Care (2014), which states, "Health and care staff will need the appropriate education and training to enable them to recognise and deliver these responsibilities in practice. Their employers and the system in which such staff work must support them in doing this."	
Marie	Short	18	8 …	Research into palliative and end of life care has	Thank you for your comment. The Committee

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Curie				historically been under-funded and there is a need for greater attention in this area. Marie Curie therefore welcomes the inclusion of recommendations for research in the guideline, which draws attention to important questions which require further research to answer. We would however like to draw attention to the work of Marie Curie and the James Lind Alliance on the Palliative and end of life care Priority Setting Partnership, which collated responses from people in the last year of life, their families and carers, and health and social care professionals regarding their priorities for end of life care research to find the top ten unanswered questions. Topics which are particularly relevant to the scope of this guideline and may warrant consideration or mention in this section of the guideline include: assessing and treating pain and discomfort for people with cognitive impairment or communication difficulties at the end of life; ensuring continuity for patients at the end of life, and how best to listen to and incorporate patient preferences in care planning.	discussed their priorities for research and made their decision based on the gaps in the evidence as identified from the systematic reviews conducted within the scope of the guideline.
Marie Curie	Short	18-19	20…-2	The guideline rightly recognises that 'the process and timescale for dying varies widely'. It goes on to state those with progressive neurological disorders may spend weeks or month in general decline, such that 'many of the principles of communication,	Thank you for your comment. We agree that it will be important where people have a terminal illness to ensure that the principles of effective communications and shared decision making are commenced much earlier than the last days of life

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				shared decision-making and pharmacological care can be initiated long before that time.' Although we recognise that the scope of this guideline is the last few days of a person's life, we believe this statement is misleading. For many people with a terminal illness, not just those with neurological conditions, good end of life care starts much earlier than the final few days. The principles outlined above, and in particular those relating to shared decision-making, good communication and early care planning (with the recognition that plans are likely to change as a person's condition changes) should ideally be adhered to from the point of someone's diagnosis or as soon as is acceptable to the patient and their family.	However, we have developed our recommendations given our remit to focus on the clinical care in the last days of life.
Marie Curie	Short	4/12	26/1	The guideline encourages healthcare professionals to seek advice from those more experienced in providing end of life care. Clinical and practical experience is an important resource for spreading best practice and we are happy to see that a more collaborative approach is being encouraged. In relation to care homes, the Marie Curie care home support service in Hywel Dda Health Board in Wales is a good example of where adopting a collaborative, advisory model before a crisis occurs supports care home staff to deliver end of life care in a person's familiar surrounding (please see here for more	Thank you for your comment. NICE is currently developing guidance in palliative care service delivery. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799

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				details of the service). Although perhaps beyond the scope of this consultation, we think it important to flag up that this collaborative approach to learning, development and caring for those who support people at the end of life is effective. Opportunities to pursue these types of services should be encouraged more generally, not just in the final days, for high quality care to become the norm. However, we are concerned that a barrier to implementation here will be the availability of experienced professionals or specialist palliative care professionals to provide advice, particularly at weekends and out of hours. Only 7% of England's Trusts that responded to recent FOI requests had 24/7 face-to-face access with a palliative care specialist. In the absence of specialist support, people being cared for in the community may face inappropriate emergency admissions to hospital towards the end of their life because the emergency services are the only available support. A recent report by Marie Curie, Triggers for Palliative Care, also found that hospitals services were often not aware of how to involve their specialist palliative care team in the care of their patients. Although addressing these issues is beyond the scope of this	

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				consultation, we believe they should be raised as they will impact on implementation.	
Marie Curie	Short	5	29	It may be worth including, 'including supportive members such as a chaplain or social worker'.	Thank you for your comment. The Committee agrees. Further detail has been added to the 'Linking evidence to recommendations' section of Chapter 6 (section 6.6)but feel that the
Marie Curie	Short	7	4	Marie Curie welcomes the inclusion of a named lead healthcare professional. We know that a lack of information, consistency, coordination of services and help to navigate the complex health system is a considerable problem and cause of stress for people who have a terminal illness and their carers and family [see Marie Curie (2014) Difficult Conversations, for more information]. Ensuring that people have the contact details of a relevant and appropriate out of hours service could help to reduce unnecessary and undesirable hospital admissions at the end of life. The Marie Curie Rapid Response service, which operates in various localities, is one example of a relevant service which the named professional should be aware of to help people being cared for in the community stay at home or in their care home throughout a crisis (for an example of how the service operates in Northern Ireland, please see here).	Thank you for your comment.
Marie Curie	Short	7	37-39	Marie Curie welcomes the guidance on producing individual care plans. We believe that further	Thank you for your comment. We are unable to provide additional detail on the content of care plans

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				information could be included on the form this should take to encourage best practice in documenting people's wishes and facilitating ease of accessibility and use across different settings, e.g. when transitioning from community to hospital care or for providers of out of hours care. Encouraging the use of best practice would be helpful; for example, Electronic Palliative Care Coordination Systems (EPaCCS) is one method which is gaining traction in England. Universal coverage of EPaCCS was a key recommendation of the Choice in End of Life Care Programme Board's 2015 Review of Choice in End of Life Care.	without specifically reviewing the evidence. The Committee consider that local policy or decision making may inform content of care plans.
Marie Curie	Short	General	General	We welcome the person-centred approach taken in this guideline. The focus on shared decision-making and establishing the goals and wishes of both the dying person and those important to them is rightly placed at the core of developing an appropriate care plan for each individual. This is in line with the Leadership Alliance's five Priorities for Care. When done correctly, it can significantly improve the dying experience of both the dying person and their family.	Thank you for your comment.
Marie Curie	Short	8	19	It may be worth suggesting the possibility of referring to any local guidelines on mouthcare.	Thank you for your comment. These guidelines may inform an existing local policy but do not feel it necessary to add this level of detail into a recommendation further discussion is provided in section 86 of the full guideline.

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Martletts Hospice	FULL	81	Table 5.8 (point 2)	Signs & symptoms, and any changes that may suggest that a person is entering the last days of life seems to have listed alphabetically rather than relevant & progressive changes – eg fatigue, loss of appetite, progressive weight loss, social withdrawal whereas mottled skin, cheyne-stoke breathing suggest that death is more imminent (hrs rather than days).	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8).
Martletts Hospice	FULL	83	general	The GDG stresses the need for improved communication between healthcare professionals & that a specialist should be consulted when there is great uncertainty. However they suggest ' a slight increase in clinician time, there are negligible upfront costs incurred for recognising dying. Diagnosing dying requires a good thorough assessment + discussion with those involved in the person's care which, in my experience takes a 'not' a slight increase in clinician's time especially if the patient is based in the community.	Thank you for your comment. This statement was meant to reflect that the recommendations relative to current practice would not drastically increase costs. Although it can often take some time to fully assess and ascertain whether someone can be recognized as dying it was felt that the recommendations outlined in this guideline would not add significant associated costs. Patients in hospital should be assessed daily anyway and this would represent only a more focused assessment. However we do recognise there could be an increase in the clinician's time if the patient is based in the community. We have edited the economic considerations in the 'Linking evidence to recommendations' section (5.8) to reflect this, which now reads: "However, in most cases, this assessment should be completed by clinicians, therefore it is unlikely there are increased upfront costs incurred for recognising

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					dying, apart from within community settings where there could be some additional costs if the clinician has to be called to do the assessment."
Martletts Hospice	FULL	134	Table 7.6 (point 15)	Named lead heath professional – point of contact rather than individual – to ensure seamless service when individuals are absent and also ensure rapid response to needs – TC especially OOH services	Thank you for your comment. The Committee agrees and feels that this recommendation supports this ideal. The recommendation encourages those delivering end of life care to identify a named lead healthcare professional, who is responsible for encouraging shared decision-making in the person's last days of life and that this identified individual should give information about how they can be contacted in addition to the contact details for relevant out-of-hours services. The communications recommendations also reinforce this by encouraging the provision of information about how to contact members of the wider team involved in the care of the dying person.
Martletts Hospice	FULL	155	39	We are seeing increasing numbers of patients dying in intestinal obstruction where the effectiveness of any antiemetic medication will be limited due to the mechanical nature of the vomiting and the risk of unwanted sedation is high if the drugs ' are increased to maximal doses '. In this situation the importance of managing the patient and families expectations around complete symptom control is essential especially when they are hoping to keep the person in their own home.	Thank you for your comment. We have amended the 'Linking evidence to recommendations' section of the guideline (9.13) to reflect the Committee's awareness of and discussion on this issue. Our recommendations also encourage HCP to discuss expectations with the patient and those important to them.
Martletts	FULL	176	24	Given comment above do not agree that vomiting	Thank you for your comment. Intestinal obstruction

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Hospice				from intestinal obstruction should have been ' beyond the scope of the guidance'. Intestinal obstruction is a common end picture for common heavily treated tumours eg. GI cancer and gynae cancers.	was not prioritised as part of the scope. .
Martletts Hospice	FULL	237	22	Cannot believe that the average length of time required by a GP: to diagnose dying, communicate this to patient and families, prescribe medications with explanation about the rationale for each, write authorisation chart for medications to be administered parentally by community nurses, contact other involved practitioners – 11 minutes???? Presume ' 'average patients' are not 'average dying patients'.	Thank you for your comment. The cost of an average GP visit was presented to the GDG as a reference point given we had no data on how long this GP visit would last in the context of the question. The GDG recognised that the length of this visit may be more. This has now been made clearer in the full guideline. It was however assumed at this point that the patient was already known to be in the dying phase and therefore the role of this GP visit would be to relieve symptoms as opposed to diagnose and communicate dying to the family.
Martletts Hospice	FULL	242		In Brighton and Hove we have special health services for a large homeless population and specialist community PC services have been involved in several cases where EoLC has been planned, anticipated and provided in shelters and hostels – the nominated PPC/D.	Thank you for your comment. You may wish to share your example of practice with the NICE team. (Please see the NICE website for further information on sharing good practice)
Martletts Hospice	FULL	217	table	Generally difficult to navigate – might be helped by different coloured / shaded cells to differentiate between treatment naïve patients and treatment constant patients.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently,

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					they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Martletts Hospice	FULL	217	table	If increasing to ' maximum doses' of opioid is described there is a danger that people will believe this is a numerical dose rather than a threshold identified in individual patients as they develop features of 'opioid toxicity'	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Martletts Hospice	FULL	217	table	Concern about introducing diclofenac into a regime in a patient who is dying – high risk of GI bleeding, nephrotoxicity And other side effects. Potential for GPs and those less confident on opioid prescribing to use diclofenac suppositories in place of the more appropriate opioids	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Martletts Hospice	FULL	218	table	Diazepam has a long half life and tds dosing seems illogical – especially if carer needs to come into the home to administer regular medications.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Martletts Hospice	FULL	219	Notes on table	Additional caution advised re hypotensive effects of levomepromazine – particularly if given iv. Increases risk of falls in agitated patients	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Medical; Ethics Alliance	Full	General		Intro; The Medical Ethics Alliance (M E A) is a coalition of six faith and non faith based medical and nursing bodies. Our objective is to initiate discussion	(ii) The imminence of death cannot be certain, and no management should take place which could cause or hasten death. Thank you for your comment. Our recommendations support your suggestions.

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				on ethics within healthcare professions and participate in public debate. The M E A welcomes the opportunity to take part in this consultation on what is to replace the Liverpool Care Pathway. We do so in the understanding that the final guidelines will in all probability, influence the end of life care for most people . Following our conference in 2013 at the R S M entitled, "Natural Death is a Pathway Needed?", we were contacted by many families who had had very distressing experiences of the L C P. In "More Care less Pathway", the Baroness Neuberger report, she says that good standard care is better than poor palliative care. We therefore recommend that good standard care be recognised more in the draft guidelines. A wider and ongoing consultation with authorities like the Royal Colleges should be encouraged. One of the problems with the L C P was that it had developed mainly from the experience of deaths from cancer. The manner of death from say, renal failure, stroke disease. C O P B etc… varies so much that it is not possible to draw too heavily on the clinical experience of mainly cancer deaths. At para 1.1 Anticipating the end of life;	(ii) The risk of thirst must be avoided and patient driven nutrition should be included. Nutrition is beyond the remit and scope of this guideline. Our recommendation on maintaining hydration encourages health care professionals to assess hydration status. (iii) A named senior doctor must be overall charge with responsibility for the individual care plan. Thank you for your comment. NICE guidelines make recommendations on treatment and processes of care rather than specifying roles of different healthcare professionals. This is particularly relevant in multidisciplinary teams where the constituency and therefore the responsible lead professional could vary from one team to another. We agree that the lead professional referred to in the guideline should be familiar to the dying person and able to assess their needs (iii) Consciousness should be preserved wherever possible. We agree and have drafted a recommendation that supports your suggestion. Health care professionals are encouraged to seek specialist palliative care advice in the event of undesirable side effects, like unwanted sedation. (vi) There should be daily reactive prescribing. The Committee has suggested that clinicians ensure that

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				This was one of the major problems with the L C P with some patients being deemed imminently dying when they were not. Most doctors have had experience of this error (myself included) but if it leads to a drug regime which is incompatible with survival, it will lead to the same problems as the L C P. Nothing but constant review and a willingness to recognise improvement will suffice. This is another reason why there needs to be a doctor in daily change who has an intimate knowledge of the patient. Family members and people with Enduring Powers of Attorney may well wish to ask certain questions such as; "Are you sure that death is imminent?" "Can you be sure that the person will not experience thirst?" "Will the drugs you give take away consciousness?" How will drugs interact?" "Will life be shortened?" "If the persons condition changes for the better, what	plans are in place for regular reassessment of pharmacological treatments. (vii) There needs to be much more research to build up a proper evidence base, especially of medication at the end of life. The Committee has made a number of research recommendations linked to the pharmacological management of common symptoms at the end of life. (viii) We welcome greater openness in discussion with the patient and relatives. There needs to be a two way dialogue. Advance directives have a limited application. Our recommendations on communication and shared decision making encourage dialogue between health care professionals the dying person and those important to the dying person. Making all health care workers aware of advance directives helps to further meet the needs of dying person, by acknowledging their wishes. . (ix) There should be daily re assessment of the person by the responsible senior doctor so that medication or the course of management can be changed. Our Committee agrees with you and have drafted recommendations that encourage health care professionals to monitor and reassess the dying

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				changes will you make? At 1.2 The importance of consciousness; Nowhere in the guidelines is there an adequate mention of the supreme importance of consciousness. It has been said "The last week of life may be the most important week of life", and this is true not only for emotional support and family communication, but also spiritual support. To rob a person of their consciousness is a grave matter which is not mentioned in the draft guidelines. There is a welcome mention about communication with the patient and family as one of the main problems with the L C P was that patients were being put on it secretly. Relatives began to suspect this and sometimes would not leave the loved one for fear that a syringe driver would be set up, and they would lose consciousness. If this happens again with the new guidelines they will be discredited. There is a problem with advance directives however, as they only become applicable if the foreseen condition actually arises. Thus they can only have a limited usefulness though as a measure of communication they are important. This may include a preference to die at home but the	person's needs, at least on a daily basis to ensure that the person's hydration and pharmacological needs are appropriate to current need.

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				person may still need admission to relieve distressing symptoms. At para 1.3, Who is responsible for the day to day management? Central to our view is that care of the dying is at least as important as care of the acutely ill and that there must be a senior doctor, be it consultant or general practitioner, with clear responsibility. This is also called for in "More Care less Pathway". That doctor should also be responsible for the individual care plan as stated in the Nueberger report. We are not sure this is clear in the draft guidelines. There is a place for multi discipline teams but these cannot take the place of the doctor with overall responsibility and an individual care plan. This doctor should also make the day to day decisions including symptom relief and prescription in the same way as they would if managing acutely ill patients. We return to our view that terminal care is as important as acute care. This may be implicit in the draft guidelines but should be clearly stated. At para 1.4 Nutrition and hydration; Many of the most distressing cases in the evidence to Baroness Neuberger were of horrifying situations	

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				that can only be described as patients dying of thirst. This is totally unacceptable! If the draft guidelines do not eliminate this danger, then they will also be discredited. As a doctor who has seen death from thirst twice, I can say it is something not easily forgotten . Dr Gillian Craig of the M E A is submitting her own evidence on this. Moistening the mouth does not relieve thirst. There is evidence for this in animal experimentation (Dogs with an oesophageal fistula were not relieved of thirst by drinking) We recognise that there has been progress in the draft guidelines on hydration and this is welcome but adequate hydration, howsoever given, is a necessity for all. We do not accept that dehydration can be diagnosed from the signs in the draft guidelines. That is far too late. Fluids should be routinely given by mouth, tube or stoma if possible, or by the intravenous or subcutaneous route if necessary. We simply do not accept the view that the dying do not experience thirst. Nor do we accept that mouth hygiene relieves thirst. The draft guidelines says nothing about nutrition. Why is this? We have learnt of deaths that are caused by both dehydration and patients who have been starved over weeks.If such deaths are to be avoided , and they are all to obvious to relatives, the guidelines needs to be much more robust. Nutrition and oral	

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				hydration should be patient driven but there is a basic need for fluids. At para 1.5 Anticipatory prescribing; Anticipatory prescribing versus reactive prescribing was one of the major problems with the L C P. There is an urgent need to address this. The elderly may be particularly vulnerable. The draft guidelines actually mentions "4 or 5" drugs without mentioning what they are. This is unclear and potentially dangerous and likely to lead to over sedation and drug interaction. There is also the likely hood that the drug regimes would become protocols, one of the main problems with the L C P. If necessary the doctor with overall responsibility can be contacted , in the same way they would have been with a patient with acute illness .Drug regimes must be based on patient need not prognosis. A lethal regime must not be allowed to build up as happened in some cases with the L CP. Evidence base of drug regimes; The draft guidelines with commendable truthfulness states in a number of places that the evidence base is "low" or "very low". Interestingly, although in the	

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				section on recommended research there is a welcome recommendation for random controlled trials, but there are no recommendations on research to close these gaps. Why not? It is well know that Diazepams and Opiates poteniate each other but their metabolism will also depend on hydration and liver or renal function and the elderly are very susceptible to sedatives. Conclusions; (ii) The imminence of death cannot be certain, and no management should take place which could cause or hasten death. (ii) The risk of thirst must be avoided and patient driven nutrition should be included. (iii) A named senior doctor must be overall charge with responsibility for the individual care plan. (iii) Consciousness should be preserved wherever possible. (vi) There should be daily reactive prescribing. (vii) There needs to be much more research to build up a proper evidence base, especially of medication	

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				at the end of life. (viii) We welcome greater openness in discussion with the patient and relatives. There needs to be a two way dialogue. Advance directives have a limited application. . (ix) There should be daily re assessment of the person by the responsible senior doctor so that medication or the course of management can be changed.	
Merton Clinical Commissioning Group	Short	General	General	Merton CCG is commissioning a new nursing team in the community that will be responsible for the coordination of care for those in the last few days and hours of life in the community. The CCG is happy to share any learning which emerges.	Thank you for your kind offer and for participating in the consultation process. Your team is encouraged to register as stakeholders on the guideline entitled 'Improving Supportive and Palliative Care' which is currently in development, with a planned publishing date of January 2018.
Merton Clinical Commissioning Group	Short	General	General	It may be helpful to consider developing a public-facing document which sits alongside the guidelines which clearly sets out what people should expect in relation to the end of life care that they receive.	Thank you for your suggestion. Other versions of the guideline include the 'Information for the Public' which presents an outline of the standards of care that can be expected by the dying person. This will be available on the final publishing date.

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Merton Clinical Commissioning Group	Short	General	General	One patient representative has raised the issue of assisted dying and enquired whether this is incorporated in the guideline. Perhaps there could be clearer messaging regarding what is and is not within the remit of the guideline, and a clear statement that assisted dying is not in scope.	Thank you for your comment. The scope document provides clear details of what has been covered in our remit. This can be found here: https://www.nice.org.uk/guidance/GID-CGWAVE0694/documents/care-of-the-dying-adult-final-scope2. Assisted dying is outside the scope of our work.
Merton Clinical Commissioning Group	Short	General	General	It may be helpful to have the context section towards the start of the document.	Thank you for your comment. The short version of the guideline is based on a standard NICE template. This text has now been moved to the beginning of the document.
Merton Clinical Commissioning Group	Short	General	General	An overarching observation is that the delivery of the guidelines will be more challenging to achieve in community settings, and various comments relating to this are included below.	Service delivery was outside the remit and scope of the guideline. NICE is currently developing palliative care service delivery guidance that may address this issue. Please note that more detail about this work can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Merton Clinical Commissioning Group	Short	General	General	It may be helpful to consider whether there could be greater clarity around the timescales associated with and the professionals responsible for delivering particular activities. Interpretation of the terms 'specialist' and 'non-specialist' may vary and it may be helpful to outline how these terms should be interpreted in the context of the guideline.	Thank you for your comment. The scope of this guideline addresses the clinical care of the dying adult in the last 2-3 days of life. We are aware that care providers for people at this time can be dependent upon both setting and clinical circumstance. We do not feel it appropriate to define categorically these staff or others terms but the Committee would wish the term 'specialist 'to be

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					interpreted as someone who has significant experience in providing care in the last 2-3 days of life or in managing specific symptoms This may be a specialist palliative care consultant or a community healthcare provider that regularly supports people at the end of life such as a general practitioner or nurse. It is these staff who may provide additional support to the non-specialist care provider at whom the guideline is aimed. These staff may include general ward or care home staff and others for whom providing end of life care is not a major part of their work for example some general practitioners or district nurses or junior doctors..
Merton Clinical Commissioning Group	Short	1	Between 5 and 6	It might be worthwhile to add 'and those close to them' at the end of the following sentence: 'It includes recognising when people are entering the last few days of life, communication and shared decision-making with the person who is dying.'	Thank you for your comment. Our choice of language is reflective of language used within the 'One Chance to Get it Right' document and we believe incorporates 'those close to them' in our reference to 'other people important to them'.
Merton Clinical Commissioning Group	Short	17	22-23	Re: 'recognition that a person was dying was not always made by an experienced clinician and not reliably reviewed, even if the person may have been improving' (This statement relates to a concern regarding the LCP). This relates to some degree to resource/ capacity issues and it is important to consider how such issues could be addressed. The LCP was intended to raise standards as is this initiative. In order to	Thank you for your comment. We believe our recommendations made in this area create the requirement to seek specialist advice in the case of uncertainty around recognition of dying. We do recognize that there are a number of care providers, not necessarily 'senior' level who are skilled, experienced and competent in recognizing dying. It will be important not to de-skills this group of care providers by always requiring senior input.

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				deliver higher quality person centred care there will be a need for additional skills and capacity in settings where dying people are cared for.	
Merton Clinical Commissioning Group	Short	18	3-5	Re: 'These were not necessarily a direct consequence of following the LCP, but due to poor implementation and without ensuring adequate staff training and supervision.' It will be important to consider what steps can be taken in order to ensure that professionals have the right skill sets and sufficient capacity to deliver the new NICE guidelines.	Thank you for your comment. We agree. . Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Merton Clinical Commissioning Group	Short	18	7-9	Re: 'It is focused on care needed when a person is judged by the multiprofessional clinical team to be within a few days of death.' It is relevant to consider the practicality of this, particularly in a community setting. It is important and helpful to make the distinction between care of the dying patient and end of life care in general.	Thank you for your comment. We do not believe it is necessary to make further distinction on this issue in the introductory text.
Merton Clinical Commissioning Group	Short	3	5-6	Re: *'It is recognised that it is often difficult to be certain about whether a person is dying.'* This is particularly challenging to achieve in a community setting compared to a bedded setting due to multiple professionals, services and organisations being involved in an individual's care.	Thank you. We understand the challenges across settings. We hope that our recommendations, which apply across settings, may provide additional support. Our recommendation about seeking specialist expertise creates an opportunity for those in the community setting to access this advice when necessary.

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Merton Clinical Commissioning Group	22. Short	23	24.	25. Re: *'Use the knowledge gained from the assessment and other information gathered from the multiprofessional team.'* This can be difficult to achieve in a community setting, for example there can be logistical issues associated with accessing a 'multiprofessional team' in a timely manner.	Thank you for your comment. The committee intend this recommendation to apply to all settings, but note that there may be challenges to its implementation. Recommendation 1.1.1 has been amended to state that the information gathered should be documented. The availability of this information may support the practitioner acting on recommendation 1.1.3
Merton Clinical Commissioning Group	Short	4	22	Re: *'Monitor for further changes in the person at least every 24 hours.'* It could be helpful to give further detail here e.g. Who? How?	Thank you for your comment. This recommendation applies to whoever is responsible for deliver care. Further detail is given in the 'Linking evidence to recommendations' section in the full guideline (please see section 5.8).
Merton Clinical Commissioning Group	Short	4	26-28	Re: *'Seek advice from colleagues with more experience of providing end of life care if there is uncertainty about whether a person is entering the last days of life.'* This may not be straightforward in the community.	Thank you for your comment. The committee noted that there may be challenges in this area but feel that advice from experienced staff is usually available on the phone if not in person.
Merton Clinical Commissioning Group	Short	7	14-17	Re: 'Establish as early as possible the resources needed for the dying person (for example, the delivery of meals, equipment, care at night, volunteer support or assistance from an organisation) and their availability.' This statement seems a little out of place where it is currently positioned. It doesn't necessarily feel like it relates to 'Shared decision-making'. It may sit better	Thank you for your comment. We have amended the guideline for clarity. This recommendation now appears under the subheading Individualised care planning. This section has been informed by the shared decision making review. This recommendation in particular was developed after the committee discussion about being clear that availability of resources locally may impact on ability

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				under the heading 'Care planning'; indeed a few other recommendations in section 1.3 may also align better with this heading.	to provide and that these issues should be discussed as part of any conversation.
Merton Clinical Commissioning Group	Short	General	General	It may be beneficial to include some information regarding sharing patient information/ records and when consent to do so should be sought.	Thank you for your comment. The following text has been added to the 'Linking evidence to recommendations' section of the full guideline: The General Medical Council has also provided guidance for doctors in this area in its document: Treatment and care towards the end of life: good practice in decision making. {GMC2010}
Merton Clinical Commissioning Group	Short	6	12	Re: 'documented in the dying person's record of care.' In the community it is not clear what constitutes the 'record of care'. Possible records include but are not limited to: GP records; community services records; hospice records; CMC/ EPACCs.	Thank you for your comment. The committee feels that there are a number of documents in which this information should be captured and our terminology is inclusive of medical records and others as they feel that it is important for all members of the different care teams to have knowledge of the dying person's prognosis.
Merton Clinical Commissioning Group	Short	7	10-13	Re: 'ensure that any agreed changes to the care plan are understood by the dying person, those important to them, the multiprofessional team and by others involved in the care of the dying person.' This can be a real challenge in a community setting where the MDT is not dedicated to End of life care and is not able to meet (virtually or in person) on a daily basis.	Thank you for your comment. The Committee sees this as an aspirational recommendation and considers this best practice and therefore important to articulate within this guideline.

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Merton Clinical Commissioning Group	Short	7	27-29	Re: 'Record individualised care plan discussions and decisions in the dying person's medical records and share the care plan with all members of the multiprofessional care team.' It would be helpful if there could be greater clarity here, for example: Which medical records should information be added to? How frequently should these steps take place? It might be helpful to add "as clinically appropriate" to enable personalised care.	Thank you for your comment. We have amended the recommendation to encourage people providing end of life care to share the care plan with the dying person, those important to them and all members of the multiprofessional team. We believe the types of record used may be subject to local arrangements as would the frequency of capturing this information and as such do not wish to add any further detail to the recommendation in this regard.
Merton Clinical Commissioning Group	Short	7	4	Re: 'Identify a named lead healthcare professional, who is responsible for encouraging shared decision-making in the person's last days of life.' This can be particularly difficult in the community, when the individual would need to lead the care provided by a range of professionals with various roles and responsibilities, many of whom may be from different organisations over whom they have no authority.	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section.
Merton Clinical Commissioning Group	Short	7	7	Re: 'The healthcare professional should: give their own contact details and also contact details for relevant out-of-hours services to the dying person and those important to them.' It may be helpful to provide greater clarity on exactly what this would entail, for example whether this would be the contact details for the organisation or an individual's contact details.	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section.

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Merton Clinical Commissioning Group	Short	8	9-11	Re: 'Ensure that shared decision-making is supported by experienced staff at all times. Seek specialist advice if additional support is needed.' This is desirable but it can be challenging to achieve.	Thank you for your comment. NICE is currently developing guidance in palliative care service delivery and the issue of staff resourcing may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Merton Clinical Commissioning Group	Short	9	26-28	Re: *'Consider a therapeutic trial of clinically assisted hydration for the dying person who has distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium.'* There are particular challenges associated with providing clinically assisted hydration in the community, for example delirium can present variably as a symptom of dehydration.	Thank you for your comment. The Committee intends this recommendation to apply to all settings and are aware that clinically assisted hydration may take place in the community, but note that there may be challenges to its implementation.
Merton Clinical Commissioning Group	Short	11	13-16	Re: *'Consider prescribing different routes of administering medication if the dying person is unable to take or tolerate oral medication. Avoid giving intramuscular injections and give subcutaneous or intravenous injections as appropriate for the setting.'* Nursing homes may not have the skills/ ability to administer subcutaneous fluids.	Thank you for your comment. The Committee feels that all of its recommendations should be relevant to the care of people in the last days of life we are cognisant that this may present issues for some settings but should be an aspiration for people to have their medication by a route most effective for their needs.

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Merton Clinical Commissioning Group	Short	12	1-3	Re: *'Seek specialist palliative care advice <u>if the dying person's symptoms do not improve promptly with treatment</u> or if there are undesirable side effects such as unwanted sedation.'* Perhaps better phrasing may be: 'if the dying person's symptoms persist despite treatment and they experience undesirable side effects'.	Thank you for your comment. After careful consideration the Committee feel that no change is required.
Merton Clinical Commissioning Group	Short	13 14 15	1-3 3-6 11-13	There could be medico-legal issues associated with the medications that are endorsed but are currently unlicensed. As these are being recommended by NICE, will licenses be sought?	Thank you for your comment. The footnotes are standard NICE text when a drug is recommended outside its licensed indication.
Merton Clinical Commissioning Group	Short	16	12-14	Re: *'Use an <u>individualised approach</u> to prescribing anticipatory medications for people who are likely to need symptom control in the last days of life.'* Although the administration of medications should be on an individualised basis, the prescribing of anticipatory medications may not be as it is not necessarily feasible to predict the complement of symptoms that the person will experience.	Thank you for your comment. We are keen to recommend the individualized approach to avoid a blanket approach to prescribing for the common symptoms at the end of life. The Committee recognised that some people die with no symptoms and were concerned at the availability of standard prescriptions which created a sense that all were appropriate to prescribe rather than consider the needs of the dying person. Recommendation 1.6.2 encourages prescribers to make that assessment as soon as possible to prepare for 'likely symptoms' and then 1.6.5 places a requirement on the care giver to review the needs of the dying person at the time of prescribing to ensure that the medications prescribed remain pertinent and individualized for needs

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Merton Clinical Commissioning Group	Short	16	27-29	Re: *'When anticipatory medications are administered, monitor and review the dying person's symptoms and any side effects daily, and give feedback to the lead healthcare professional.* It would be helpful to clarify whether this is the same lead mentioned on pg 7.	Thank you for your comment. We do not feel it appropriate to specify that this is the lead professional responsible for supporting shared decision making. We believe this maybe dependent on people's setting or transfers between settings at this time. We also recognize that differing roles maybe played by differing members of the team ,For example, the GP may support shared –decision making at home but refer to a lead specialist prescriber within the hospital for advice on appropriate prescribing decisions.
Merton Clinical Commissioning Group	Short	16	8-11	Re: *'Prescribe anticipatory medication as early as possible for people with anticipated or changing needs for symptom control medication in the last days of life. Ensure that suitable medications and routes are prescribed as early as possible.'* There can be reluctance to prescribe anticipatory medication due to potential waste. However, reactive prescribing has inherent delays due to staff time required to collect the medication; common challenges can be availability of drugs nearby, especially at weekends. Perhaps the key recommendation here is to ensure that there is rapid access to symptom control medication. (e.g. It may be that there is a readily accessible 24 hour pharmacy which can dispense the required range of medicines which may circumvent the need to prescribe anticipatory medication in some cases and hence reduce	Thank you for your comment. These issues are discussed within the 'Linking evidence to recommendations' section of chapter 10 of the full guideline. Service Delivery, including access to medications, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.

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				medicines wastage).	
MHA	Short	general	general	The NICE guidelines would benefit from a better understanding the importance of supporting families and friends in the time immediately after their loved one's death. For care homes, ensuring that we plan for the best care for people in the last days of their life begins when a person comes to live with us and it doesn't end with their last breath. We also aim to provide a supportive and appropriate environment for the families of the dying adult.	Thank you for your comment. Service delivery, including 'bereavement support' is beyond the remit and scope of this guideline. NICE is currently developing guidance on palliative care service delivery which may cover a wide range of service delivery topics. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
MHA	Short	general	general	We would also suggest that the national GP contract is amended to include a specific responsibility for GPs to offer proactive and enhanced care to people living in care homes, centrally negotiated, especially in the last days of life, rather than leaving this to local areas, local GPs and local care homes to sort out.	Thank you for your comment. Service Delivery, including decisions around staff responsibilities and roles, are beyond the remit and scope of this guideline. NICE is currently developing guidance on palliative care service delivery which may cover a wide range of service delivery topics. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
MHA	Short	general	general	Each person is a unique individual and their attitudes to dying will be very much their own. Each MHA home serves a different group of individual residents	Thank you for your comment. Our recommendations encourage health care professionals responsible for end of life care, to

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				and in homes specialising in dementia and/ or nursing care, there will be particular issues that require a different approach. The NICE guidelines would benefit from highlighting this.	explore the individual capacity and needs of the dying person. We believe that our guidelines promote the requirement for an individualized approach which will be of relevance to care providers in all your homes.
MHA	Short	general	General	Good end of life care begins in creating a culture of care and openness. Our workforce is trained in MHA's 'Final Lap' approach – from the day when our residents move in, staff explore ways of raising/ responding to the subject of the end of life with residents. We would be delighted to share this further with NICE and show how it works in action.	Thank you for your kind offer, and for participating in the consultation process. Could we also encourage your organisation to register as stakeholders on the current guideline in development: Improving Supportive and Palliative Care? This guideline addresses service delivery and may cover training issues. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
MHA	Short	general	general	The NICE guidelines are clearly intended to provide a checklist to help all those involved in the last days of a person's life. Whilst checklists can be helpful, we felt that there is more opportunity for the guidelines to provide a stimulus to the good overall care of the dying adult as well as the more clinically focused checklist.	Thank you for your comment. The aim of the guideline was to provide clinical guidance for all health care professionals in the following key areas: • Recognising dying • Shared Decision Making • Communications • Symptom management • Maintaining Hydration. Other areas, considered to be part of the overall care of the dying adult were beyond the remit and scope of this guideline but the Committee feel that

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					this should be an inherent aim for all care providers without the requirement for evidence based guidance.
MHA	Short	18	19	The last days of life form an integral part of providing care, support and accommodation for older people – care homes are a key part of this landscape. The NICE guidelines seem to focus on the last days of life in hospitals and hospices – only casual reference is made to care homes. Over the last 10 years, an older person becoming a resident in a care home does so at a later stage of life than ever before and often is increasingly frail when they come to live with us. This means that the NICE guidelines should more clearly recognise that for many people their last days of life will be in a care home.	Thank you for your comment. The Committee feels that all of its recommendations should be relevant to the care of people in the last days of life regardless of setting. We believe this to include care homes acknowledging the issues you raise.
MHA		6 7	22 & 19	In the section on Shared decision-making it both refers to implementing (pg 6, ln 22) and creating an individualised care plan (pg 7, ln 19). We feel this is a mixed message, with the potential for planning to be an after thought. Again it would be helpful of the guidance recommended advanced care planning as the first step in the care for the dying person, to ensure all areas of importance for that person are covered.	Thank you for your comment. The Committee agrees that shared decision making and the creation of individualised care plans are key to the delivery of individualised end of life care. Recommendations have been drafted that address these areas for healthcare professionals to address these items. As the remit of the guideline is last days of life we are unable to comment outside of this timeframe although we make reference to the advance care plan where it has been created in advance of the last days of life, We have introduced a sub heading to clarify recommendations that refer to care

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					planning.
MHA	Short	6	3	The NICE guidelines seem to have missed the opportunity to promote the importance of the advance care planning approach. The focus is very much on the very last days of life, which does not seem to be very different from the Liverpool care pathway, but actually, planning for death needs to happen much earlier. Advanced care planning in this section on Communication appears to be a long way down the list and should have greater prominence. If Advanced Care Planning has taken place it could be a first port of call for the multi-professional team.	Thank you for your comment. The focus of this guideline is on the clinical care required in the last 2-3 days of life (see section 4.2.4.1 of the full guideline). The Committee have drafted recommendations to ensure that a framework exists to best support the dying persons who may not have put an advance statement in place or considered advance decisions to refuse treatment. The committee feels it is important to have these discussions with the dying person and to also offer an opportunity to individuals who have an articulated care plan to revise this is their needs, wishes and goals have changed. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
MHA	Short	6	3	Understanding and following the person's end of life wishes is intrinsic to a person's care in the last days of their life. It is also important for the families/ relatives to know and understand their wishes to avoid any potential tension between the person's wishes and the relatives' wishes. The NICE guideline could be more explicit about the importance of this.	Thank you for your comment. The views of those important to the dying person with respect to future care and the person's goals and wishes are considered by the Committee to be very important when gathering and documenting information; particularly after it is thought that a person may be entering the last days of life. How much, those important to the person are involved in communication, decision making and care would be

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					led by the dying person where possible. The guideline encourages healthcare professionals to prioritise the wishes, goals and needs of the dying person in the delivery of individualised end of life care.
MHA	Short	7	27	Effective partnership with health and other professionals must be in place to help deliver excellent care for a person in last days of life. The NICE guidelines would benefit from more explicit reference to this, particularly in a care home setting.	Thank you for your comment. The guideline is aimed at all healthcare professionals who might be involved in the care of a person who is nearing death in any setting where NHS care is provided. It is specifically targeted towards non-specialists working in primary care or in care homes and to healthcare professionals working in a wide range of clinical specialities in which people may die, but who do not have specialist level training in end of life care. The recommendations support communication across the wider team and the identification of a named lead who can encourage shared decision making in the person's last days of life, ensuring that any agreed changes to the care plan are understood, not only by the dying person and those important to them, but also the wider multiprofessional team and by others involved in the care of the dying person.
MHA	Short	general	general	Key to this is to support dying residents by creating an environment and care plan for their last days in accordance with their expressed wishes, with a	Thank you for your comment.

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				palliative approach to manage their pain/ other symptoms and their psychological, social and spiritual needs, offering a dignified setting, alerting relatives and friends when the end of life is approaching and trying to allow our residents to die in the place they want to.	
Mike Stone	Full	general		Dear 'NICE' and Bee, I have no idea who this will reach at NICE - I would like it to reach Mark Baker, because I would like to discuss something he said on BBC Radio 4 yesterday with him (see later). Apparently as an individual, I am not supposed to comment on the draft guidance NICE released yesterday: although I am making enquiries of my local HealthWatch, I am going to make a comment. The NICE draft writes about drinking thus: 22. Support the dying person to drink if they wish to and are able to. Check for any difficulties, for example, swallowing problems or risk of aspiration. Discuss the risks and benefits of drinking with the dying person, the multiprofessional team and others involved in the care of the dying person. That first sentence has got an issue of interpretation,	Non Registered Stakeholder. No response needed.

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				with the words 'able to' - and the third sentence talks about a discussion, but it does not make clear what happens if discussion leads to disagreement. Bee's LACDP came up with this, on page 89 of 'Once Chance To get It Right': 10. The dying person must be supported to eat and drink as long as they wish to do so and there is no serious risk of harm (for example through choking). However if there is likely to be a delay in assessing their ability to swallow safely, alternative forms of hydration must be considered and discussed with the person. Nursing and medical records on the assessment of intake must be kept. 11. If a dying person makes an informed choice to eat or drink, even if they are deemed to be at risk of aspiration, this must be respected. The LACDP's section 11, seems to be 'missing' from the NICE draft (from my 'first very-partial glance') but the LACDP are legally correct - 'clinicians describe risks, mentally-capable patients decide which risks to take' is the correct legal situation to start from. Ditto the NICE section 28, which is not clear who is doing the decision-making: it is the patient, if mentally-capable, who 'does the considering'.	

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				Moving to what Mark Baker said on the Today programme yesterday, at about 8-15 am he was describing and explaining the draft guidance, and as part of that Mark said: "…decisions about the end of life need to be taken in conjunction with the person concerned if they are able to and with those close to them rather than these decisions made by doctors on their behalf, and there is a widespread belief within the profession that do not resuscitate orders are a clinical decision but they are a decision to be made in conjunction with the patient and their families" I was talking to Bee on the phone two weeks ago, and during the conversation I told Bee that Tessa Ing at the DH and I had a 'deep disagreement' about this 'clinical decision' issue: I insisted that decisions about treatment which is potentially clinically-successful are never 'clinicial decisions' because if the patient is mentally-capable the decision rests with the patient, and if the patient is mentally-incapable the MCA does not state that 'the clinicians consult with the family and friends, and then the clinicians make the best interests decision' (I insist that the MCA states that a decision is legally defensible if the decision-maker has complied with section 4(9), and that nowhere in the Act does it	

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				state what clinicians keep writing - as Mark said on the BBC '... there is a widespread belief within the profession that do not resuscitate orders are a clinical decision but they are a decision to be made in conjunction with the patient and their families'). I also agree with Mark about the LCP: http://www.bmj.com/content/350/bmj.h386/rr 'It was entirely predictable that the LACDP's 'replacement' for the Liverpool Care Pathway, has confused some healthcare professionals. One reason the LCP was heavily criticised, is that it was [apparently] seen by some HCPs 'as a process into which patients are fitted', whereas good end-of-life care involves fitting the treatment provided to the clinical needs and wider-life requirements of individual patients. Two patients in identical clinical situations, might have very different objectives and therefore make different choices about which treatments to accept - people are not all alike, 'we are not tins of baked beans'.' There is something at the heart of the MCA - and absolutely fundamental to 'best-interests decision-making' - which is blindingly obvious, but never	

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				mentioned by clinicians: I described it in a BMJ piece (which should say 'if new laws did NOT effect change'): http://www.bmj.com/content/348/bmj.g2043/rr/700882 'But most of all, professionals seem to be blind to the following piece of logic – and it appears to prove that the widely-held belief that 'clinicians consult with family and friends, but ultimately the clinicians make the best interests decision', isn't consistent with the MCA. As a layman, I am not 'expert' in either medical ethics, nor in case law – yet, if I were appointed as a welfare attorney, then without my expertise in those areas being magically improved by my appointment, I would nevertheless acquire the power to make best interests decisions about the provision or withholding of offered treatments. So it is clear, that the Act does not say, that family and friends are incapable of making satisfactory best interests decisions [about medical treatment]: the change when a layman becomes an attorney, is not in the validity of his or her best interests decision-making, but rather in the authority the layman possesses. And, clinicians seem to believe that section 42 of the MCA gives them the same sort of legal authority as section 6(6) gives to attorneys and deputies – this does not appear to be true.	

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				Once you have accepted that section 6(6) does not have 'the senior clinician' as a section (c), and that legal authority stops after attorneys and deputies, this 'ultimately the senior clinician makes the decision' seems to be a purely clinical belief, and not something within the Act. In my opinion, the MCA was intended to strengthen patient self-determination, and to promote decent treatment of the mentally incapable - it wasn't created to protect professionals, nor to make life easier for professionals. And the MCA doesn't make life easier for professionals. Intuitively there are likely to be tensions between patient autonomy and concepts related to safeguarding: and between audit/process and rapid responsiveness. Patient confidentiality is not invariably an easy fit with section 4(6) of the Act, and the 'instruction to mindset' imparted by 4(6) is absolutely fundamental to the MCA. The differences and interactions between mental capacity and mental health are complex: as is a professional concern which I would express as 'even if I do what seems to be legally correct and sensible here, I know I will be heavily criticised by someone'. But especially for patients who are in their own homes, when a family carer might be faced with a situation which forces that layman to make a decision, it isn't appropriate [considering my earlier 'proof' that normal laymen must in theory be capable	

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				of making 'good' best interests decisions] for the 'balance points' of these tensions, to be set by professionals alone. A much better approach, for situations of ongoing care [such as end-of-life] would be to adopt what I term the Core Care Team approach, and to stress discussion and integration between those persons, lay and professional, who are most deeply involved in an ongoing manner with the patient and the patient's care – to try and facilitate, by information sharing and discussion, good decision-making by anyone who is 'supporting the patient in an ongoing way'. The objective of my Core Care Team approach, would be to try and ensure that whoever is alone with the patient [in the patient's own home] is adequately informed about 'the situation viewed holistically'. A level of understanding of the patient's overall situation, which 999 paramedics or A&E clinicians, could never possess.' What I would like NICE or Mark to tell me, is the answer to this question. Somebody posted this, anonymously, on Nursing Times a couple of years ago: My 87 year old father suffered with chronic heart and renal failure, he spent years going in and out of	

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				hospital at the GP request. He had decided that enough was enough, he didn't want to have more tests, catheters, cpap so took the decision not to allow mum to call an ambulance when he was nearing the end of his life. He died at home surrounding by his family. If I modify that to the following, then what does NICE think the answers to the question(s) I pose are ? An 87 year old father suffers with chronic heart and renal failure, he spent years going in and out of hospital at the GP request. He had decided that enough was enough, he didn't want to have more tests, catheters, cpap so took the decision not to allow his daughter to call an ambulance when he thought he was nearing the end of his life. The daughter said to her dad 'We should call someone' and he said 'No, no, no !!! Whoever you call, I am likely to end up in hospital - especially if I have lost consciousness before anybody arrives. I am resigned, and happy to, die at home, and if that is to be today then so be it - if it looks as if I'm dying, let me die and do not call anyone'. QUESTION(s): what should the daughter do, if her dad 'slumps into unconsciousness' - and if she respects his instruction and doesn't call anybody	

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				until after he has (it turns out) died, has she done anything 'wrong', and how should she be treated when she does call someone after her dad is dead ? My opinion is pretty obvious, on this one - see my recent BMJ pieces at: http://www.bmj.com/content/350/bmj.h2877/rr http://www.bmj.com/content/350/bmj.h3181/rr http://www.bmj.com/content/350/bmj.h3181/rr-2 Best wishes, Mike Stone PS NICE tells me on page 26: 3.3.2 What this guideline does not cover Care after death (care of the body, certification and bereavement). If patients are in their own homes, and you are covering the 'run-up to death', then it is peculiar that the behaviour immediately post-mortem is NOT covered (and don't hide behind 'we can't do that, because police and coroners are involved' please) - Bee knows how persistently I hammer away at this issue !	

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				PPS Late added note (I wrote the above yesterday evening, and I added this when starting to work through the guidance this morning). There is a Marie Curie piece at http://blog.mariecurie.org.uk/2015/04/08/new-conversation-terminal-illness/#comment-65442 titled 'What our new conversation about terminal illness should look like'. I sent in a comment to it, which can be found below the piece: this NICE guidance, from what I have read so far, rather 'makes my point' - I would recommend reading the comment online as my pasting below might be less well formatted: One Response to what our new conversation about terminal illness should look like 1. Mike Stone says: 15 April 2015 at 12:21 pm I read Changing the Conversation a few days ago. But where is 'the conversation about the 'non care-provision' aspects of end-of-life' ? For example, where is 'the conversation' about the detailed 'rules/mechanism' for 'who makes decisions about whether a potentially successful treatment	

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				should be applied or not, if the patient cannot decide him/herself' ? Where is the conversation, about how an MCA section-4 best-interests decision, can withhold a potentially successful life-sustaining treatment, in the face of section 4(5) of the MCA ? Where is the conversation, about whether 999 paramedics should be told to 'trust what live-with relatives say, as the default position' ? Where is the conversation, about the absurdity of a widespread clinical belief, that 'a verbal refusal of a life-sustaining treatment is not legally binding' [when it clearly is legally binding, if made 'face-to-face with a treating clinician, during a situation of ongoing clinical care']? Where is the conversation, about this piece of absurdity (it is connecting DoLS with certification/verification of death – there is no such logical connection) which a care home manager recently raised on Dignity In Care: 'Statement of intent is put in place by g.p when they expect someone to pass within two weeks it is renewed if needs be . Since dols have been introduced you can't have statement of intent if dols in place.' Where is the conversation, about whether 'clinical confidentiality' or section 4(6) of the Mental Capacity Act, take precedence ? http://www.bmj.com/content/348/bmj.g4094/rr/70333	

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				3 Where are these 'conversations' between professionals and patients and family carers, about the way that 'differing perspectives affect mindsets and interpretations of law' ? I can find 'conversations' about care provision – but not about all of these other things, and those other things do significantly affect 'the user experience' !	
Motor Neurone Disease Association	short	general		Although section 1.2.1 advises that the cognitive status and any possible speech, language or other communication needs should be taken into account when establishing the needs and expectations of people who may be entering the last days of their life, the guideline does not go on to offer advice on end of life care for people with cognitive impairments or communication needs. This should be addressed.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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Motor Neurone Disease Association	short	3	11-12	The current physiological, social, spiritual and psychological needs of the person must also be assessed; without this, it is impossible to make meaningful assessments of changes in these needs.	Thank you for your comment. The Committee anticipate that gathering information may include an assessment of current needs if applicable and that this would be down to clinical judgement.
Motor Neurone Disease Association	short	4	22	This sentence should be strengthened: for many people, monitoring will need to be much more regular than every 24 hours; the current stipulation of 'at least every 24 hours' is inadequate and may give some professionals the impression that this is generally an acceptable minimum. Professionals should be encouraged to monitor for further changes much more regularly.	Thank you for your comment. The recommendation provides a minimum of 'at least every 24 hours' so does not preclude more frequent monitoring.
Motor Neurone Disease Association	short	5		Section 1.2 should include a stipulation that the dying person be assured that someone will be available, though a specified route or point of contact, for these purposes at all times.	Thank you for your comment. The Committee agrees that the dying person should be provided with the contact details for team members. Recommendations to this effect have been included in the shared decision making section, where healthcare professionals are encouraged to give information about how they can be contacted and also contact details for relevant out-of hours services to the dying person and those important to them.
Motor Neurone Disease Association	short	6	19-22	We agree that the implementation of the dying person's care plan should be discussed with honesty and transparency, but urge that it should also be done with sensitivity; there is enormous potential for such discussions to become so honest as to be brutal. There may be a historical problem of dying people and those around them not being made	Thank you for your comment. The Committee appreciates the challenges of communication in end of life care and have recommended that members of the multiprofessional team have access to experienced staff at all times and are also encouraged to seek the support of specialist staff where required. We agree with the imperative to

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				aware of their position because care professionals over-prioritise sensitivity, and this is clearly undesirable; but it is not an either/or choice. Care professionals must be able to strike an appropriate balance between sensitivity and honesty – this is not easy, but it is precisely in order to assist with difficulties of this sort that guidance is needed.	communicate with sensitivity and as a guide, the committee relied on guidance provided in the NICE guidance entitled, Patient Experience in the adult NHS services. A cross reference to this guideline has been included. More information on this guideline can be found at: https://www.nice.org.uk/guidance/cg138.
Motor Neurone Disease Association	short	9	13-14	The double negative in this statement makes its meaning highly obscure. If this item of guidance is to be retained, it must be re-written: we recommend removing the double negative, and casting it in the active voice rather than the passive (eg 'death may well occur at the same rate even if the dying person is given clinically assisted hydration'). We also query whether it is entirely correct to say that a lack of clinically assisted hydration is unlikely to hasten death – depending on why the person is dying and how quickly, a lack of hydration surely could accelerate the process.	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given.
Motor Neurone Disease Association	short	12	23-25	We are pleased to see the guidance not to offer oxygen for breathlessness as a matter of routine; for people with MND, the administration of oxygen can be fatal.	Thank you for your comment and for participating in the consultation process.
Motor Neurone Disease Associati	short	17	10 - 11	Education in respect of communication at the end of life must be refreshed regularly for all clinicians and care professionals.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will

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on					have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
National Bereavement Alliance	Long	26	40	We note that this guideline does not cover care after death (care of the body, certification and bereavement). We are concerned that bereavement has been specifically excluded from several current NICE guidelines in development (this guideline, also the guideline on short term interventions to regain/retain independence). We are concerned that opportunities to issue guidance around bereavement support are being missed. If bereavement is to be excluded from this guideline, we would like to see a commitment that the forthcoming guidance on supportive and palliative care will cover bereavement, including in cases of sudden death including suicide.	Thank you for your comment. This issue was not prioritised as part of the scope. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
National Bereavement Alliance	Long	26	40	It would be helpful if this guideline could include guidance on the 'pre-bereavement assessment' recommended by the Palliative Care Funding Review (PCFR). There is an expanding literature on the value and suggested content of such an assessment (eg Machin 2015; Sealey et al 2015; Aoun et al, 2014), however there is a lack of detail about how the PCFR's recommendation should be met.	The guideline has not been able to address all issues relevant to the care of the dying adult. This issue is beyond the remit and scope of this guideline.

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National Bereavement Alliance	Short	7	26	After 'if any specified' insert new bullet point: 'family and carers' (including children and young people's) support needs before and after death'.	Thank you for your comment. Service delivery, including 'bereavement support' is not included in the scope of this guideline. NICE is currently developing guidance on palliative care service delivery and this topic may be included in that guideline. More details can be found at the following link: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
National Bereavement Alliance	Long	134	87-107	We welcome the emphasis on communication and shared decision-making in the guidance. Feeling prepared for the death is related to better outcomes for family members and carers after the death, including fewer symptoms of complicated grief (Barry et al 2001; Schulz et al 2015) and less depression and anxiety (Herbert et al 2006)	Thank you for your comment. Unfortunately care after death and bereavement are outside the scope if this guideline and we are unable to comment.
National Bereavement Alliance	Long	134		Recommendation 17: After 'if any are specified' insert new bullet point: 'family and carers' (including children and young people's) support needs before and after the death'.	Thank you for your comment. The Committee consider "those important to the dying person" to also include family members such as children and young people and therefore feel no change is required. As care after death is outside of the scope we are unable to provide further detail.
Newark & Sherwood CCG	full	138 on		Given the poor quality and unconvincing evidence of the use of assisted hydration plus the practical issues setting it up (complex in community as no mechanisms) and expense issues of providing this in the community I would like to see the balance of the advice in the guideline reflect this.	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee

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					wanted to highlight the lack of evidence around survival and that it is uncertain whether clinically assisted hydration will prolong life or the dying process or hasten death if it is not given. The Committee were aware of the challenges of providing fluids within a community setting but were aware of local services where this had been commissioned and were therefore aware that this was possible.
Newark & Sherwood CCG	short	8	23	Our local community nursing provider suspended use of oral sponges a few years ago after an isolated event. The hospice continues to use them where needed but discrepancies sometimes give rise to practical and expectation difficulties. It would be useful to have more guidance if possible on use of these and whether there has been any research about them.	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline
Newark & Sherwood CCG	short	10	14 on	We welcome the clear direction here. We have recently updated our anticipatory medicines protocol and would be happy to share this.	Thank you for your comment.
Newark & Sherwood CCG	short	11	158	Whilst at least daily review is clinically necessary GPs struggle with this concept and are not always pro-active or supportive of it. Emphasising the potential multidisciplinary approach to this (including the community and care home nurses) together with close communication would be helpful.	Thank you for your comment. After careful consideration the Committee feel that no change is required. We have not specified the person to undertake this review but would consider that it is an essential requirement for any prescriber of medication to review to ascertain benefits and harms
Newark & Sherwoo	short	12	14-17	It would be helpful to list appropriate and ideally simple pain assessment tools in the document	Thank you for your comment. An evidence review was not conducted on the use of pain assessment

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d CCG					tools in the last few days of life, however the Committee chose to make a recommendation about their use based on their own clinical experience. Further detail has been added to the 'Linking evidence to recommendations' section of this chapter in the full guideline (please see section 9.5).
Newark & Sherwood CCG	short	13	18-25	Comment on the relative drawbacks of cyclizine use in the last days should be included here and suggestion as to best general anti-emetic if cause is not clear (eg levomepromazine)	Thank you for your comment. The Committee noted that the summary of product characteristics from the manufacturer of cyclizine gives a special warning and precaution for use. The Committee discussed that it was important that clinicians were aware of this advice, but was aware of the lack of evidence regarding the efficacy and harms of cyclizine in the end of life setting and therefore was unable to make any specific recommendations in this regard. Further detail has been added to the 'Linking evidence to recommendations' section in the full guideline (9.13).
Newark & Sherwood CCG	short	15	11	It would be helpful to mention the form of ophthalmic drops of atropine, given orally. GPs are unlikely to use the full document or refer to the drug tables at the end of the document.	Thank you for your comment. We do not usually describe form of drugs administered. Further information is provided in the 'Linking evidence to recommendations' section of chapter 9 (section 9.30)
Newark & Sherwood CCG	short	16	2-7	This statement appears to imply that anticipatory prescribing is optional. However previous national guidance and our current local policy (Nottinghamshire) states that it is best practice to anticipate and prescribe for ALL patients when estimated prognosis is weeks. I can supply this on request together with a copy of our linked	Thank you for your comment. The focus of this guideline is the last2-3 days of life. Our recommendations address anticipatory prescribing in this time frame. They identify a need to anticipatorily prescribe for anticipated symptoms but that before any of these medications are administered the needs of the individual are re-

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				prescribing template.	assessed to avoid blanket or inappropriate prescribing.
Newark & Sherwood CCG	short	17	6	We have a locally devised simple flyer for carers and healthcare providers on recognising dying and a document that records advance care plans (devised specifically to facilitate a shared decision approach) together with clinician guidance for its use.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
NHS Blood and Transplant	Short & Full	General		We would like to see reference to the option of organ and tissue donation included in end of life care planning. We think it should be part of routine communication regarding end of life care where the person has the potential to donate organs or tissues. We also think it would be helpful to cross reference NICE CG135 and the GMC guidance on Treatment and care towards the end of life, good practice in decision-making. With 21 million people in the UK registered to donate organs, consideration should be given to checking the NHS Organ Donor Register to establish the individual's wishes.	Thank you for your comment. The Committee recognise that organ donation is important in end of life care planning. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas were considered more likely, during scope development, to have a wider impact on clinical practice. As such no specific evidence reviews on organ donation in end of life care planning were undertaken and specific recommendations were not made as the evidence base for them was not evaluated.
NHS Blood and Transplant	Short and Full	General		ICU clinicians we work with have commented that the guideline has only limited relevance to end of life care within and ICU and to this extent failes in its promise to cover 'any adult who may be entgering the last days of their lives in any setting that is	Thank you for your comment. During scoping the importance of care of the dying adult in the intensive care setting was raised. An ICU clinician was recruited as part of the Committee and took part in the formulation of the recommendations. The

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				covered by NHS services'. Given the added complexity of the ICU environment it would be helpful to clarify the extent to which the guideline does or does not apply to such areas. Alternatively the guideline could be expanded to accommodate the needs of this particular patient group.	Committee believes that the recommendations made are applicable in all settings where patients receive end of life care.
NHS Blood and Transplant	Short	6	Line 23 [para 1.3.2, shared decision making]	Missed opportunity to reference organ and tissue donation as an end of life care wish	Thank you for your comment. The Committee considered this and their discussion has now been outlined in the 'Linking evidence to recommendations' section of the Shared Decision Making section of the full guideline (7.6).
NHS Blood and Transplant	Short	6	Line 3 [para 1.2.5, communication]	Missed opportunity to reference organ and tissue donation as an end of life care wish	Thank you for your comment. The Committee considered this and their discussion has now been outlined in the 'Linking evidence to recommendations' section of the Shared Decision Making section of the full guideline (7.6).
NHS Blood and Transplant	Short	11	1 [para 1.5.3 pharmalogical	This paragraph does not take account of organ donation and the potential of pharmacological ante mortem interventions, whose benefit lie within a broader framework than that of symptom control.	Thank you for your comment. The Committee recognises that organ donation is important in end of life care planning. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas were considered more likely, during scope development, to have a

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			interv ention]		wider impact on clinical practice. As such no specific evidence reviews on organ donation in end of life care planning were undertaken and specific recommendations were not made as the evidence base for them was not evaluated. Further detail has been added to the 'Linking evidence to recommendations' section in chapter 7 of the full guideline.
NHS City and Hackney	Short	General		Good coverage of documentation of wishes in care plans and MDT working including reference to advance care planning and adherence to this but could be a bit stronger on sharing ACP or any alterations made with appropriate health professionals and family – ensure all health professionals know about and can act within pts wishes	Thank you for your comment. We agree and have recommended that the ACP outputs be part of the shared decision making process. We are unable to include addition detail in the short version of the guideline, but do expand on this in the full version 'Linking evidence to recommendations' section. We have made amendments to a number of recommendations to clarify that the important information of relevance from the advance care planning process includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
NHS City and Hackney	Short	General		Could be a bit stronger on ensuring that pt and family/carers know who to contact in particular circumstances (mentions contact numbers but could be more clear on who to contact when/for what)	Thank you for your comment. We have carefully considered the order of the recommendation and feel that no change is required. The Committee feels the recommendation is clear and that it is up to local policy/decision makers to give further detail.
NHS City	Short	Gen		Doesn't really have any information about who might	Thank you for your comment. The Committee

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and Hackney		eral		identify (and how they might communicate with GP/others as needed) if person is in last days of life	consider GPs to be part of multiprofessional care team and several recommendations are relevant under the communication section. In addition the guideline recommendations are aimed at all healthcare professionals delivering NHS care in the last days of life.
NHS City and Hackney	Short	General		Good coverage of reducing long term benefit medications and polypharmacy	Thank you for your comment.
NHS England	Full	249		The term 'noisy respiratory secretions' and its definition are inaccurate as already mentioned above.	Thank you for your comment. We have amended the definition to read: Secretions within the upper respiratory tract or pharynx causing noisy, gurgling respirations in the last hours of life. Sometimes known as the 'death rattle'.
NHS England	Full	249		The definition for 'shared decision making' seems incomplete as it does not state who is involved in the process, and who has the ultimate say in the decision.	Thank you for your comment. This has been amended in line with the NHSE definition for Shared decision making. It now reads: A process in which patients, when they reach a decision crossroads in their health care, can review all the treatment options available to them and participate actively with their healthcare professional in making that decision.
NHS England	-	-	-	Empty field	Empty field
NHS England	Full	245		Advanced care planning – the letter 'd' at the end of 'advanced' needs to be deleted. Also, the full description of this term and the 'advance care plan' need to be included	Thank you for your comment. We have amended the guideline to refer to Advance Care plans and Advance care planning, a definition is included in the glossary of the guideline.

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NHS England	Full	85	13	The term 'advanced' in relation to 'advance care planning' should not have a 'd' at the end of it – it alters the meaning of advance care planning altogether – the whole guideline (full and short) needs to be scrutinised to eliminate this common error.	Thank you for your comment. This has been edited throughout the guideline.
NHS England	Short	General	General	Care of the dying and support to those who are important to them is applicable to most sectors of health care delivery. The training, education and development requirements of a generic workforce seem not to be reflected within the draft NICE guidance. Training might include assessment skills, skills in clinical decision making and evaluating the risks and benefits of clinical interventions, particularly in relation to hydration which can be an emotive issue for staff and carers / family members. Could recognition of the e-learning modules (e-ELCA http://www.e-lfh.org.uk/programmes/end-of-life-care/) and RCN e-modules be included?	Thank you for your comment. Service delivery, including 'training, education and development requirements' are beyond the remit and scope of this guideline. NICE is currently developing guidance on palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
NHS England	Short	General	General	Much of the current training in care of the dying is delivered by the charitable sector and/ or specialist palliative care teams with little recognition of the impact on capacity of these scarce resources.	Thank you for your comment. Service Delivery, including training is beyond the remit and scope of this guideline. NICE is currently developing the palliative care service delivery guideline which may cover this topic. Please note that more detail about this work can be found at the following link:

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					http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
NHS England	Short	General	General	One Chance to Get It Right (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf) outlined ten high level statements recommended as a framework to underpin all workforce development relating to care in the last days of life irrespective of level of practice, occupational group, or work setting. Would it be appropriate to reference this?	Thank you for your comment. The NICE guideline does not reference other non-NICE guidelines. However, the full version of the guideline does reference the importance of the document to which you refer as part of its introduction to the guideline in chapter 2. Additionally Service delivery, including 'workforce development' was beyond the remit and scope of this guideline. NICE is currently developing the palliative care service delivery guideline which may cover this topic. Please note that more detail about this work can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
NHS England	Full	247		The term 'end of life' is defined here as 'people in the terminal stages of illness' – this is an unhelpful definition as there remains such a lot of confusion about the term 'end of life care' which refers to people considered to be in the last year of life. What does 'terminal stages' mean? – it would be best to avoid the term altogether or use the full description of 'end of life care' as set out in the glossary of One Chance to Get it Right.	Thank you for your comment. This has now been amended to: End of life: a time frame when people are considered likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with : a) Advanced, progressive, incurable conditions b) General frailty and co-existing conditions that mean they are expected to die within 12 months c) Existing conditions if they are at risk of dying from a sudden acute crisis in their condition

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					d) Life-threatening acute conditions caused by sudden catastrophic events.
NHS England	Full	248		The term 'Liverpool Care Pathway' – it is unhelpful to define it as 'a UK care pathway (excluding Wales) covering palliative care options for people in the final days or hours of life.' Since the publication of More Care Less Pathway, the use of the LCP in England has been phased out completely, so the definition is out of date, and wrongly implies that it is still in use, or still can be used in this country.	Thank you for your comment. We have amended this definition to provide clarity that it is no longer in use. It now states: A care pathway covering palliative care options for people in the final days or hours of life used in the UK (excluding Wales) until July 2014. The pathway has now been withdrawn from use.
NHS England	Full	79	15	The terms 'triage pulse' and 'triage respiration' are unclear – need to be explained or defined	Thank you for your comment. This has been added to the evidence statement.
NHS England	Full	80	Fig. 3	The conceptual framework for recognising dying is not self-explanatory - it seems to have combined factors which help with recognising dying, with actions that are needed (e.g. communication). If retained, it will need explanation.	Thank you for your comment. Further explanatory text has been added.
NHS England	Full	81	Rec 1	3rd bullet point should come first, as that would be the starting point of any such assessment – arguably 4th bullet point comes immediately after that – then the rest follow.	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8).

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NHS England	Full	81	Rec 2	10th bullet point is impressive as it implies a causation that is unproven – it should be described as 'noisy rattling breathing' which is what would be observed – in many ways, it would be clearer if the 4th bullet point were to be changed to 'changes in breathing, in particular Cheyne-Stokes and/or noisy rattling breathing' (and the 10th bullet point can then be deleted)	Thank you for your comment. We have chosen to use noisy respiratory secretions to distinguish between the different mechanisms of noisy breathing and the pooling of fluid in the pharynx. We will keep this term and because of the different mechanisms not combine with Cheyne-Stokes on the list.
NHS England	Full	108	Rec 8	It would be more logical for this to come before rec 7 and perhaps even before rec 6.	Thank you for your comment. After careful consideration the committee felt no change was required and that it is important to establish communication needs prior to discussing prognosis.
NHS England	Full	109	Rec 12	The wording of this rec is not particularly helpful to those who need support from this guidance, as it doesn't give any guideline for how to 'sensitively address' – it may need to be a 'consider rec' in which case you could then include some areas of consideration, including exploring the reasons with the dying person, explaining why those important to them will find it difficult to have information withheld, asking if there is any aspect of information that they would be willing (or unwilling) to be shared to avoid an all-or-nothing scenario, seeking senior support, etc.	Thank you for your comment. This recommendation has now been removed although discussion on this issue remains in the Linking evidence to recommendations section of chapter 6.
NHS England	Full	111	1	There is quite a lot of duplication between this whole section on shared decision making and that of the previous section on communication – understandably as these are closely interlinked. I would like to suggest that you combine these two	Thank you for your comment. As the sections contain different review questions we have kept them as 2 chapters, however we agree they are linked and have cross-referenced where appropriate.

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				sections (perhaps entitled 'Communication and decision making' – the advantage is that you can address duplication and allow a more logical link between communicating about likely imminence of dying with discussions and decision-making about what the person wants to happen. By removing the term 'shared' from decision making, it will also enable the recommendations to distinguish more clearly between (a) decision-making when the dying person has mental capacity, and (b) decision-making when 'best interests' has to be used (cf Mental Capacity Act) because the dying person lacks mental capacity. This division will also enable the different role of 'those important to the dying person' to be made more clearly in these two circumstances. For example, rec. 13 overlaps quite a lot with rec. 6 and 7; rec.14 overlaps quite a lot with rec. 10. I appreciate they have slightly different focus but it would make the guidelines more succinct and logical for the clinician.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We believe that the terminology of shared decision-making is appropriate in the context of our review question. We wished to understand how the dying person, their loved ones and their multiprofessional team could best work together to ensure that decisions made considered and met (where possible) the dying person's wishes (see section 7.1 for further information behind the intention of the evidence review that informed these recommendations. We have not undertaken a review of capacity or 'best interests' as these issues

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					are defined in law.
NHS England	Full	134	All	In relation to decision-making, it is critically important to distinguish between the situation when the dying person has mental capacity and when he/she has not. This is particularly important in relation to the role and responsibility of those important to the person, and health professionals. This is often confusing to those close to the patient who may feel that it is their 'right' and 'responsibility' to make decisions on behalf of the patient – some feel burdened by this. In any case, they do not have a 'right' to decision-making (however much they should be consulted) unless they had been appointed an LPA. There must be full compliance with the Mental Capacity Act. The Act is often poorly understood and imprecisely applied by professionals, and NICE guidance provides a crucial opportunity to make this very clear for professionals and public.	Thank you for your comment. We wished to understand how the dying person, their loved ones and their multiprofessional team could best work together to ensure that decisions made considered and met (where possible) the dying person's wishes (please see 7.1 for further information behind the intention of the evidence review that informed these recommendations. We have not undertaken a review of capacity or 'best interests' as these issues are defined in law. However, the committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
NHS England	Full	136	Para 2	The GDG refers to 'people with reduced capacity defined in the Mental Capacity Act' – it is important	**Thank you for your comment. The sentence has been amended to explain the nature of lack of**

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				to note that such a state (reduced capacity) does not exist – the person must always be assumed to have mental capacity unless the formal test is applied and the person is shown to lack mental capacity, therefore a person either has or does not have mental capacity. It is important that references to the MCA are absolutely precise.	**capacity.** Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We have also made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
NHS England	Full	91	Fig 4	The theme map is excellent – very clear and comprehensive.	Thank you for your comment.
NHS England	Short	General	General	Throughout the guidance there is a clear direction to involve the dying person, and those who are important to them, in shared decision making, ascertaining their level of understanding regarding	Thank you for your comment. The NICE Improving Supportive & Palliative Care for Adults with Cancer 2004 is being updated as part of the palliative care service delivery guidance. Please note that more

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				prognosis and nearness of death and establishing their needs, wishes and expectations. These responsibilities require health professionals to have high level communication skills, and confidence and competence in their application of these skills. We would recommend that NICE consider the inclusion of the availability of communication skills training in a similar manner to NICE Improving Supportive & Palliative Care for Adults with Cancer 2004.	detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
NHS England	Full	150	Rec 26	The practicalities of providing clinically assisted hydration needs to be discussed, in addition to the risks and benefits – for example, in the home setting, it is unlikely that intravenous fluids can be given, so it may necessitate a hospital or hospice admission (though not all hospices can provide this); on the other hand, subcutaneous fluids may be possible. It needs to be part of that discussion. Here the reference back to decision-making will be important, again distinguishing between decisions by the patient who has mental capacity, from best interests decisions in the case of patients who lack mental capacity.	Thank you for your comment. The Committee intend this recommendation to apply to all setting and are aware that clinically assisted hydration may take place in the community, but note that there may be challenges to its implementation. Further detail has been added to the 'Linking evidence to recommendations' section. A link to the shared decision making chapter, where the Mental Capacity Act is discussed has also been added.
NHS England	Full	156	1-5	The reference to death rattle as 'noisy respiratory secretions' is inaccurate and should not be used – instead, it should refer to 'noisy rattling breathing' which describes the phenomenon without assuming a causation that has no evidence base. The rest of the paragraph goes on to describe this further – such unproven assumptions should not be described	Thank you for your comment. The committee agree that the wording in this section should be changed and this now states "are thought to arise" to reflect the uncertainty in causation. After careful consideration the Committee considered that as the noise is not always rattly the term noisy rattling breathing was not appropriate.

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				as factual in NICE guidelines. It would be acceptable to refer to this as 'it is thought that…..' which at least confers the concept of unproven causation. The distinction between death rattle and the pharyngeal secretions related, e.g. to MND, needs to be made as in the latter situation, the use of anticholinergics is indeed justifiable, based on a physiological understanding of what's going on.	
NHS England	Full	160	Rec 31	2nd sentence, should add 'fully re-assess' before 'manage it promptly'…… - too often, clinicians jump to increasing drug dosages without fully reassessing the pain. The wording in rec 31 and 32 might need rearranging to make this work.	Thank you for your comment. We agree that reassessment is important and as such made a separate recommendation on this - see rec 1.5.8: Ensure that plans are in place for regular reassessment, at least daily, of the dying person's symptoms during treatment to inform appropriate titration of medication. This recommendation is included within the general pain management section of the chapter (recommendation 61 in section 9.34)
NHS England	Full	192	1	All the points I've made in row 14 above apply throughout this section.	Thank you for your comment.
NHS England	Full	207	Rec 49	The same point applies about the term 'noisy respiratory secretions' – the guidance to reassure and explain is excellent – I would like to have seen more explicitly a reference to the option of not having treatment being offered – I appreciate that you make a reference to this in rec. 51 but this appears to be consideration given by clinicians. Those important to the dying person have sometimes reported that they went along with the	Thank you for your comment. Recommendation 51 has been drafted based on the assessment and establishment of level of distress. A trial of therapy is implied if there is distress caused and following discussion of fears and concerns. After careful consideration, the Committee did not wish to amend or add to their recommendations.

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				treatment of death rattle because they thought that was the only option.	
NHS England	Full	207	Rec 50	The recommendation 'non-pharmacological measures' without giving examples is unhelpful to clinicians, and also the reference to the secretions here again. Repositioning is something that is reported to help with some patients some of the time (though poor evidence) – this could be cited as an example of a non-pharm measure.	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
NHS England	Full	208	Para 1	It is stated that the GDG took the view that 'this causes carer and family distress' – the GDG might like to know that there is no evidence to support this, and some evidence to contradict this view. Carers and family are often distressed because their loved one is dying and also if they hear the noise but nobody explains to them what is going on, so they make assumptions about this sound being an indicator of discomfort, pain, drowning, etc. It is indeed the reason why treatment is often initiated, but often by staff who make the assumption about family and carer distress.	Thank you. This has been amended.
NHS England	Short	12 13 15 26	19 16 3 6	Greater use of non-pharmacological treatments for symptoms at end of life is to be welcomed, both to avoid over-medication and side effects. Could NICE provide more specific guidance on non-	Thank you for your comment. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in

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				pharmacological treatments?	the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
NHS England	Full	54	15-16	The pathophysiology of noisy breathing at the end of life (death rattle) remains unproven, so it is inaccurate to state 'noisy breathing from pharyngeal and tracheal secretions'.	–Thank you. This text has been amended.
NHS England	Full	212	Rec 54	medicines that should be stopped include those that feel burdensome to the person, not just those that are not providing benefit or may cause harm.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
NHS England	Full	212	Rec 56	4th bullet point – should include 'potential side effects', not just risks of medication	Thank you for your comment. We believe that the first bullet point in this recommendation (benefits and harms) is inclusive of the risks of medication and therefore have not included it as a separate point.

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NHS England	Full	222	Table 6	At the top of the column under 'No' – there should be a reminder to the clinician that pharmacological treatment may not be necessary or desirable, before the list of drugs, given that the evidence that the drugs make any difference is so weak, unlike the other symptoms.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Full	General		Within tables of evidence, variation over superscript lettering, some n brackets, some not.		Thank you for your comment. This has been amended.
NHS Gloucestershire CCG		General		Very clear and easy to understand although it leans towards a medical model approach to care. It is very much geared to an in-patient environment, acute/community hospital or hospice, rather than a person's own home. The section that covers pain management does not cover psychological pain or explore the links between this and physical distress. More could be made of the key role that staff have in supporting families, particularly in the immediate aftermath. In terms of implementation it will be the	Thank you for your comment. The Committee feels that all of its recommendations should be relevant to the care of people in the last days of life regardless of setting. NICE is currently developing guidance in palliative care service delivery and the issue of training and education may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.

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				individualised approach to care planning, identifying clinical need and implementing individualised interventions that will be the most difficult to achieve. The art of individualised care planning has been lost and simply doesn't happen anymore. The training of staff in this guidance needs to be looked at, perhaps at a local level, with local training solutions identified based upon a targeted approach, otherwise this guidance will just sit on the shelf and not be implemented. In particular, the knowledge of the drugs most often used in EoL is very patchy SH across Drs and Nurses and this guidance is heavy on the pharmaceuticals.	Non-pharmacological management and care after death are beyond the remit and scope of this guideline. However the Committee acknowledge the importance of non-pharmacological approaches and have made a number of consensus recommendations in the absence of an evidence review to reflect this. The discussion in the LETR section of chapter 9 acknowledges the factors that may influence the decisions around pain management and the different types of pain including physical and emotional pain, and spiritual and psychological distress considered by the Committee when drafting the recommendations. Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
NHS Gloucestershire	Full	21	46	A comma is needed after the word residence.	Thank you for your comment. This has been amended.

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CCG					
NHS Gloucestershire CCG	Full	21	50	We are concerned that there is no mention here of medications to manage secretions. We appreciate there is a need for more evidence but at present, they should be prescribed.	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	22	15	Expected NOT expecte	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	23	13	Professionals NOT professions	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	23	28	Sentence should read 'in THE care of the elderly'	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	23	31	Sentence should read 'for THE clinical care'	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	23	37	Sentence should read 'a person is dying AND how to communicate'	Thank you for your comment. This has been amended.
NHS Gloucestershire	Full	23	46	Sentence should read 'in THE care of dying people'	Thank you for your comment. This has been amended.

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CCG					
NHS Gloucestershire CCG	Full	24	3	Sentence should read 'such as THOSE with'	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	245	Acronym	Should read ALZHEIMER'S disease not Alzheimer disease	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	246	Acronym	Assisted hydration – this has been defined as fluids administered via a drip or gastric tube but would this not specifically relate to clinically assisted hydration whereas the term assisted hydration could include, holding a cup to help someone drink.	Thank you for your comment. This has been amended, assisted hydration has been removed throughout the document
NHS Gloucestershire CCG	Full	247	Acronym	There should only be one full-stop after the definition	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	FULL	31	9.3	Should state OPIOIDS and not opiates – this is in several places within this section.	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	35	15	Sentence requires a SPACE between or and markers	Thank you for your comment. This has been amended.
NHS Gloucest	Full	35	17	Sentence requires a COMMA between recovery and then	Thank you for your comment. This has been amended.

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ershire CCG					
NHS Gloucestershire CCG	Full	35	34	Sentence requires a FULLSTOP between protocols and For	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	85	13	Sentence should read ADVANCE care planning not advanced	Thank you for your comment, This has been amended throughout the document.
NHS Gloucestershire CCG		General		It's a good document and will be very useful in practice. As always with conditions like heart failure the difficulties of prognosis are particularly pertinent. This seems to be acknowledged; the document is trying to avoid referring to specific diseases and keep the advice as generic as possible which is sensible.	Thank you for your comment and for participating in the consultation process.
NHS Gloucestershire CCG	Full	244	Acronym	Should read ADVANCE care planning not advanced care planning	Thank you for your comment. This has been amended throughout the document.
NHS Gloucestershire CCG	Full	245	Acronym	Should read ADVANCE care plan not advanced care plan	Thank you for your comment. This has been amended throughout the document.
NHS Gloucest	Full	20	17	This should be advance not advanced	Thank you for your comment. This has been amended, here and throughout the guideline.

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29/07/2015—9/09/2015

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
ershire CCG					
Full	General		Section 1.1 is repetitive and should be structured; themes grouped, better ordered in terms of likely chronological order of events/need to address issue.	Thank you for your comment. We have added headings to this section for clarity.	
NHS Gloucestershire CCG	Full	20	38	We are concerned that this statement may lead to poorly communicated information. I am unaware of any evidence to corroborate the statement that patients become dehydrated at the end of life and that altered renal function/skin turgor is not part of the dying process.	Thank you for your comment. This text has been amended.
Full	21	13	We are concerned that this statement does not make sense and will be confusing to clinicians/practitioners in terms of what is expected of them.	That you for your comment. Further detail has been added. Please note that the appendix contains additional information about the design of the proposed trial.	
NHS Gloucestershire CCG	Short	4	21	Suggest this should state potential for recovery rather than recovering with comment to then initiate discussion over whether a patient wishes to continue pursuing that recovery. We feel that it is important that general physicians remember to acknowledge patients may wish to stop treatments even if they could on paper 'recover'.	Thank you for your comment. This recommendation is about the health care professional assessing the patient to be in the last days of life, and does not refer to treatment decisions. We have drafted a recommendation which discusses shared decision making and highlights patients' goals and wishes as an important factor to consider when creating an individualised plan of care.
NHS Gloucestershire	Full	55	Table 12	Within prognostic or diagnostic factors – sentence 'signs and symptoms including in at least 1 of the following categories' does not make sense.	Thank you for your comment. This has been amended and now reads: 'signs and symptoms including at least 1 of the following categories'.

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CCG					
NHS Gloucestershire CCG	Full	63	8-9	Sentence should read 'approach TO care'	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	82	Last section of table	Sentence should read ' they will receive DIFFERENT' not differentiate	Thank you for your comment, this has been amended.
NHS Gloucestershire CCG	Full	59-60	Within table	Within column 4 section mortality at 2 days, the b after bias should be superscript throughout section.	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG		General		The depth of the analysis in the report is impressive. We would like to offer thoughts around the sensitive way in which we can strive to understand the dying person's willingness to discuss their position openly and whether or not we should ever rely on the comments of "people important to the dying person" Many still have the view that "you shouldn't talk about death" and automatically will assume this to be particularly true of the dying. Sometimes the dying are fully aware but think the family couldn't cope if this were addressed openly. The dying person remains quiet lest they should upset others and the rest are therefore convinced that their view of the dying one's attitude is correct. Often this leads to an awful sense of isolation for the dying. Worse still, if there is dissent amongst the family there can	Thank you for your comment. The recommendations on communication and shared decision making aim to make the communication between the dying person and those important to them easier. They make reference to finding the most appropriate person to have that conversation. The committee discussed at length some the issues you refer to and believe that, within the context of a guideline approach, they have made sufficient recommendations in this area.

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				be very strong emotions engendered with very negative consequences after the death. I can't see any easy solution except that the most sensitive and skilled staff at as early a stage as possible try to ascertain the dying one's wishes and also seek their permission to be very open with the family preferably in the actual presence of the dying one. Over the longer term we need, as a society, to make these sort of discussions commonplace well away from the expected event so that they can be conducted in a positive manner. The sort of approach in the BBC's programme on "Planning a good death" has much to recommend it.	
NHS Gloucestershire CCG	Short	7	27	We have experience of a countywide document for communicating individuals care wishes/needs and would be happy to share this.	Thank you for your comment. Our colleagues at NICE may be able to use the document you refer to as part of their implementation support. We will forward your comment to them.
NHS Gloucestershire CCG	Short	7	15	Delivery of meals seems less relevant to the last days of life and may be confusing. Again, this may be an appropriate place to highlight out-of-hours alerts/arrangements.	Thank you for your comment. The Committee disagrees, and felt that this was a good example of one area that would need to be considered when planning care in the last days of life. This information should help guide appropriate shared decision making with the dying person.
NHS Gloucestershire	Short	5	10	With emphasis in the literature recently we would suggest that assessing cognition and information needs should be the first step here.	Thank you for your comment. The Committee felt that an important part of attempting to meet the communication needs of the dying person would

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CCG					involve first establishing who they would like to have access to information related to their last days of life. As a guide the committee relied on guidance provided in the NICE guidance entitled, Patient Experience in the adult NHS services. More information on this guideline can be found at: https://www.nice.org.uk/guidance/cg138
NHS Gloucestershire CCG	Full	111	15	Sentence should read - For example a PERSON not persons	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	111	19	Sentences should read HOURS not ours	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	113	Table	Almack 2012 column 4 – Should read ADVANCE care planning not advanced	Thank you for your comment. This has been amended throughout the guideline. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
NHS Gloucestershire CCG	Full	115	Table	Boot 2014 column 4 – Should read ADVANCE care planning not advanced	Thank you for your comment. This has been amended throughout the guideline. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare

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NHS Gloucestershire CCG	Full	131	Table	Column 3 – Should read ADVANCE care planning not advanced	Thank you for your comment. This has been amended throughout the guideline. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
NHS Gloucestershire CCG	Full	136	Table	para 2, line 6 – should read ADVANCE care planning not advanced	Thank you for your comment. This has been amended throughout the guideline. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
NHS Gloucestershire CCG	Full	136	Table	Para 7 – second sentence does not make sense.	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	87	Table 23	Review strategy last line – a SPACE is needed between information and on	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Short	5	1	We are concerned that there will be an impact upon training needs around communication for clinicians and also a need for clinical supervision/debrief where in depth discussions are frequently taking place.	Thank you for your comment. Service delivery, including training of staff is outside the scope of this guideline. There is a service delivery guideline in production that may address this issue. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-

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					cgwave0799.
NHS Gloucestershire CCG	Short	7	27	We are concerned that there will be difficulties communicating decisions across numerous IT systems to ensure all services ranging from acute to community to voluntary to emergency services have appropriate information.	Thank you for your comment. Service delivery, including the coordination and standardised use of IT systems, is outside the scope of this guideline. There is a service delivery guideline in production that may address this issue. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
NHS Gloucestershire CCG	Short	general		Where comments are made to seek specialist advice, there will be a huge impact upon specialist palliative care services both in and out of hours.	Thank you for your comment. The committee believed that generally, specialist palliative care advice is currently available to health care professionals delivering end of life care to dying persons either face to face or by phone, so it is the view of the Committee that their recommendations will not put additional strain on existing resources. However, the committee is aware that there is intention to review the optimal organisation of current resources and that this issue may be addressed by the palliative care service delivery guideline currently being produced by NICE. More detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.

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NHS Gloucestershire CCG	Short	7	20	DNACPR has not been mentioned, this may be an appropriate section.	Thank you for your comment. We recognise that CPR and DNAR decisions are an important area in care of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas are more likely to have a wider impact on clinical practice. DNAR discussions will not be included in this guideline.
NHS Gloucestershire CCG	Full	111	34	This should state Lasting Power of Attorney for Health and Welfare which has superseded the previous enduring power of attorney.	Thank you for your comment. This has been amended to read as follows: They may have appointed someone to have an Enduring Power of Attorney (which would only be valid if made before 1st October 2007), or a Lasting Power of Attorney for personal welfare which came into effect after the introduction of the Mental capacity act in 2005. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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NHS Gloucestershire CCG	Short	7	7	We are concerned that there needs to be a realistic expectation over access to a named clinician. This should be made explicit for hospital/community settings. This may also be an appropriate place to highlight out-of-hours alerts/arrangements.	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section.
NHS Gloucestershire CCG	Short	6	16	We are concerned that there will be an impact upon training needs around communication for clinicians and also a need for clinical supervision/debrief where in depth discussions are frequently taking place.	Thank you for your comment. Service delivery, including training of staff is outside the scope of this guideline. There is a service delivery guideline in production that may address this issue. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
NHS Gloucestershire CCG	Full	149	7	Should read DEHYDRATED not dehydrate	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	151	Table	Column 2, para 1, line 9 – should this read HYPERcalcaemia and not hypocalcaemia	Thank you for your comment. This has been amended.
NHS Gloucestershire	Short	9	1	We are concerned that this would be difficult to fully implement in all care settings especially community settings due to lack of training/skills/resources to	Thank you for your comment. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing

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CCG				support artificial hydration. We would be concerned that this may impact on patients achieving care in their preferred setting if clinicians do not have further training to understand the issues around artificial hydration.	guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
NHS Gloucestershire CCG	Short	9	13	Were the experiences of two people within the UK who chose to stop eating and drinking recently considered within this section? Their experiences were reported in the media.	Thank you for your comment. The Committee drew on both clinical evidence identified through the systematic review and from their clinical experience to formulate this guidance.
NHS Gloucestershire CCG	Full	150	8.6 no.24	I believe oral hygiene sponges have been removed from clinical practice.	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.
NHS Gloucestershire CCG	Full	153	Para 2, last line	We are concerned that an alert was placed over use of oral hygiene sponges – may have been withdrawn in some areas.	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.
NHS Gloucestershire CCG	Short	8	26	We are concerned that an alert was placed over use of oral hygiene sponges – may have been withdrawn in some areas.	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.
NHS Gloucestershire CCG	Full	162	Para 7, last line	Should read ADVANCE not advanced	Thank you for your comment. This has been amended and now states: They also acknowledged that in some situations shared decision making can be complex and difficult to formulate, and if so

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					additional support from specialist palliative care services should be sought.
NHS Gloucestershire CCG	Short	15	15	We are concerned that assessment at least every 12hours will be difficult to achieve in every care setting, especially community settings due to limited resources.	Thank for your comment. The Committee note that this may present some challenge but feel that where medicines are being used to manage symptoms it is not unreasonable to expect that the prescribing clinician would want to measure benefit within this time frame and the Committee felt it important to formalize this in a recommendation. Service Delivery is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
NHS Gloucestershire CCG	Short	15	3	We would suggest giving examples of non-pharmacological management such as regular repositioning, postural drainage and on occasion, gentle suctioning.	Thank you. The Committee acknowledges the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' section in Chapter 9 of the full guideline.

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NHS Gloucestershire CCG	Short	16	12	We are concerned that this will impact upon clinical teams both within the hospital and community settings. This is due to time constraints and also clinical knowledge in making decisions over choice of medications. This is turn will impact upon specialist palliative care due to increased need for advice and education.	Thank you for your comment. The Committee note that this may present some challenge but feel that where clinicians are prescribing medicines it is not unreasonable to expect that they would want to individualize and tailor that prescription to need rather than provide a blanket set of options. the Committee felt it important to move towards this approach in light of the findings of the Neuberger review and wished to formalise this in a recommendation. Service Delivery, including staffing and training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
NHS Gloucestershire CCG	Full	163		First sentence of paragraph – we are concerned that this is incorrect statement. 'renal patients with chronic pain who would usually be given a package of fentanyl and opioids such as diamorphine for pain'. Diamorphine is contra-indicated in patients with advanced renal failure and not routinely used within chronic pain anyway.	Thank you for your comment. The Committee discussed patients with chronic pain and renal impairment and this has been captured in the 'Linking evidence to recommendations' statement for this chapter. The group is aware that caution was advised in the use of opioids in renal impairment, especially where a drug or its active metabolites have significant renal elimination, and thus the potential for accumulation. The group is also aware of the advice given by the British National Formulary in this area. The 'Linking evidence to

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					recommendations' section states: The Committee wanted to highlight the importance of taking into consideration other comorbidities and other medications the dying person is taking when making prescribing decisions. They chose not to make any specific recommendations about pain management in different patient groups, and suggested that clinicians should follow their normal prescribing practices as at any other time of life.
NHS Gloucestershire CCG	Full	189	26	We are concerned that this statement may lead to poorly communicated information. I am unaware of any evidence to corroborate the statement that patients become dehydrated at the end of life and that altered renal function/skin turgor is not part of the dying process.	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Full	Section 9.3	General	Consider addition of corticosteroids – altered blood glucose may be a useful measurable outcome	Thank you for your comment. Blood glucose was not prioritised as an outcome for this review. No evidence was identified for corticosteroids.
NHS Gloucestershire CCG	Short	11	16	We feel that intravenous administration of medications/fluids needs to be given more context. Subcutaneous route is the most commonly used at the end of life as it is often difficult and distressing to try and cannulate patients who are dying. Where a line is in situ, this can be made use of but it would be very rare to suggest siting an IV line in the dying phase.	Thank you for your comment. The Committee recognise that the subcutaneous route is widely used because gaining IV access in dying adults may be difficult and distressing. We have added additional context in the 'Linking evidence to recommendations' section (9.34) of chapter 9 to clarify this.
NHS Gloucest	Full	190	10	This does not make sense.	Thank you for your comment. This has been amended.

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NHS Gloucestershire CCG	Full	210	7	Should this read 23 – 92% (we think hyphen missing)	Thank you for your comment. This has been amended.
NHS Gloucestershire CCG	Short	12	21	This infers that clinical situations such as pulmonary oedema must be treated but in some situations, they can only be managed, for example a patient who is dying may become anuric and if they then develop pulmonary oedema, diuretics could in fact cause harm and not give benefit so in such a situation, a clinician can only manage the symptoms. We are concerned this statement may lead to inappropriate aggressive management.	Thank you for your comment. The Committee wished to make this recommendation to identify those circumstances where symptoms may be improved by treating reversible causes. They believe this would always be supported by appropriate clinical judgement. Please see the 'Linking evidence to recommendations' section of chapter 9 (9.9) for further detail.
NHS Gloucestershire CCG	Full	217	Table re pain relief	There is no mention to consider renal function to assist with choice of opioid	Thank you for your comment. An evidence review undertaken during this guideline did not identify any evidence for choice of opioids in patients with renal failure in the last days of life. The Committee agreed that this is a difficult clinical issue but felt unable to make a specific recommendation given the paucity of evidence. In the introduction to this section it is suggested that specialist advice should be sought if there are uncertainties including renal impairment. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, the prescribing tables are now being

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					further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Full	222	Table 6		Column 2, row 3- should be a SPACE between up to and every	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Full	213	Point 59 in table		Refers to syringe pump – previously referred to as syringe driver within the rest of the document – I believe syringe pump is in fact the correct term.	Thank you for your comment. This has been amended throughout the document.
Full	218, 220	Table 2 and table 4		Clonazepam is now no longer available in parenteral form	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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					implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
NHS Swindon Clinical Commissioning Group	Full	54	17	It is noted as very helpful to have the definitions in the scope in order to demark *palliative care* and *care of the dying patient* and also the potential for recovery for which more detail may be useful.	Thank you for your comment. Please see the glossary in the full guideline
NHS Swindon Clinical Commissioning Group	Short	5	1.2.1-1.2.7	Many complaints nationally are noted at end of life care due to poor communication. Sensitivity of communication must be noted according to timeliness of prognosis delivery to the person and their families and those important to them	Thank you for your comment. The Committee agrees that communication when delivering end of life care is an important and sensitive topic. The guideline recommends that healthcare professionals discuss the dying person's prognosis with them as soon as it is recognised that they may be entering the last days of life and that those discussions include those important to the dying person if the dying person wishes. Recommendations also encourage the multidisciplinary team to provide the dying person and those important to them with opportunities for further discussion if needed. We agree that sensitivity in communication is important and as a guide the committee relied on guidance provided in the NICE guidance entitled, Patient Experience in the adult NHS services. A cross

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					reference to this guideline has been included. More information on this guideline can be found at: https://www.nice.org.uk/guidance/cg138.
NHS Swindon Clinical Commissioning Group	Short	8	1.4.2	Clearer definition of what 'frequent' mouth care means (including sips of fluid) would be welcomed to support and give confidence to staff delivering care.	Thank you for your comment. Further detail is in the full guideline, 'Linking evidence to recommendations' statement in section 8.6 of the full guideline. No specific review was conducted on mouth care so further detail within the recommendations is not possible.
NHS Swindon Clinical Commissioning Group	Short		1.5.1 When it is recognised that a person may be entering the last days of life, review their current medication	Further detail on the commonly prescribed drugs unlikely to offer 'symptomatic benefit' could be useful to support the clinicians in reducing the burden of poly pharmacy. Decision making on stopping drug treatment may be very difficult. It is recognised that there is a significant medication burden placed on patients with advanced illness. Polypharmacy is prevalent for this group of patients, placing them at high risk of drug-drug and drug-host interactions. Prescribing may be driven by risk factors and disease guidelines rather than a rational, patient-centred approach.	Thank you for your comment. We agree that it may be difficult to rationalise current medication and that other risk factors and disease guidelines are appropriate. Further detail has been added to the 'Linking evidence to recommendations' section.

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			and, after discussion and agreement with the dying person and those important to them, stop any previously prescribed medicines that are not providing sy		

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			mpto matic benefi t or may cause harm		
NHS Swindon Clinical Commissioning Group	Short		1.5.20 Consider non-pharmacological methods for treating nausea and vomiting in a person in the last days	The guidance had little information what these might be and detailed definitions would be welcomed. The use of complementary therapies in the context of the dying patients would prove useful, particularly for non-acute care.	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.

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			of life.		
North West London Healthcare	Full	27 Table 1		Note: Paracetamol IV should indicate that it should be dosed appropriately for weight as per BNF as there have been deaths from IV paracetamol overdose By intravenous infusion over 15 minutes, adult and child over 50 kg, 1 g every 4–6 hours, max. 4 g daily; adult and child 10–50 kg, 15 mg/kg every 4–6 hours, max. 60 mg/kg daily; e.g. elderly 35kg patient will need 1g bd or 500mg qds	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
North West London Healthcare	Full	28 Table 2		Note: Table 2: Prescribing for management of breathlessness in adults in the 1 last days of life In renal failure , use oxycodone as better renal profile than morphine	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
North West London	Full	28 Table 2		Orally or sublingually • Lorazepam 0.5-1 mg up to 4 times a day Note; Sublingual lorazepam is off-label	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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Healthcare					symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
North West London Healthcare	Full	31 Table 4		Table 4: Prescribing for management of anxiety (with or without 1 agitation) in adults in the last days of life Orally or sublingually • Lorazepam 0.5-1 mg up to 4 times a day Note: Sublingual lorazepam is off-label	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
North West London Healthcare	27. Full	28. 30 Table 3		29. Note: Table 3: Prescribing for the management of nausea and vomiting in 1 adults in the last days of life Note:a) Be aware that some anti-emetics are contraindicated or should be used with caution in certain people (for example, cyclizine in heart failure or in people with delirium, domperidone or	Non Registered Stakeholder No response required

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				metaclopramide in bowel obstruction, levomepromazine may lower seizure threshold) Not to prescribe dopamine antogonists like haloperidol and metoclopramide in PARKINSONS Patients	
North West London Healthcare	Full	32 Table 5		Table 5: Prescribing for management of delirium (with or without 1 agitation) in adults in the last days of life Be careful of prescribing dopamine antagonists in patients with PARKINSONS, consider lorazepam,	Non Registered Stakeholder. No response required.
Northern England Strategic Clinical Network	Full	250		This is another misinterpretation of the MCA. The document defines 'Surrogate Decision maker – Health care proxies for people who lack capacity, almost always family members'. Under the MCA. ONLY someone with LPA for health and welfare may act as a Decision Maker in England and Wales. This is often a family member or close friend; if there is no appointed Attorney, then the Decision-maker is the lead clinician who would make a decision in the patient's best interests following appropriate MCA processes. Also note that for EoL decision making, LPA must also have agreed responsibility for life limiting decisions	Thank you for your comment. We have made further amendments to the document to more accurately reflect the implications of the Mental Capacity Act. We have added to this definition as follows: 'Only someone with a Lasting Power of Attorney for health and welfare may act as a Decision Maker in England and Wales

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Northern England Strategic Clinical Network	Full	245	table	Advanced should read Advance	Thank you for your comment. This has been amended throughout the document.
Northern England Strategic Clinical Network	Full	20	17	Advanced care planning.... should read.... Advance care planning: see comments on poor alignment with Mental Capacity Act.	Thank you for your comment. This has been amended, here and throughout the guideline.
Northern England Strategic Clinical Network	Full	85+general	13	Typo: Advance – this error occurs throughout the document and requires careful editing	Thank you for your comment. This has been edited throughout the guideline.
Northern England Strategic Clinical Network	Short	22	1-7	This discussion was widely appreciated by our respondents.	Thank you for your comment.
Northern England Strategic Clinical Network	Short	general	general	Some definition of levels of training or experience may help to address the concern expressed by many respondents that the skilful discussions required to follow this Guideline require the presence of adequately qualified staff. This will be a commissioning issue (numbers and seniority of staff) and an employer issue (access to training and support).	Thank you for your comment. Service delivery, including staffing, training and support, are beyond the remit and scope of this guideline. NICE is currently developing guidance on palliative care service delivery and this may address the issues highlighted in your comment. Please note that more detail about this work can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-

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					cgwave0799.
Northern England Strategic Clinical Network	Short	General	general	There is a clear divide in the feedback received across our network between rural settings and urban areas. This largely concerns application of the Guideline at home, with comments suggesting that the Guideline is more appropriate for a hospital or hospice setting. This appears to apply in areas where there is a lack of policies about specific aspects of care at home, e.g. sc fluids; access to specialist support. Suggest that the Guidelines pre-amble/intro includes the consideration that 'the best death possible' should be a right whatever the setting. These Guidelines have been developed to support best possible care at the end of life, and in settings where clinicians would not currently be able to apply the advice herein, any gaps in the necessary policies and/or resources should be addressed.	Thank you for your comment. The Committee believe that their recommendations should apply across all settings. We have provided additional clarification to this effect on the front page of the short guideline and in the introductory text in both the short and full versions of the guideline.
Northern England Strategic Clinical Network	Full			We believe that the text of the Guideline, and not solely the recommendations, offers an opportunity to educate palliative care non-specialists in knowledge, some skills and particularly attitudes. For this reason we have noted any areas where nuancing of the text may help to shape public and professional knowledge and attitudes. This is not intended to be pedantic, but to form a composite whole of your text that would offer clear and consistent attitudes to, for example, working with uncertainty and working	Thank you for your comment. Our 'Linking evidence to recommendations' statements in each of the chapters include the detail of the Committee's discussion and could be utilised by others to form the type of document you describe. However, we do not feel that creating a composite version is necessary for the purposes of a national guideline.

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				within the framework of the Mental Capacity Act, both of which are threads that run throughout end of life care and, indeed, throughout your document.	
Northern England Strategic Clinical Network	Full			We have noted a few of the typographical errors in the document, which has clearly been finalised in haste to allow adequate time for synthesising the evidence, but we assume that a full editing process will take place before the finalised version is produced. We have only noted those typos that change the sense of a sentence or that are technical, medical or legal spellings/expressions.	Thank you for your comment and for participating in the consultation process. We look forward to final editing on the complete work.
Northern England Strategic Clinical Network	Full			There are ethical tensions in the care of dying people, and these become explicit at points in the guideline. It would be worth noting the ethical considerations and co-opting a specialist in medical ethics (I know co-optee Dr Julian Hughes has expertise in this area, although a specific ethical consideration has not been covered here). For example, the ethics of providing treatment to a patient, that is intended only for the comfort of others, is addressed both in the treatment of pharyngeal secretions and in the provision of hydration. It would be helpful to have an ethical commentary and possibly also a review of ethics publications in this area.	Thank you for your comment. The expertise from Dr. Julian Hughes, who was recruited as a co-opted expert for the guideline, provided the Committee with an over-arching sense of the ethical issues in play at end of life to inform their recommendations. NICE guidelines do not undertake review of publications outside of clinical evidence.
Northern England Strategic Clinical	Full			Is it anticipated that the many evidence-based regional prescribing guidelines would be replaced by this Guidance? If so, what are the timelines for review and replacement?	We are aware there will be numerous local prescribing guidance, and we would anticipate generic advice provided in this guideline, informing local prescribing at end of life timelines will need to

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Network				Although the evidence base for end of life care is scanty, it is growing and in the meanwhile extrapolation from evidence for palliative care prescribing prior to the dying phase is a logical and helpful way forward. Across the UK, local guidelines have been prepared on this basis that are 'user friendly' for non-specialists, and these ensure a consistency of message locally from specialists to their generalist colleagues. They cross-refer to standard texts including BNF and PCF. In places, these draft Guidelines are at odds with both those texts in terms of dose and route recommendations; suggest you cross-refer to avoid confusion, and justify any difference from those texts. If this Guideline is to be useful, local adaptations will need to be written (taking into account, for example, local drug pricing; availability of drug delivery systems; availability of out of hours specialist support, etc). An introductory comment to the prescribing guidance section to this effect would be helpful.	be agreed relative to local circumstances. Thank you for your comments on the prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Full			There is evidence that caring for dying patients and their families is stressful for staff. Stress is reduced by access to appropriate skills training, skills-building supportive supervision, and clinical supervision/case debriefing. As funding in the NHS becomes scarcer, these resources are being eroded and staff burnout is an increasing risk for generalists and specialists alike, particularly in teams where the burden of these	Thank you for your comment. Service Delivery, including skills training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-

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				difficult and skilled conversations falls disproportionately on the few individuals who are perceived to have the necessary skills by their colleagues. We suggest that you include some reference to staff skills, resources for training and support, and access to support within the Guideline.	cgwave0799
Northern England Strategic Clinical Network	Full			Empty field	Empty field
Northern England Strategic Clinical Network	Full	20	33	Suggest a further research question that in our local experience has been helpful: What would be the impact of using language that shares uncertainty whilst imparting the gravity of the situation? For example, would using the expression 'sick/unwell/ill enough to die' enable patient and family to be aware of the need to consider death as a possibility, including in those situations when care is still being given with appropriate life-saving/ resuscitative intent (e.g. admissions unit; ICU; wards when acute deterioration is life-threatening and yet a trial of intervention is appropriate)? Would use of such a phrase give clinicians a phrase they find useful and this reduce incidence of the possibility of dying not being discussed with patient/family?	Thank you for your comment. We agree that research on language would be useful; however the Committee has prioritised the broadest range of activity to understand how to reduce the impact of uncertainty. They did not feel the need to prioritize any further research questions.

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Northern England Strategic Clinical Network	Full	21	39	We agree that this is important; it is ethically dubious to give drugs to a patient simply to comfort other people.	Thank you for your comment.
Northern England Strategic Clinical Network	Full	21	9	In our local regional experience, Previous proposals to investigate the impact of hydration status on incidence of delirium in the dying ran into significant problems when seeking ethics approval: patients would be unable to consent to enter study at point of entry (delirium) therefore consent for randomisation 'should delirium occur, and should there be clinical indecision about whether assisted hydration would be of benefit' was declined. GDG is urged to consider guidelines to RECs regarding the minimising barriers to research in this important area where patients are vulnerable, yet still able to participate in research if prior permission has been given.	Thank you for your comment. The Committee recognise that research at end of life is difficult and agree that people should be able to participate in research if prior permission has been given.
30. Northern E	31.	32	33.	34. Proposal to have a 'reactive prescribing arm' in a community based study is likely to cause outrage. Availability of drugs is poor and takes time in the community; most of the week is 'out of hours.' Unless the likely useful drugs are made available via a community base during the study, patients in the 'reactive prescribing' arm will be in a	Thank you for your comment. The Committee recognise the challenges in conducting research in this area and would expect further details on drug availability to be discussed in any research proposal. This has been discussed in the linking evidence to recommendation section of the full guideline, but we are unable to give further detail in this part of the guideline.

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nglandStrategicClinicalNetwork				'worse treatment than usual' group. However, if the drugs are artificially 'more available' during a study, this will not reflect the true amount of delay in usual availability.	
Northern England Strategic Clinical Network	Full	22	2	Rephrase: ...for administration if clinically required/indicated when it is recognised that someone is entering the final days of life. Avoid the suggestion of 'carte blanche' that is well discussed later in the document.	Thank you for your comment. This has been amended.

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Northern England Strategic Clinical Network	Full	23	26	Principles should read Priorities in keeping with the published information from One Chance doc	Thank you for your comment, this has been amended and changed to 'five broad priority areas'.
Northern England Strategic Clinical Network	Full	24	11	GDG ….Guideline development group: should be defined the first time the expression is used.	Thank you for your comment. This has been amended, the acronym is defined where it first appears in the guideline.
Northern England Strategic Clinical Network	Full	244	Table	ACP is Advance Care Planning, not Advanced; PPC is Preferred Priorities of Care, not Prepared	Thank you for your comment. Advance care planning and preferred priorities for care have been edited throughout the document.
Northern England Strategic Clinical Network	Full	247	table	Glossary: End of life: definition: People in the terminal stages of an illness……? confusion from EoLC programme definition: people are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with: advanced, progressive, incurable conditions general frailty and coexisting conditions that mean they are expected to die within 12 months existing conditions if they are at risk of dying from a sudden acute crisis in their condition life-threatening acute conditions caused by sudden catastrophic events.	Thank you for your comment. This has now been amended in line with definition used in 'One Chance to get it Right'.
Northern	Full	32	Table	Add 'time to symptom relief' as an outcome, and as	Thank you for your comment. We are unable to

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England Strategic Clinical Network			Chapter 10 Outcomes	a measure of delay between identifying symptom and gaining control/relief. This will be important in measuring any additional delay (or not) in reactive prescribing group.	retrospectively add outcomes to this section. This text reflects the outcomes considered important to the Committee.
Northern England Strategic Clinical Network	Full	51	4	We support your decision not to undertake an economic analysis on these grounds. Might it be useful to recommend that a future economic analysis exercise should be considered when more robust data are available?	Thank you for your comment. If more robust data is available when this guideline is considered for update in line with the NICE guidelines manual (see: http://www.nice.org.uk/article/pmg20/chapter/1%20Introduction%20and%20overview) , due consideration will automatically be given to undertaking a new economic analysis. We do not consider it necessary to add text here for this purpose. Also, in the areas of the guideline where we felt lacked the most evidence, research recommendations have been made and health economic considerations have been explicitly outlined in these proposals.
Northern England Strategic Clinical Network	Full	general		Thank you for the opportunity to comment. We recognise and appreciate the amount of work that has gone into finding and assessing evidence to write this draft Guideline, and thank the GDG for it.	Thank you for your comment.
Northern England Strategic Clinical	Full	general		The formatting of the early pages, intended to take the reader quickly to the evidence pages by clicking on the document, made it very difficult to read and comment by annotating the text of the pdf in	Thank you for your comment. We suggest that our current format is acceptable and evidence can be quickly found using the navigation pane. Given the size of the document, we've found it necessary to

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Network				preparation for synthesising the comments onto the feedback form. Suggest NICE considers addressing this difficulty, e.g. insert regular 'go to evidence' boxes for each point, but don't format all text in this way.	include hyperlinks throughout the text for easier use.
Northern England Strategic Clinical Network	Short	18 19	20-31 1-7	Suggest that these helpful, over-arching comments should be at the start of the Guideline to 'frame' the document.	Thank you for your comment, we agree. This has now been moved
Northern England Strategic Clinical Network	Short	20	24 - 26	Lots of assumption here. People approaching the end of life can have reduced consciousness. Complex issue with little evidence. It would be helpful to include reference to your helpful discussion of changing consciousness arising as death approaches, not caused by drugs, as in the Full Guideline.	Thank you for your comment. We have edited this text.
Northern England Strategic Clinical Network	Short	22 23	13-29 1-2	The results of this would be interesting given the pressure on GP and OOH services already. Ethical concerns regarding the challenge of investigating 'reactive' prescribing, giving less good care than current practice.	Thank you for your comment
Northern England Strategic Clinical	Full	81		Recommendation to use ECOG is not aligned with recommended use of AKPS in Palliative Care Funding review. Our team have just switched from ECOG to AKPS.	Thank you for your comment. After careful consideration the example of ECOG has been removed from the recommendation and replaced with: Functional observations, for example

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Network					deteriorating performance status, social withdrawal, changes in communication. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline.
Northern England Strategic Clinical Network	Full	81	Table line 10	Important to note that ascertaining loved ones' views is in order to support them, and NOT in order that loved ones' views determine treatment of patient.	Thank you for your comment.
Northern England Strategic Clinical Network	Full	81	Table line 24	Mottled skin… Suggest add 'and other signs of reduced peripheral perfusion e.g. pink pressure points; pinched nose; cold extremities despite being covered.'	Thank you for your comment. This is an example based on the evidence review. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8).
Northern England Strategic Clinical Network	Full	82	Table. Relative values of dif outcomes	The last paragraph here is a really important point as the Neuberger Review suggested identifying or developing 'tests that will indicate when a person is dying.' Your thorough review of qualitative/experiential and quantitative evidence demonstrates that a 'test' is not feasible and would not replace clinical experience and intuition, supported by whatever clinical information is available.	Thank you for your comment
Northern	Full	83	Table.	The concept of 'sick enough to die' pertains here:	Thank you for your comment.

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England Strategic Clinical Network			Other considerations. Second paragraph	treatment may be aimed at preventing dying, and yet also ensuring that if death cannot be prevented, all the applicable key preferences of the patient have been addressed e.g. presence of loved ones, management of symptoms, attention to personal spiritual beliefs, etc.	
Northern England Strategic Clinical Network	Short	34	19 20 1 - 15	We suggest that highlighting that some of these signs can be seen in people who are reversibly ill is important. For example, agitation can be a sign of treatable delirium.	Thank you for our comment. Reversible causes are discussed in the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8). After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity.
Northern England Strategic Clinical Network	36. Short	37	38.	39. Several specialist palliative care respondents noted that many of the symptoms/signs of 'dying' may, in fact, be present during the last weeks of life. Perhaps more thought about combinations of findings, along with trajectory or rate of change, might help, particularly for generalists.	Thank you for our comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. These examples are based on the evidence review, but the Committee do note that these may occur outside of the last days of life. They acknowledge the difficulty in recognising dying and discuss this in the introduction and 'Linking evidence section of the full guideline (please see section 5.8).

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Northern England Strategic Clinical Network	Short	3	2 - 18	excellent	Thank you for participating in the consultation process.
Northern England Strategic Clinical Network	short	3	5	"It is recognised that it is often difficult to be certain about whether a person is dying." Suggest that this is written in bold and/or underlined.	Thank you for your comment. We do not feel that underlining adds value and have made no change.
Northern England Strategic Clinical Network	Short	3	8	Suggest add a comment about 'whether dying, recovering or in the case of uncertainty, the KEY principles of communication, support, and individualised planning should be applied in a compassionate and sensitive way by those involved in their care	Thank you for your comment. We agree that communication and shared decision making are very important and have made several recommendations in these areas that should be implemented at every stage in the last days of life.
Northern England Strategic Clinical Network	short	3	9	'If it is thought that the person may be entering the last days of life….' Suggest add 'and all reversible causes have been excluded'	Thank you for our comment. Reversible causes are discussed in the 'Linking evidence to recommendations' section of the full guideline (5.8).
Northern England Strategic Clinical Network	Short	3 - 16	general	One locality commented that sections read well and provide clarity for decision making. However, they felt that there were omissions to be addressed: • There is nothing about prescribing for patients with established renal failure at end of life and how this influences prescribing. • There is nothing about the management of palliative care emergencies e.g. fitting,	Thank you for your comment. This is intended to be general guidance for all healthcare professionals. We are unable to comment on specific diseases and conditions. We do however discuss the impact of renal failure within the 'Linking evidence to recommendations' sections within the full guideline (please see section 5.8) and sought advice from a co-opted renal specialist.

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				spinal cord compression and major bleed at end of life. • There are no guidelines for the management of steroids into the end of life period. • There is no guidance on management of the patient with an ICD device and how this gets deactivated. • There is nothing about spirituality or cultural issues and how this should be addressed at end of life.	Given time and resource constraints, palliative care emergencies, management of steroids at end of life and ICD devices were not prioritised for this guideline as other review areas were considered more likely, during scope development, to have a wider impact on clinical practice. We would note that further detail on spirituality and cultural issues are discussed within the communication and shared decision making chapters of the full guideline (chapters 6 and 7). The scope document also provides clear details of what has been covered in our remit. This can be found here: https://www.nice.org.uk/guidance/GID-CGWAVE0694/documents/care-of-the-dying-adult-final-scope2
Northern England Strategic Clinical Network	Short	4	1.1	Reference to secretions mainly mentions noisy secretions not issues with actual/ visible secretions this occurs on occasions.	Thank you for your comment. We have chosen to use noisy respiratory secretions to distinguish between the different mechanisms of noisy breathing and the pooling of fluid in the pharynx.
Northern England Strategic Clinical Network	Short	4	11	Lack of appetite often occurs several weeks before death – this could lead to a premature diagnosis of being close to death.	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Some examples based on the evidence review are included here, but we acknowledge that these are examples only and clinical judgement should be used.

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					Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (5.8) and a specific example of treatable causes that are inhibiting someone from eating and reference to GMC guidance has been added. We are unable to further comment on nutrition as it is outside the scope of this guideline.
Northern England Strategic Clinical Network	41. Short	42	43.	44. blood results are not signs and symptoms - you could add "deterioration in relevant lab results".	Thank you for your comment. The Committee agree that unnecessary investigations should be avoided, but that, if available, they may provide useful information. Available investigation results have been moved to the stem of the recommendation to avoid confusion with other signs or symptoms of recognising dying.
Northern England Strategic Clinical Network	Short	4	4	Whilst it is acknowledged amongst staff that patients can sometimes sense that they are dying, many people who are not dying worry about it : one locality's response expressed reservations about this being regarded as a sign of approaching death, saying that we really need to avoid seeming to return to the LCP "four criteria".	Thank you for your comment. This is an example and the introduction text states that these recommendations supplement the individual clinical judgement that is required when making decisions about the certainty of prognosis and how to manage any uncertainty.
Northern England Strategic Clinical Network	Short	general	general	Dealing with uncertainty. There is a tension in managing end of life care where dying has manifest suddenly in a previously well or 'fairly well' person, or when there is some (possibly diminishing) hope of reversing dying. The	Thank you for your comment. We agree. Recommendation 1.2.4 specifically addresses the requirement to discuss uncertainty.

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				guideline merits a brief discussion of dealing with and conveying uncertainty to patient, loved ones and staff at the top of the Guideline, noting that this reference to uncertainty pertains throughout the Guideline. Locally, we have found use of the expression 'sick enough to die' a useful way to convey the gravity of a situation where death would not be unexpected and yet where perhaps recovery may occur.	
Northern England Strategic Clinical Network	Short	p3 to p 4	19 15	One respondent commented that, in section 1.1.2, signs and symptoms aren't listed logically e.g. Cheyne-Stokes breathing before fatigue and loss of appetite and weight loss. This suggests that your listing by alphabetical order should be made more explicit.	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8).
Northern England Strategic Clinical Network	Full	12 item 10	39	'Advance Care Plan' is too vague , and many versions of AC Planning involve plans that may not be about end of life care, but rather for emergencies or other aspects of care when capacity is lost. In this instance, better to 'plan for care if Sick enough to Die.' This would have the benefit of raising awareness of the idea of making such a plan.	Thank you for your comment. The committee consider Advance Care Plan to be standard terminology and of relevance to our work. We have defined this in the glossary of the full guideline.
Northern England Strategic Clinical	Full	12	39	If patient has capacity, advance care plan or ADRT could be looked at but clinicians should ask patient about their current wishes, irrespective of what they previously have written as they may have changed	Thank you for your comment. We agree and note the recommendation states "explore with the dying person and those important to them". Additional detail on mental capacity has been added to the full

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Network				their minds. The Advance Statement and/or ADRT are only relevant if patient does not have capacity/unable to communicate.	guideline. We feel that a number of our recommendations identify the need to review the dying person's wishes in the last days of life particularly recommendation 19 (please see section 2.3.7). Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Northern England Strategic Clinical Network	Full	13	12	Poor English needs re-writing. This sentence could mean that friends/carers can request that information is withheld from patient, and clinicians could agree to this OR it could be families need to be challenged when they request clinicians to withhold information (presumed intended meaning). Also consider possibility that family requests clinicians to inappropriately discuss, rather than inappropriately withhold, information that the patient does not have capacity to deal with or that may be judged harmful to them (as per the Tracey Verdict 2014).	Thank you for your comment. We assume you are referring to recommendation 12. The intention of this recommendation is to ensure that the needs of the dying person are considered a priority over the needs of the family who may wish to withhold information from the dying person about their prognosis. Further information has been added to the 'Linking evidence to recommendations' section of chapter 6.
Northern England Strategic Clinical	Full	13	18	It is good that this does NOT specify 'doctor' as in the community/ care homes (and on hospital wards at nights and weekends) patients and families are often better known to nurses.	Thank you for your comment. As well as not specifying the specific professional, the committee equally did not wish to specify a seniority but felt it more important to note that a level of experience in

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Network				Specify 'appropriately qualified' lead healthcare professional. Organisations should ensure that their staff have adequate training in care at end of life; they should take responsibility for declaring the minimum required grade and any additional training; and they should facilitate staff attending such training. Currently this is not the case. Particular problems arise in the community because GPs, out of hours GP services, and community nursing staff do not belong to the same provider organisation: CCG leadership may be required to agree how 'named lead clinician' will be identified and provided.	supporting shared-decision making was of greater importance. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Northern England Strategic Clinical Network	Full	General		The Mental Capacity Act is not well interpreted at key points in the guidance. There is already widespread confusion and ignorance within the NHS, so this Guideline is an opportunity to enable better understanding and compliance. For example: • From the draft Guideline, it is not clear that in Law, a competent patient's current wishes override any prior expression of wishes either written or verbal. Therefore, plans written in advance only apply if the patient either lacks capacity or is so weary that they elect to ask the team to follow a previously-expressed wish. • From the draft Guideline, it is not clear that the decision-maker for a patient who lacks capacity is either the clinician in charge of	The committee agree that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision making however the purpose of our review was to understand how the dying person, their loved ones and their multiprofessional team could best work together to ensure that decisions made considered and met (where possible) the dying person's wishes (see 7.1 for further information behind the intention of the evidence review that informed these recommendations. We have not undertaken a review of capacity or 'best interests' as these issues are defined in law. Further discussion on these issues is already provided in the 'Linking Evidence to recommendations' section of the relevant chapters in the full guideline on these issues. We

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				their care (who, if a doctor, must follow both MCA process and GMC guidance) or an appropriately-appointed Attorney for Health and Welfare, with additionally-granted authority for life-limiting decisions under the circumstances of making a decision about end of life care. • It would be helpful if the Guideline makes explicit that the decision is made following a Best Interests process that includes ascertaining the therapeutic possibilities with the advice of someone expert in the condition, and then follows a specific process that considers the patient's view including any interpretation of 'family bonds' that the patient would consider, ensures that no judgement has been formed based on observers' judgement of quality of life (which is of vital importance to the Disabled Community), and chooses the 'least restrictive option.' • From the draft Guideline, it is not clear that discussions with those close to the patient are entirely to discern the views the patient would have expressed were they competent to do so. The personal wishes of the loved ones are not material to the decision about care. They are, however, very important in ensuring that their own needs for information	have made further additions to the guideline to provide context and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. Our references to those important to the dying person throughout the guideline stress the need to provide support to these groups and not to replace the requirement to act in the best interests of the dying person. We note your references to 'Deciding Right'. The guideline has not been able to address all issues relevant to the care of the dying adult. DNACPR is beyond the remit and scope of this guideline.

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				and support are addressed by the caring team, especially if the best interests process leads to a decision with which they disagree or have reservations. A variety of guides to using the MCA is available. Here in the NE we use the easy to follow 'Deciding Right' framework that provides rapid guidance (including a smartphone app) and regionally-recognised forms for recording assessment of capacity, recording of a Best Interests process decision, an Emergency Health Care Plan (which may be a step-up and save a life plan as much as a plan for supporting best end of life care in the place of choice); an ADRT form; and a region-wide DNACPR form. See http://www.nescn.nhs.uk/common-themes/deciding-right/ Other areas are adopting Deciding Right, which is aligned with Resuscitation Council guidelines.	
Northern England Strategic Clinical Network	Short	6	24 - 36	Suggest reversing the order of 'dying person's goals and wishes' with 'whether there is ACP/decision' to emphasise that if the dying person has capacity, their CURRENT wishes are to be respected regardless of any previously made plans. See general note in comment9 and 94 about MCA	Thank you for your comment. We have made amendments to this recommendation to state that as well as any advance statements or decisions to refuse treatment, the current needs of the dying person should be established. Recommendations encourage healthcare professionals to prioritise the goals, wishes and needs of the dying person and to be aware that these may change during the delivery of end of life care.

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Northern England Strategic Clinical Network	Short	5	1 – 29	There is quite a bit of repetition of concepts such as discussions around prognosis, advance care planning, identifying an appropriate lead for discussions. To make the document as user-friendly as possible, some respondents suggested that some of these be streamlined, including section 1.3 to a lesser degree.	Thank you for your comment. The Committee feels that each of these recommendations highlights and encourages key elements of the communication and shared decision making process, and present a framework for communication in the delivery of end of life care. The shared decision making section has been edited to include a sub-heading for 'individualised care planning' for greater clarity.
Northern England Strategic Clinical Network	Short	7	15	We note "delivery of meals" but accept may refer to provision of meals.	Thank you for your comment. The Committee believes the recommendation as edited does not require amendment.
Northern England Strategic Clinical Network	Short	5	13 - 16	This replicates some of the information in section 1.2.4, but without the caveat of conveying uncertainty. One respondent would suggest removing it. The second part of section 1.2.5 also repeats some of this information, and it does not need to be linked to the first part.	Thank you for your comment. The Committee's intention is to first ensure that a discussion takes place with the dying person, recommendation 1.2.4 that you refer to covers the provision of information and further opportunities for discussion and recommendation 1.2.5 seeks to ensure that any pre-articulated goals and wishes of the dying person are considered. The committee sees all the elements described in each recommendation as a key to the communication process.
Northern England Strategic	Short	5	18	Can be challenging in practice - difficulties have arisen around identifying most appropriate professional to explain prognosis due to length of	Thank you for your comment. The Committee has recommended that the most appropriate and available healthcare professional should be

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Clinical Network				time professional has been involved with patient and knowing what has been said previously (if not documented), as per 1.3.6 pg. 7. (transfers from other areas)	identified to lead these discussions. This was thought to be best practice, given that the multiprofessional team would vary according to patient need, setting of care and across Trusts. The committee feel it important to recognize that the most appropriate person may be the person with the most experience of having these conversations. This does not always equate to seniority Please note, however, that it has also been recommended that the multiprofessional team should be supported by experienced staff at all times and have the ability to seek further specialist advice if additional support is required. The committee has also recommended that care planning be shared, not only with the dying person and those important to them, but also, all members of the multiprofessional care team.
Northern England Strategic Clinical Network	Short	5 - 8	All	We are concerned that this recommendation implies that communication begins when dying is recognised. Most of the guidance is appropriate from the time of palliative diagnosis; and to facilitate a "good death," beginning advance care planning at the earliest possible time is crucial. Respondents said that although the communication elements are good, most of these elements need to be discussed much earlier in the patient journey. Cumbria locality has a 'Deciding Right' (Advance Care Planning) facilitator who educates the general public, professionals, patients and families in	Thank you for your comment. The guideline covers the clinical care of adults who are in the last few days of life (defined as last 2 to 3 days). The Committee believes it's important to recommend these standards for communication and shared decision making in an effort to ensure that healthcare teams in all settings, maintain an individualised approach to care of the dying person and prioritise the person's goals, wishes and needs, They acknowledge that this this process should ideally be undertaken before the last few days of life but are unable to comment beyond making

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				advance care planning; and a Six Steps to success facilitator who delivers an End of Life Care Programme for care homes and domiciliary care. This at times is well received, but has been challenging to embed in practice. Embedding this into practice will remain an ongoing task.	reference to any pre-defined advance statements or advanced decisions to refuse treatment.
Northern England Strategic Clinical Network	Full	111	5	Important to emphasise that even if a person lacks capacity, they may still be able to express an opinion.	Thank you for your comment. The recommendations support the prioritisation of the goals and wishes of the dying person and encourage healthcare professionals to remain mindful of this during the delivery of end of life care.
Northern England Strategic Clinical Network	Full	135	Recommendation 21	Add here: if the dying person is lacks capacity to engage in shared decision-making, then their known views must be taken into account by a transparent 'best interests process' as described by the Mental Capacity Act.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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Northern England Strategic Clinical Network	Full	136		Suggest MCA terminology: Advance decisions	Thank you for your comment. The Committee has drafted a recommendation that encourages healthcare professionals, as part of any shared decision-making process to take into account whether the dying person has an advance statement or advance decision in place. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Northern England Strategic Clinical Network	Full	136	Table para 2	Add here: if the dying person is lacks capacity to engage in shared decision-making, then their known views must be taken into account by a transparent 'best interests process' as described by the Mental Capacity Act.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Northern	Full	136	Table	Add at end: and with whom.	Thank you for your comment. This has been

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England Strategic Clinical Network			para 4	It is important that the records show who participated in decision-making, and also with whom any information has been shared.	expanded on within the 'Linking evidence to recommendations' section of the chapter. (please see section 7.6)
Northern England Strategic Clinical Network	Full	110	Para 4	No recommendation made about comms skills. This is a pity, because finding resources to train staff will only happen if there is leverage e.g. via a NICE recommendation.	NICE is currently developing guidance in palliative care service delivery and the issue of education and training may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Northern England Strategic Clinical Network	Full	111	19	Spelling mistake – OURS should read HOURS	Thank you for your comment. This has been amended.
Northern England Strategic Clinical Network	Full	111	21	This would be a 'best interests process' decision as described by the Mental Capacity Act. As soon as/if the patient recovers capacity, their choice overrides a decision made on their behalf.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting

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					decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Northern England Strategic Clinical Network	Full	111	34	Enduring power of attorney is an old term and only relevant for dealing with financial matters. Need to identify if there is a Lasting Power of Attorney for Health and Welfare decisions, if discussing health related decisions, and whether the LPA (H&W) has specific power for potentially life-limiting decisions if end of life discussions are at play.	Thank you for your comment. This has been amended to read as follows: They may have appointed someone to have an Enduring Power of Attorney (which would only be valid if made before 1st October 2007), or a Lasting Power of Attorney for personal welfare which came into effect after the introduction of the Mental capacity act in 2005. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Northern England Strategic Clinical Network	Full	111	5	Where a patient lacks capacity, any decision made must be reached in compliance with the Mental Capacity Act. Easy guides to ensure compliance and to record decisions, including Emergency Healthcare Plans and DNACPR orders, assessment of capacity, and the process/discussion by which decisions were reached are available e.g. Deciding Right (http://www.nescn.nhs.uk/common-themes/deciding-right/).	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area.

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					Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Northern England Strategic Clinical Network	Full	118		Diagram – there are 2 boxes both containing 'Denial about prognosis' – should one be deleted or contain different information?	Thank you this has been amended.
Northern England Strategic Clinical Network	Short	7	18-26	Suggest that you make clear that MDT opinion may be via telephone discussion with relevant colleagues, as several of our commentators interpreted this guidance as convening a meeting of relevant professionals which is impossible at short notice and/or out of hours, particularly in a community setting.	Thank you for your comment. We agree and detail has been added to the 'Linking evidence to recommendations' section of the full guideline to clarify this.
Northern England Strategic Clinical	Short	8	9	There is a resource implication here: many areas do not have 24 hour, 7 day access to specialist palliative care advice.	Thank you for your comment. This has been recognised and is discussed in the full version, 'Linking evidence to recommendations' section. NICE is currently developing guidance in palliative

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Network					care service delivery and the issue of staff resourcing may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Northern England Strategic Clinical Network	Short	general	general	Mental Capacity Act. Almost all people lose capacity for personal decision-making as death approaches. Under these circumstances, the MCA applies to decisions about their care. Is it worth including a brief reminder at the beginning of the Guideline in both full and short formats, to remind clinicians that they are obliged by Law to follow a best interests process that: • Ascertains treatment possibilities from someone who has appropriate expertise (so may need to speak to a colleague or have an urgent review of the patient by e.g. cardiologist, palliative care clinician, neurologist etc) • Consults the patient (who may be able to express an opinion even if lacking capacity for a decision) and others who can express the patient's known wishes; • Avoids making assumptions on the basis of presumed quality of life or other factors of the patient's appearance (and this clause is of vital importance to the Disability Rights lobby) • Ensures that no-one is motivated by a desire to	Thank you for your comment. Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We have made amendments to a number of recommendations to clarify that the important information of relevance from an advance care planning process includes; advance statement,

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				bring about the death of the patient? (So especially applies to this specific NICE guideline) • Considers any previously-expressed wishes, feelings, beliefs and values, whether or not in writing • Considers the option that is 'least restrictive' to the individual. This is quite a challenge: for example, if s/he wishes to die at home but is currently in ICU, the process must discuss whether remaining in hospital yet alive or leaving hospital yet dying is less restrictive. • Takes into account any family bonds or personal responsibilities that the patient would consider The process and decision must then be recorded, including names of all involved. This is not as time-consuming as it sounds; mostly it is formalising and recording conversations that take place anyway. The accurate recording is particularly helpful when the infamous 'granddaughter from abroad' arrives and challenges either the decisions, the grounds on which they were made or the level of patient advocacy involved, or whenever a query or even a complaint arises flowing the death.	advance decision to refuse treatment and lasting power of attorney for health and welfare.
Northern England Strategic Clinical	Full	152	Other cons para 1	'hypocalcaemia' = typo, should read 'hypercalcaemia'	Thank you for your comment. This has been amended.

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Northern England Strategic Clinical Network	Full	153	Para 3	Re: management of hydration: Is it worth noting that the presence of an enteral tube does not oblige a caring team to provide enteral fluids unless these are requested by the patient and/or agreed to be appropriate/in the patient's best interests?	Thank you for your comment. The Committee have considered your suggestion, but feel that it is providing too much detail.
Northern England Strategic Clinical Network	Full	154	Para 5	We have to ask ourselves whether provision of hydration simply to satisfy concerns of family is ethical practice. For example, you are querying the use of anticholinergic agents for 'death rattle' in other parts of the guideline, on the basis that the treatment is not for the patient but for the onlookers.	Thank you for your comment. The order of the recommendations reflects the Committee's decision that the dying person should be supported to drink by oral means first if they wish and are able to before clinically assisted hydration is considered. The decision to consider a trial of clinically assisted hydration should be based on an individualised approach taking into account benefits and harms.
Northern England Strategic Clinical Network	Short	8	23	Suggest that you include artificial saliva/gels.	Thank you for your comment. The Committee did discuss the use of artificial saliva, , however, a recommendation wasn't made because this topic wasn't formally included in the scope of the guideline. This is further discussed in the full guideline, 'Linking evidence to recommendations' statement in section 8.6.
Northern England Strategic Clinical Network	Short	8-10	All	Most of our respondents felt maintaining hydration section to support professionals and families is very well written. We draw the GDG's attention back to our reservations about offering sc fluids to comfort family rather than patient, which is discussed in full document but not repeated here. One respondent expressed concern that there is 'no	Thank you for your comment. The Committee intend this recommendation to apply to all settings and are aware that clinically assisted hydration may take place in the community, but note that there may be challenges to its implementation. Further detail has been added to the 'Linking evidence to recommendations' section of the full

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				robust guidance for sc fluids in the community.' It may therefore be worth explicitly mentioning community care here.	guideline. NICE is currently developing guidance in palliative care service delivery and this issue may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Northern England Strategic Clinical Network	Full		Other cons para 2	'…sedative drugs given for pain relief or seizure control…' This sentence must be rephrased to avoid giving the false impression that pain relief is always associated with sedation.	Thank you this has been amended.
Northern England Strategic Clinical Network	Full	15	general	Seeking correctible causes of some symptoms: whilst finding and treating the cause may be desirable in some circumstances, where investigations are difficult e.g. when at home, time should not be lost awaiting investigations. Treatment of distress is priority.	Thank you for your comment. We agree these recommendations are intended for an individualised approach to maximise the comfort and safety of the dying person.
Northern England Strategic Clinical Network	Full	161	Other cons para 1	'reassurance.' Reassurance seems to be the wrong word here. Perhaps providing company, companionship, information about what to expect - but reassurance is not possible, or suggests 'false optimism' as referred to elsewhere in this draft guideline.	Thank you this has been amended,
Northern England	Full	162	Para 1	'… match choice of medication to the severity **and cause** of pain.'	Thank you this has been amended,

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Strategic Clinical Network				One of the principles of palliative care is to manage causes of symptoms; for example, use of opioids for colic would be naïve and less helpful than recognising and managing colic appropriately.	
Northern England Strategic Clinical Network	Full	162	Para 2	Use of diamorphine. This needs better explanation, e.g. 'when a large dose is required, the greater solubility of diamorphine reduces the volume to be injected subcutaneously (more comfortable) or to be swallowed (less effort).'	Thank you this has been amended,
Northern England Strategic Clinical Network	Full	162	Para 7	'specialists in pain and symptom control' will avoid the cross-referrals, muddle and/or delay that arise in hospitals when referrals are made to either/or/neither of pain management services and palliative care teams.	Thank you for your comment. After consideration the Committee felt no change was required.
Northern England Strategic Clinical Network	Full	163		Many respondents felt this lacked clarity. Fentanyl IS an opioid. Suggest 'opioids not requiring renal clearance, e.g. fentanyl group.' Many renal units avoid diamorphine and other opioids where toxic accumulation of soluble metabolites can occur as renal function diminishes and/or dialysis is reduced/interrupted by illness.	Thank you for your comment, this has been amended,
Northern England Strategic Clinical Network	Full	174	Para 1	Seven day availability of order and supply of oxygen is an important point, and could be supported by a recommendation that localities ensure that oxygen can be made available 24/7.	Thank you for your comment. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-

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					cgwave0799.
Northern England Strategic Clinical Network	Full	176	13	…sedation, which is a common side-effect of ***some*** anti-emetics … Add 'some.' Remember that statements like this, that can be interpreted appropriately by specialists, may lead to public mistrust of the whole class of drugs. See overarching comments about use of the Guideline as a vehicle for education.	Thank you for your comment. This has been amended.
Northern England Strategic Clinical Network	Full	18 213 & 214	12	Should a clinician wait until 'more than 2 or 3 prn doses' of a drug are given in a 24hour period – this could mean that a CSCI is not started until the patient has had 4 prn doses in 24hours. Perhaps it could state that a CSCI of medication should usually be prescribed if a patient has needed 2 or more prn doses in 12 hours.	Thank you for your comment. After careful consideration the Committee feel that no change is required.
Northern England Strategic Clinical Network	Full	18	2, and then throughout document	Possibility that cyclizine may significantly exacerbate heart failure: although this is physiologically possible, is it a problem in clinical practice? Naming it in the guideline is likely to reduce its use when management of nausea is a clinical priority, even in the presence of heart failure.	Thank you for your comment. The Committee noted that the summary of product characteristics from the manufacturer of cyclizine gives the following special warning and precaution for use. The Committee discussed that it was important that clinicians were aware of this advice, but was aware of the lack of evidence regarding the efficacy and harms of cyclizine in the end of life setting and therefore was unable to make any specific recommendations in this regard. Further detail has been added to the 'Linking evidence to recommendations' section in the full guideline (9.13).

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Northern England Strategic Clinical Network	Full	182		Recommendation 43 to use hyoscine butyl bromide first line. At recent advanced course in pain and symptom management a review of the evidence suggests octreotide first line and butylbromide second line (ask Andrew Wilcock for the evidence)	Thank you for your comment. As stated in the full guideline: As there was no clear evidence that octreotide was the more clinically effective option, yet it was considerably more expensive, the Committee decided to recommend its use only for when hyoscine butylbromide produced ineffective results.
Northern England Strategic Clinical Network	Full	182 - 3	Table Trade off	What is the evidence that patients would consider sedation to be a benefit? The Neuberger Report takes the view that sedation was usually unwanted in the opinion of complainants. There is ambivalence in the commentary about whether unintended sedation is a harm or a benefit. This needs to be addressed.	Thank you for your comment. This has been amended.
Northern England Strategic Clinical Network	Full	183	Table: Other cons	This is, as you have stated, opinion of the GDG rather than evidence. With all respect, if opinion is to be used in place of evidence, then at least specialist opinion should be used as a 'clinical reference group.' Evidence from other areas is available and can be readily interpreted for palliative and end of life care. Using a receptor-based prescribing protocol, and using the evidence that the drug's binding to its receptor predicts its efficacy (no evidence in end of life patients; lots in fit sailor and aviators, in chemotherapy-induced n&v; PONV; etc.), then the causes of emesis in the last days of life are most frequently those ascribed to the Vomiting Centre and therefore most likely to respond to anti-H1, anti-	Thank you for your comment. We are following standard methodology as stated in the NICE methods manual : https://www.nice.org.uk/media/default/about/what-we-do/our-programmes/developing-nice-guidelines-the-manual.pdf The recommendations are based on evidence review unless in the absence of evidence, expert opinion of the Committee is sought and consensus recommendations made.

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				cholinergic or possibly anti 5HT2 receptors. Of these choices, anti-H1 are the least sedative i.e. cyclizine, and should be the drug of first choice in EoL Guidelines unless a clear cause of emesis unrelated to the VC has been diagnosed e.g. uraemia; recent chemotherapy; hypercalcaemia.	
Northern England Strategic Clinical Network	Full	184	Para 1	Nasogastric tubes are intrusive, stimulate nausea via pharyngeal touch, and may only reduce intermittent vomiting at the expense of causing continuous nausea if no anti-emetic is used. There is a small place for NG suction as an active treatment to empty the stomach in terminal restlessness related to gastroparesis; this (in clinical specialist experience) is effective in avoiding distressing terminal regurgitation/vomiting, but is a rare necessity.	Thank you for your comment. We have added additional detail to this Chapter (please see section 9.13).
Northern England Strategic Clinical Network	Full	184	Para 5	'The GDG acknowledged that some people may benefit and prefer a drug with a sedative side effect. They also highlighted the importance of making the dying person and those important to them aware that the level of consciousness in a dying person can naturally alter in the last days of life independent of medication. ' This is a very important point; there is little public knowledge, experience or understanding of the winding-down process involved in normal dying, leading to wide misbelief that people are 'sedated' by their doctors, or even 'helped to die.' In any re-draft, please retain this important point.	Thank you for your comment.

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Northern England Strategic Clinical Network	Full	188	3	This is a vital part of EoL decision-making and is widely misunderstood. Perhaps it is worth the GDG including an over-arching paragraph about making decisions when a patient lacks capacity, with reference to the MCA and the practicalities of good decision-making and good note-keeping, including: - use of MCA1 as a quick record of establishing capacity or lack of, when a major decision is to be made - use of MCA2 as a quick clinical record of the process of reaching a specific best-interests decision (e.g. to offer a drug that may have sedative side effects; to proceed with/withhold artificial hydration) and a guide to best-interests process - ensuring clarity throughout the Guideline that discussion with loved ones during a best-interests discussion is in order to represent the views of the patient, and not either to ask the loved ones to make the clinical decision, or to ask them what they would want at this point - further, ensuring clarity throughout the Guideline that asking loved ones to represent the known wishes of a patient during a best-interests discussion is in distinction to the separate but important consideration of care for the loved ones, and understanding their viewpoint, particularly if a best-interests decision conflicts with the loved-one's own preferred view	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Northern	Full	204	19	Glycopyrronium ***bromide not pyronium***	Thank you for your comment. This has been

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England Strategic Clinical Network					amended.
Northern England Strategic Clinical Network	Full	210	Para 3	4-hourly monitoring: This has resource implications in community: consider over-arching comment on availability of resources to deliver adequate care and monitoring in the patient's preferred place.	Thank you for your comment. We agree and have added in "depending on setting".
Northern England Strategic Clinical Network	Full	223	17	for each group, say 'e.g.' before examples to avoid unintended suggestion that, for example, only morphine or diamorphine should be used in EoL care.	Thank you. This has been amended.
Northern England Strategic Clinical Network	Full	238	Table	Hospital admission cost: This takes no account of length of stay. Is it appropriate to assume only one night? Also, stay would come via Admissions Suite or A&E in many hospitals where direct admission to a ward is no longer permitted, with higher unit costs. Thus, the cost of a single GP visit that ends in admission is far higher than the calculation shown here.	Thank you for your comment. The costs provided are meant to provide some reference to the Committee when making recommendations and considering additional costs. The NHS reference cost of an admission represents the cost of a single episode (we have clarified this in the table) and it is based on the average length of stay for that episode; therefore the cost is not for a single day of admission. The GP cost also reflects an individual who just needs the prescribed medication to relief their symptoms and therefore they may not necessarily be admitted.
Northern Engla	Full	239	Rec 63	For nausea and vomiting, and possibly also for pain, add 'consider most likely triggers and prescribe appropriately' (e.g. painful colic is not	Thank you for your comment. The Committee have made a number of recommendations that require the assessment of likely cause to inform prescribing.

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nd Strategic Clinical Network				best treated with opioids; gastric stasis is not best treated with haloperidol; uraemic nausea is not best treated with cyclizine). Tables of drug recommendations also require modification to consider triggers to symptoms --> best therapeutic options.	We have carefully considered the wording of the recommendation and feel that no change is required.
Northern England Strategic Clinical Network	Full	240	10	'…when the dying person is actively having symptoms that could be managed, requiring hospital admissions…' suggest re-phrasing as 'possibly leading to unwanted hospital admission'	Thank you for your comment. We have carefully considered the wording of the recommendation and feel that no change is required
Northern England Strategic Clinical Network	Full	240	Trade-off	Anticipatory prescribing is not only a community issue: for people already dying in hospital, anticipatory prescribing allows the medical team that knows the patient to prescribe appropriately in-hours, and also reduces delays in getting both the drugs and a prescriber to the patient when symptoms arise.	Thank you. We have added your suggested detail to the relevant section of the full guideline.
Northern England Strategic Clinical Network	Full	241	general	Address inconsistencies between identifying a 'lead clinician' who may or may not be a doctor (the word 'physician' is used in penultimate para on p241	Thank you. This has been amended.
Northern England Strategic Clinical	Full	241	Last para	…avoid situations where a person is experiencing unmet pain control. Suggest you say ***symptom*** control: nausea, breathlessness and anxiety can be equally as	Thank you. This has been amended.

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Network				distressing as pain to patient and loved ones.	
Northern England Strategic Clinical Network	Full	241	Other cons para 2 and general	One big Trust responded to say that draft Guidance suggests that anticipatory prescribing proforma is not recommended however audit evidence in that Trust (with an electronic order set) suggests that this does not lead to over prescribing and ensures safe prescribing, adjustment to patient need, and good symptom management. They would not wish to lose this service improvement, and the current draft guidelines suggest that they should abandon this practice.	Thank you for your comment. This guideline recommends an individualised approach to anticipatory prescribing. It is a reminder that even if a prescribing proforma exists, extreme care should be taken to ensure that only the tailored medications are prescribed based on individual need. We are keen to avoid a blanket approach to prescribing when the person may not have or ever have the symptoms.
Northern England Strategic Clinical Network	Full	243	16-21	Ethical implications here: if symptoms can be anticipated, is it ethical not to prescribe for them? I wouldn't advise a member of my family to agree to participate in such a randomised study!	Thank you for your comment. The proposed trial is comparing anticipatory prescribing to reactive prescribing and is not intended to withhold treatment from anyone.
Northern England Strategic Clinical Network	Full	243	Table	…for example, reassurance, dark towels in haemorrhage … would 'calming presence' be a better description than 'reassurance' here?	Thank you for your comment. This has been amended.
Northern England Strategic Clinical Network	Full	General		Use 'opioid' rather than 'opiate' throughout. Currently there is a mixture of terms.	Thank you, we will change opiate to opioid throughout the guideline.
Northern England Strategic	Short	11	9	We are unaware of evidence to support this statement, and we frequently palliate symptoms of end-stage heart failure leading to e.g. distended liver	Thank you for your comment. The Committee noted that the summary of product characteristics from the manufacturer of cyclizine gives the following special

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Clinical Network				causing nausea, using cyclizine. Particularly at the end of life, unless cyclizine is known to cause pulmonary oedema, there is no basis for this caution.	warning and precaution for use: Cyclizine should be used with caution in patients with severe heart failure or acute myocardial infarction. In such patients, cyclizine may cause a fall in cardiac output associated with increases in heart rate, mean arterial pressure and pulmonary wedge pressure. The Committee discussed that it was important that clinicians were aware of this advice, but was aware of the lack of evidence regarding the efficacy and harms of cyclizine in the end of life setting and therefore was unable to make any specific recommendations in this regard. Further detail has been added to the 'Linking evidence to recommendations' section in the full guideline (please see section 9.13).
Northern England Strategic Clinical Network	Short	12	23-25	Several respondents disagreed with 1.5.16 "do not routinely start oxygen/only us if…" because, in their experience, some people find it helps and, in the dying, we don't want a potentially helpful intervention to be denied. Suggest rephrase positively as "consider oxygen for patients with hypoxaemia, but reassess whether this is beneficial". However, we recognise that this is at variance with your evidence review in the Full Guideline.	Thank you for your comment. As you state, this recommendation reflects the evidence identified and the Committee feel no change is required. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (please see section 9.5).
Northern England Strategic Clinical	Short	12 13	26 1-3	Can be streamlined into "consider a benzodiazepine and/or an opioid".	Thank you for your comment. The order of bullets reflect the evidence identified and therefore recommends an opioid, a benzodiazepine and then a combination of the two. The group felt no change

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Network					was required.
Northern England Strategic Clinical Network	Short	12	4	Suggest include non-pharmacological measures e.g. heat packs, massage	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Northern England Strategic Clinical Network	Short	13	16-17	Reference/reminder about non-pharmacological treatments is helpful.	Thank you for your comment.
Northern England Strategic Clinical Network	Short	14 15	21-25 1-2	We agree it is important to highlight this.	Thank you for your comment.
Northern England Strategic Clinical Network	Short	15	3-5	Expansion on these maybe helpful.	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail

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					can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Northern England Strategic Clinical Network	Short	16	15	Use of dose ranges – there is marked differences between areas in delivering EoLC. Some prescribe ranges to allow for prompt titration, whereas other areas do not, requiring authorisation from doctors to increase doses. Specific recommendation on the safety/desirability of prescribing dose ranges would be appreciated.	Thank you for your comment. Given the paucity of evidence we are unable to prescribe doses/ranges. The Committee did not feel able to comment on the issues you outline. We recognize the tension between the need for prompt titration but also recognize that in some circumstances, ranges being made available might encourage an automatic increase in dose rather than prompt a re-assessment of an individual and the consideration of the wider picture. The Committee made a recommendation that prompts care givers to seek specialist advice promptly if symptoms are not controlled with current medication (please see recommendation 1.5.9)
Northern England Strategic Clinical Network	Short	16 to 17	1 2	One respondent expressed concern about the prescribing examples and guidance: that the suggestions will become prescriptive and there will be error in prescribing. See also comment 5	Thank you for your comments on the prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Northern England Strategic Clinical Network	Short	16 to 17	12	Many respondents wondered whether, rather than making specific recommendations about particular drugs, doses, routes and titration plans, the NICE guideline should ask localities to ensure adherence to local prescribing guidance. See also comment 5	Thank you for your comment. NICE guidance is evidence based and should inform local policy and decision making.
Northern England Strategic Clinical Network	Short	16 to 17	12	References are made to valid pain assessments not specified.	Thank you for your comment. Additional detail has been added to the full version of the guideline 'Linking evidence to recommendations' section in chapter 9. As no specific evidence review was undertaken, we are unable to give detail in the recommendation.
Northern England Strategic Clinical Network	Short	Appendix A	general	It may be helpful to have some specific recommendations for symptom management in patients with renal failure, in particular opioid recommendations.	Thank you for your comment. An evidence review undertaken during this guideline did not identify any evidence for choice of opioids in patients with renal failure in the last days of life. The Committee agreed that this is a difficult clinical issue but felt unable to make a specific recommendation given the paucity of evidence. In the introduction to this section it is suggested that specialist advice should be sought if there are uncertainties including renal impairment. Additionally, because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This

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					important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Full	212	Rec 56	'for example prescribing cyclizine to manage nausea and vomiting may exacerbate heart failure' Is there evidence that this is a clinical problem, rather than a hypothetical problem based on assumptions about mechanisms of action? Nausea triggered by oedematous organomegaly in heart failure would be best palliated via reduction of autonomic afferent stimulation of the vomiting centre in the brainstem, and cyclizine would be the drug of first choice as the highest binding and least sedative. Casual reference to this possible side effect of cyclizine will mitigate against good symptom management for people with heart failure who experience nausea.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Full	215	26	Worth noting that symptoms can recur whilst awaiting re-siting of iv access; even in hospital setting, when comfort is of paramount importance, writing up sc route for back-up, or transferring entirely to sc administration, will help to avoid loss of symptom control if iv route is lost.	Thank you for your comment. This text has now been removed from the guideline. However, **b**ecause of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, the prescribing tables are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee and will be made available on the NICE website. ..
Northern	Full	216	11	These starting doses assume that the patient is	Thank you for your comment on the prescribing

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England Strategic Clinical Network				naive to this drug; if the patient is already taking the drug (or an equivalent medication) then their starting dose may be higher. Seek help if uncertain.	tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Full	217		Is there a continuous subcutaneous infusion of Ibuprofen available as stated on table, even under specialist guidance? Diclofenac rarely used even by specialists and it is questionable they should be recommended especially as diclofenac can cause tissue necrosis. Ibuprofen subcut is not even available	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Full	217	Note A	Generally, assume a laxative will be necessary, rather than complicating EoL care with constipation.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Full	217	Opioids	'Consider increasing dose up to the maximum dose of the medication if the dying person is still in pain.' This sounds like a recommendation to 'go large' rather than to titrate. Needs rewording.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Full	217	table	Some services expressed concern that the starting dose of opioid for opioid naïve patients is lower than they would normally recommend and lower than recommendations in several major national guidelines. This led to further concerns about inconsistency amongst national guidelines and responsibility for keeping the NICE Guidelines current.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Northern England Strategic Clinical Network	Full	218	midazolam	1. half-life of midazolam is v short so qds subling or sc 2-4h may be too widely spaced. 2. Do not recommend iv use of midazolam outside an ICU setting; it has delayed onset of effect and can cause resp depression.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Full	218	table	Specialist teams expressed concern over use of NSAIDs at end of life	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical	Full	219	table	It would be helpful to group by indication, e.g. haloperidol as first line with CTZ stimulation (uraemia; hypercalcaemia); cyclizine as first line for VC stimulation (raised Intra-cranial pressure;	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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Network				retropharyngeal tumours; bulky intra-abdominal or pelvic disease); domperidone/ metoclopramide as prokinetic agents if large vomits with little nausea, when small bowel is not thought to be obstructed, etc.; anticholinergics (which are omitted from this table) for vestibular causes. Also requires an overarching comment about reducing triggers to nausea if timely and appropriate. Second line should be to reconsider the triggers to nausea and consider adding an anti-emetic that works a different way. This point is not easily made from this table of recommendations. Although there are no data from studies at the end of life, there are data that indicate that receptor-based prescribing of anti-emetics is more effective than e.g. metoclopramide for every cause of nausea in humans (e.g. aero-nautical industry; chemo-induced emesis). The evidence that levo is anti-emetic at CTZ is lacking; it may be rather that its sedative effect prevents expression of nausea at higher doses, although it should be a (weaker than cyclizine) anti-emetic at the VC. Suggest re-drafting of guidance for N&V, co-opting specialist advice if necessary.	being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Northern England Strategic Clinical Network	Full	220	Anxiety	Be aware that long half-life of diazepam may lead to accumulation: once-daily dosing should be sufficient.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Full	222	table	PCF4 guidance is to give Glycopyrronium 200 microg prn, not 400 microg prn as stated here; another example of clash with national recognised guidelines	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Full	general	general	Local respondents felt concern that the prescribing guidance is complicated and unclear. Numerous drugs are suggested with unclear guidance. Some suggested it may be better to say "evidence is poor but we would recommend…. X,y,z" Make it clear and	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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				succinct.	implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Full	general	general	Local specialists said prescribing guidance too complicated for generalists. More specialist knowledge required to use especially anti emetics section. Is this really for generalists or for specialists to use in the creation of more succinct guidance?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	25 26	10-32 1-4	Respondents thought that, although important to have these caveats, most non specialists will not feel able to make some of these nuanced decisions (eg licensed versus non licensed/ syringe driver compatibilities etc.) and as such may find the guidance not very helpful/ user friendly.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be

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					made available on the NICE website.
Northern England Strategic Clinical Network	Short	27	2	The use of Diclofenac and Ibuprofen po, sc or CSCI/24 hours is an unusual choice to use at EoL – due to risk the adverse effects such as bleeding and necrosis over injection site (PCF5). Since most regions have their own guidelines, would it be more practical to guide practitioners to their local guidelines. And also refer to PCF5 as a resource See also comment 5	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	27	Pain	Our respondents would not recommend the routine use of subcut NSAIDs or IV paracetamol to non-specialists. .	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic	Short	27	Table	There is no guidance on opioid switching (either what it means or its indications for use).	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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Clinical Network					symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	27	Table	In (a) there is neither guidance on which laxative or which antiemetic treatment to use.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	27	Table	I am not sure that (c) is clarifying or confusing	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This

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					important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	short	27	table	Our respondents think that your suggested starting doses of opioids are too low for most patients. This may lead to inadequate symptom control. Suggest increase, with a footnote to consider lower doses in frail elderly.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	27	Table 1	Opioids section: "Consider increasing dose up to the maximum dose" – perhaps needs changing to "consider titrating up dose" and including something about there being no ceiling dose/dose should be titrated to that which manages the pain and does not cause undue side effects. Beware stating 'increase dose to maximum dose' without qualifying by saying 'titration' 'in steps of 20-30% day, evaluating after each dose increase' or 'by taking effects of prn doses into account.'	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern	Short	27	Table	• concerns over the use of introducing things	Thank you for your comment on the prescribing

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England Strategic Clinical Network			s 1-6	like NSAID if we are addressing care in the last days of life - does this require clearer guidance; • mentioning IV route in the guidelines could make this an acceptable route of administration, whereas SC is the route of choice in last days of life; • no reference made to practitioners accessing Local Guidelines re the medication type used in various regions; • the timings of giving prn medications e.g. 2-4 hourly Morphine & Midazolam, Hyoscine butylbromide given 6-8 hourly;	tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	27-33	tables	Our network would not support recommendation of iv route at end of life, because of symptom escape if iv line is lost; only appropriate location for iv drugs in ICU settings.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical	Short	27-33	tables	A community locality that relies on primary care almost entirely, commented: These tables are all very messy and potentially dangerous in the wrong hands. I can imagine non-specialists not being	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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Network				helped by this table.	being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	short	28	table	Our respondents think that your suggested minimum prn dose interval for opioids is too long. This may lead to inadequate symptom control. Suggest hourly prn.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	28	table	Our respondents would not recommend the routine use of rectal diazepam or IV midazolam for breathlessness, and would argue that this is not helpful and potentially irrelevant for most non specialists. The long half-life of diazepam in someone who is in the last few days of life is unsafe too; we would prefer recommendation of something a little more short acting.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain

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					targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	28	table	subcut clonazepam is no longer available.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	28 - 31	table	Unsafe to use iv midazolam outside setting that can manage airway: clearly not desirable at EoL. SC route entirely acceptable; buccal if circulatory failure means non-absorption from skin.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England	Short	30	table	Our respondents regret the lack of guidance on which antiemetic to use in which circumstances: they	Thank you for your comment on the prescribing tables. Because of the recognised importance of

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Strategic Clinical Network				advocate a scenario/receptor-based prescribing protocol.	supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	30	table	Could include a comment on choice of anti-emetic and matching this to mechanism of nausea/vomiting if this is known or suspected	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	30	table	Include warning about the use of the antidopaminergic drugs in Parkinson's and related disorders as well as checking for extrapyramidal side effects.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently,

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					they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	30	table	The dose limits of levomepromazine are lower than those recommended in the PCF or BNF.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	31	table	Our respondents think that your suggested minimum prn dose interval for sc midazolam is too long. Longer interval may result in uncontrolled anxiety/agitation.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Northern England Strategic Clinical Network	Short	31	table	A word on extrapyramidal side effects would be vital.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Northern England Strategic Clinical Network	Short	Additional		We note that there is no discussion around use of midazolam for any indication other than anxiety or breathlessness, and its use is limited to relatively low doses. The guidance "does not discuss palliative sedation as this is not part of its scope". We presume that the reason for this is to avoid the risk of deep sedation being used without critical thought, and this makes sense. In addition, the first thing we would hope would be done for an agitated patient would be treating the underlying symptoms as above. However, we think the guideline should at least acknowledge that use of higher doses of these drugs may be reasonable or necessary in certain circumstances, even if just to include a section saying "refractory agitation, which persists despite control of existing symptoms and management of	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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				reversible causes, may require use of higher doses of midazolam (sometimes up to XXmg) or levomepromazine (sometimes up to XXmg). Seek specialist advice if needed." This will at least lay a foundation for involvement of specialist palliative care in this symptom, and highlight that further options exist.	
Northern England Strategic Clinical Network	Short	General	All	Some respondents in our Network felt that in relation to the short version, the guidelines were easy to follow and to understand. Others felt that generalists would struggle to follow the prescribing instructions.	Thank you for your comment. We are pleased that some members four the guidelines easy to follow. Regrading the prescribing tables, because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	18	11	Consider life-limiting rather than chronic.	Thank you for your comment. The Committee has reviewed this and believe the text is clear as is currently edited.
Nottingham	Short	19	23	Typo does not dos	Thank you for your comment. This has been amended.

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University Hospitals NHS Trust					
Nottingham University Hospitals NHS Trust	Short	10	21	Make it clear that discussion with dying patients should be done 'where feasible' recognising that they may not be able to take part in discussions due to their clinical condition.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Nottingham University Hospitals NHS Trust	Short	6	4	Typo pPlan should be Plan.	Thank you for your comment. This has been amended.
Nottingham	Short	6	15	Consider adding seek specialist advice.	Thank you for your comment. This recommendation has now been removed although discussion on this

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University Hospitals NHS Trust					issue remains in the Linking evidence to recommendations section of chapter 6.
Nottingham University Hospitals NHS Trust	Short	7	7	Clarify what contact details you are recommending, secretary's phone number, ward extension number or personal mobile.	Thank you for your comment.The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section.
Nottingham University Hospitals NHS Trust	Short	15	9	Add the recommendation to assess the effectiveness of the medication after one hour.	Thank you for your comment. We state that review should be at least 12 hours which reflects the evidence considered in this area. This does not preclude more frequent monitoring.
Nottingham University Hospitals NHS Trust	Short	11	15	It would be preferable to state avoid intramuscular and intravenous routes and be clear in the guidance that the subcutaneous route for medication is preferred.	Thank you for your comment. After careful consideration the Committee feel that no change is required as this should always be an individualised choice.
Nottingham University Hospitals NHS	Short	12	17	Add talk to the relatives/loved ones to help understand the patients pain behaviour.	Thank you for your comment. Your point is covered within the 'Linking evidence to recommendations' section of the full guideline (please see section 9.5).

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Trust					
Nottingham University Hospitals NHS Trust	Short	12	20	Add e.g. fan therapy.	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Nottingham University Hospitals NHS Trust	Short	12	9	There is more to pain management than prescribing therefore in line with the rest of the guidance make it clear here that non pharmacological interventions e.g. repositioning, need to be considered alongside any prescribing decisions.	Thank you for your comment. We agree and have added an additional recommendation on non-pharmacological management of pain.
Nottingham University Hospitals NHS Trust	Short	13	17	Give some guidance on the non-pharmacological methods for treating nausea that you have in mind e.g. acupuncture acupressure, sea bands etc.	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.

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Nottingham University Hospitals NHS Trust	Short	14	12	Add nicotine withdrawal.	Thank you. We have listed examples here and are aware that others also exist and expect healthcare professionals to use clinical judgment to explore these.
Nottingham University Hospitals NHS Trust	Short	14	24	Use and not or.	Thank you for your comment. After careful consideration, the Committee did not feel any amendment was necessary.
Nottingham University Hospitals NHS Trust	Short	15	5	Clarify the non-drug measures e.g. repositioning, give some guidance on the use of suction.	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Nottingham University Hospitals NHS Trust	Short	15	6	State that if the patient has an iv infusion; consider discontinuing if the burdens are outweighing the benefits.	Thank you for your comment. Further discussion on this issue can be found in Chapter 9 of the full guideline.

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Nottingham University Hospitals NHS Trust	Short Appendices	296	2	Palliative Care Formulary (PCF4) has been used inappropriately as a reference. This is out of date, the Palliative Care Formulary 5th edition (PCF5) was published in 2014. It is also inappropriate to use it as a cost reference as all information comes from the BNF and Drug Tariff.	Thank you for your comment. For certain administration methods the data on cost was unavailable from the BNF and drug tariff, in such instances we have referred to the PCF which we have now updated to the PCF5.
Nottingham University Hospitals NHS Trust	Full	General	General	It was disappointing that the Palliative Care Formulary 5th edition (Twycross, Wilcock and Howard 2014), appeared to warrant scant mention. The PCF provides essential, independent information on the use of drugs in palliative and hospice care and is widely acknowledged by palliative care specialists as an authority on prescribing for both generalists and specialists. It is frequently referred to by the UKMI and is the adopted reference source for NHS Scotland. The associated website (www.palliativedrugs.com) has 30,000 registered health professionals, 55% from the UK. If the PCF had been consulted more widely, a number of the inaccuracies in the guideline should not have arisen. We are particularly surprised and concerned by multiple basic errors in the tables for best pharmacological management at the end of life, including recommendations to generalists on the use of drugs that are rarely used by specialists (detailed below).	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingh	Full	217 -		The clinical points above related to drugs and drug	Thank you for your comment on the prescribing

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am University Hospitals NHS Trust		222		doses also apply to the tables in the full guideline, however there are inconsistencies between the two sets of tables, e.g. in spelling (ibuprofen is spelt incorrectly in one place in the full guideline table 1 but correctly in the short guideline), formatting of footnotes (they are numbers in the short guideline and letters in the full guideline) and general formatting, leading us to believe that the tables are different versions.	tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	24	15	**Recommendation**: Reference to the Palliative Care Formulary in the text may be useful.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS	Short	25	10	**Recommendation**: Reference to the Palliative Care Formulary in the text may be useful.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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Trust					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	25	19	**Recommendation**: Listing the medications in order of preference, rather than alphabetical, would be more helpful to a generalist. Consultation with the Palliative Care Formulary would have helped in this.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	25	31	**Recommendation**: more detail needs to be provided here and/or insert more specific wording such as 'seek specialist advice before attempting to mix medications in a syringe pump'.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Nottingham University Hospitals NHS Trust	Short	25	5	**Recommendation**: Consultation of the Palliative Care Formulary would have been helped in developing the tables ensuring accurate, relevant recommendations, and may have avoided the errors detailed below.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	27	2	**Error:** rectal diclofenac 50mg is usually up to three times (not twice) a day	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University	Short	27	2	**Error:** there is no parenteral formulation of ibuprofen, therefore it cannot be given by continuous subcutaneous infusion (CSCI); it is also spelt incorrectly in the full version of the tables	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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Hospitals NHS Trust					being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	27	2	**Rarely used by specialists:** diclofenac by CSCI is infrequently used in palliative care	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	27	2	**Rarely used by specialists:** paracetamol by intravenous infusion is not commonly used in palliative care.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	**Developer's response** Please respond to each comment
					targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	27	2	**Recommendation**: remove the inclusion of paracetamol from the CSCI column as it is confusing to have it listed there but saying that it is not given by CSCI	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	27	2	**Error:** use of 'maximum dose of the medication' is potentially misleading for opioids; this may be interpreted as the upper end of the doses given in the table. Although the text introduces the tables (and that they are starting doses), the tables need to stand alone and so greater use of explanation in footnotes is recommended and that ultimately the dose of the opioid should be titrated against pain and acceptable undesirable effects (with no absolute 'maximum').	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham	Short	27	2	**Error:** Sulphate should be sulfate throughout **all** of the tables	Thank you for your comment on the prescribing tables. Because of the recognised importance of

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University Hospitals NHS Trust					supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	27	2	**Error:** the infusion period 24h is missing for morphine CSCI, i.e. morphine sulfate 10-20mg/24h.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	27	2	**Recommendation**: there should be information that breakthrough doses should be prescribed for p.r.n. alongside morphine CSCI	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently,

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					they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	27	2	**Recommendation:** include diamorphine dose as an alternative parenteral opioid, given that it is the only opioid on the national out of hours formulary.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	27	2	**Recommendation:** if there are unwanted opioid side effects change 'consider switching to a different opioid' to 'seek specialist palliative care advice'	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Nottingham University Hospitals NHS Trust	Short	27	2	**Recommendation:** footnote a should state it is relevant for opioids	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	28	2	**Recommendation:** if there are unwanted opioid side effects change 'consider switching to a different opioid' to 'seek specialist palliative care advice'	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospital	Short	28	2	**Error**: clonazepam injection is not available except as a special order product, thus not suitable to recommend for generalist setting. Midazolam should be first-line, it is widely available and on the national out of hours formulary	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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s NHS Trust					implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	28	2	**Error**: there is a number '4' after the word diazepam that should be a superscript reference. We suggest removing reference numbers from in front of doses and replacing with letters as per the tables in the full guidance. This also occurs in tables 4 and 5	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	28	2	**Recommendation**: footnote a should state it is relevant for opioids	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be

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					made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	30	2	**Comment:** although the doses are low, generally haloperidol dose for injection is usually half that recommended by mouth. The use of the same dose by both routes may be wrongly interpreted by a generalist that when swapping from oral to parenteral the same dose of haloperidol is used.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	30	2	**Error**: prochlorperazine oral dose, usually give a higher stat dose if acute vomiting before regular maintenance dose	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham Universit	Short	30	2	**Error**: prochlorperazine buccal tablets, no maxmimum frequency given	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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y Hospitals NHS Trust					symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	30	2	**Error**: levomepromazine 6mg oral tablets are available as a special order. Because of the cost difference many organisations recommend 6.25mg (i.e. quartering a 25mg tablet).	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	30	2	**Error**: Cyclizine can be given IV	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This

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					important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	30	2	**Error**: the dose units are inserted in the incorrect place in the levomepromazine subcutaneous section	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	30	2	**Recommendation**: footnote b should also state that cyclizine is incompatible with 0.9% saline and should be diluted with water for injection only	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingh	Short	31	2	**Error**: clonazepam injection not available except as	Thank you for your comment on the prescribing

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am University Hospitals NHS Trust				a special order product, thus not suitable to recommend for generalist setting.	tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	31	2	**Comment:** we question if the recommendation for clonazepam orally once at night is appropriate in this setting.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS	Short	32	2	**Comment:** we question if olanzapine and risperidone orally act sufficiently quickly enough if patient is imminently dying.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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Trust					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	32	2	**Error**: olanzapine is not available as a 2.5mg orodispersible tablet	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	32	2	**Comment:** risperidone orodispersible tablets are very expensive	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Nottingham University Hospitals NHS Trust	Short	32	2	**Comment:** although the doses are low, generally haloperidol dose for injection is usually half that recommended by mouth. The use of the same dose by both routes may be wrongly interpreted by a generalist that when swapping from oral to parenteral the same dose of haloperidol is used.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	33	2	**Error**: usual starting dose of glycopyrronium by SC injection is 200microgram not 400microgram	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University	Short	33	2	**Comment / rarely used by specialists:** we would not generally recommend transdermal patches for this indication, we would question they would act sufficiently quickly and be of a sufficient dose	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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Hospitals NHS Trust					being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	33	2	**Rarely used by specialists:** SL atropine, not a routine choice in palliative care	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	33	2	**Error**: dose range for glycopyrronium CSCI is missing (present for the other CSCI drugs)	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain

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					targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	33	2	**Error**: hyoscine butylbromide CSCI starting dose should usually be 20mg/24h with a range to 60mg/24h, not 60mg/24h starting dose	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottingham University Hospitals NHS Trust	Short	33	2	**Comment:** Glycopyrronium injection can be given sublingually for this indication	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Nottinghamshire Healthcare NHS Foundation Trust	Full	General	General	Our main thoughts are that it is really useful document, timely with well written and meaningful guidance to support clinicians in practice. However would have been even more useful to have called it palliative/end of life guidance to improve clinicians focus on palliative phase of illness Health Partnerships would like to have noted that a lot of what Nice recommends in the Care of the dying adult guidance, we are already achieving or working towards. Following the independent review of the Liverpool Care Pathway. Health Partnership introduced the EOL tools including EPaCCS, ACP, GSF Prognostic indicators and Priorities of Care documentation. These tools are already helping us achieve the objectives in the latest guidance. The Eastern Cooperative Oncology Group (ECOG) performance status would be useful to put with Health Partnerships prognostic indicators when assessing when someone is entering the last few days of life. A general comment We have the 'One Chance to Get it Right' document setting out 5 priorities for care. This NICE guidance has some aspects that cross over, but it doesn't follow the same format and headings. It would be a missed opportunity to not tally the two together	Thank you for your comment. We are pleased that our recommendations are currently being implemented in your area and you see the value of ECOG status in line with your current prognostic indicators. The title of the guideline reflects the remit provided to us by NHS England. The context and introductory sections to both the full and short versions of the guideline provide the focus and context for the work which is the last 2-3 days of life. The Committee considered the policy documents that outline the five priorities of care at all times but drafted their recommendations after due consideration of the evidence. Reference is made throughout the guideline to the current policy documents relevant to this area. Our recommendations that make reference directly to specific drugs (for example1.5.22 and 1.5.30) have been made after full review of the evidence and should be implemented accordingly. Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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				The education planner for palliative care would support the training required and building on and complementing the existing education programme we have in place The Anticipatory drugs used in Nottinghamshire are not always first line treatment in the latest Nice guidance consultation, however they are listed as an alternative or second line treatment.	members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottinghamshire Healthcare NHS Foundation Trust	Full	244	2	Acronym for PPC is 'Preferred Priorities for Care', not 'Prepared Priorities for Care'. And – many people use this acronym for 'Preferred Place of Care'. Need to ensure this is clear in final document	Thank you for your comment. This has been amended
Nottinghamshire Healthcare NHS Foundation Trust	Short	3	2	Need to add a comment about considering reversible causes for the deterioration	Thank you for our comment. Reversible causes are discussed in the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8).
Nottinghamshire Healthcare NHS Foundati	Short	4	4	Changes in communication (for example talking about the nearness of death) - we don't think is a good example of a sign of death, having difficulty talking because of a lack of energy is more of a common sign.	Thank you for your comment. This example is based on the evidence review but we agree there are other examples.

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on Trust					
Nottinghamshire Healthcare NHS Foundation Trust	Short	7	27	Share the care plan with all members of the multi professional care team. There is not mention here or elsewhere about gaining consent for sharing information.	Thank you for your comment. The Communication and Shared Decision Making recommendations encourage healthcare professionals delivering end of life care to prioritise the personal goals and wishes of the dying person and this includes establishing their communication needs and expectations.
Nottinghamshire Healthcare NHS Foundation Trust	Short	27 & 28	1	Opioids – 'consider increasing dose up to the maximum dose' – this statement is used for non-opioids appropriately. It is not appropriate for opioids.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottinghamshire Healthcare NHS Foundati	Short	30	1	the box relating to 'Yes' and 'Second line' – needs a specific suggestion, not just a repeat of the text above	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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on Trust					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Nottinghamshire Healthcare NHS Foundation Trust	Short	30 & 32	1	Levopmepromazine differing doses suggested for N+V and delirium. This may be appropriate when considering symptoms individually, but in reality we are advising anticipatory medications for all symptoms. It is safer to have one dose only prescribed if using levomepromazine for these symptoms.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Palliative Care Pharmacists Network (PCPN)	Full	249		Question mention of narcosis as the palliative care use of opioids are for analgesia only	Thank you for your comment. We recognize the palliative care use of opioids is for analgesia. The definition provided is inclusive of this use, but refers to the common unintended side-effect of sedation, which has been a problem with opioids in experienced hands.
Palliative Care Pharmacists Network	Full		general	Is there a rationale for only using English language studies?	Thank you for your comment. We agree this could be a bias, however we do not have the resources for translation services. NICE guidelines do not routinely include non-English language studies, as detailed in the NICE guidelines manual: "**Searches**

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(PCPN)					**should be limited to studies reported in English"** https://www.nice.org.uk/media/default/about/what-we-do/our-programmes/developing-nice-guidelines-the-manual.pdf
Palliative Care Pharmacists Network (PCPN)	Full	245		Question use of capital letters in the first definition	Thank you for your comment. This has been amended.
Palliative Care Pharmacists Network (PCPN)	Full	248		Suggest removing common causes of nausea as non relevant to causes in palliative care	Thank you for your comment. This has been amended.
Palliative Care Pharmacists Network (PCPN)	Full	250		Syringe pumps are not mainly for IV administration but for SC use in palliative care	Thank you for your comment. The definition provided is inclusive of the term in its broadest context and not an indication of its function in the context of this guideline.
Palliative Care Pharmacists Network (PCPN)	Full	65		Outcomes – important Adverse effects of treatment section – inconsistency using **this** vs **it** 4th bullet point – opiates should read opioids – this needs to be consistent throughout the document comma required after 'itching'	Thank you for your comment. This has been amended throughout the guideline.

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Palliative Care Pharmacists Network (PCPN)	Full	81/82		Would including under no 2 and relative values of different outcomes, available investigation results such as renal function or radiological imaging prompt people to perform unnecessary and inappropriate tests?	Thank you for your comment. The Committee agree that unnecessary investigations should be avoided, but that, if available, feel they may provide useful information. Available investigation results have been moved to the stem of the recommendation to avoid confusion with other signs or symptoms of recognising dying.
Palliative Care Pharmacists Network (PCPN)	Full	148	21	NHS supplies catalogue Aud 2015 BD Saf-T-Intima 24g needle £2.38 each Alaris flow controller FKA 139 £1.37 (used in some locations) use 500ml 0.9% N Saline bags to aid flow to SC route (2 x 500ml in costings) add drip stand cost/hire add decontamination costs of drip stand add sharps disposal/clinical waste	Thank you for your comment. Some of the costs (needle, flow controller, saline bags) you have quoted would be already included in the cost of the standard giving set, which has been included in our cost calculation. Other costs (drip stand, decontamination, sharp disposal/clinical waste) are considered negligible when calculating the cost per patient as they are divided between several patients. Therefore we do not feel the costs we have reported need to be changed.
Palliative Care Pharmacists Network (PCPN)	Full	137	16	Requires training for administration in community and unfamiliar to GPs	Thank you for your comment. Service Delivery, including training and education, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Palliative	Full	149	1	Use 500ml 0.9% N Saline bags to aid flow to SC	Thank you for your comment. Resource use and

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Care Pharmacists Network (PCPN)				route (2 x 500ml in costings) as above	costs were agreed with the Committee and were deemed appropriate for the majority of care. It was recognised that there may be some variation in practice, however it was felt that this would not have a substantial impact on cost.
Palliative Care Pharmacists Network (PCPN)	Full	Sect. 10.1	16-20	Drugs in brackets should be prefixed 'e.g.'	Thank you for your comment. This has been amended.
Palliative Care Pharmacists Network (PCPN)	Short	10	7	Add worsening chest secretions	Thank you for your comment. The Committee consider this to be covered under 'fluid overload' and feel that no change is required.
Palliative Care Pharmacists Network (PCPN)	Short	8	26	MHRA alert on sponges detaching from stick presenting a choking hazard. Consider using moi-sticks	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.
Palliative Care Pharmacists	Short	9	26	Is there a preference between IV or SC when both routes are available in the proposed setting or is this based on the patient preferences, risks and benefits. Are there any benefits of using IV over SC?	Thank you for your comment. We are unable to provide this level of detail in the guideline, but expect this to be based on individual circumstances and clinical judgement.

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Network (PCPN)					
Palliative Care Pharmacists Network (PCPN)	Full	164	15	Cochrane review 2010 of benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant disease in adults not included No studies of benzodiazepines e.g. lorazepam included No studies of bronchodilators if wheeze from malignant tumour obstruction included	Thank you for your comment. The Cochrane review on benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases was reviewed for inclusion in this review. However owing to the population used for the Cochrane systematic review being wider and including patients outside of the last days of life, this was not included in the systematic review for this guideline. One study featuring a benzodiazepine intervention arm was included in the evidence review on the pharmacological management of breathlessness. The Navigante et al (2006) study included arms of Midazolam, and Morphine + Midazolam. No studies including bronchodilators for the treatment of breathlessness in the last days of life were identified in the search used.
Palliative Care Pharmacists Network (PCPN)	Full	155	11	Organ failure, muscle weakness **or** (not and) progression of cancer	Thank you for your comment. This has been amended.
Palliative	Full	155	1st	A very negative introduction and we cannot agree	Thank you for your comment. This has been

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Care Pharmacists Network (PCPN)			para	with the broad last statement "many of the medications……cause a degree of sedation or other side effects that could lead to ……..**a more rapid deterioration in the dying person**	amended.
Palliative Care Pharmacists Network (PCPN)	Full	155	28-9	The sentence starting on line 28 doesn't make sense: The non-physical elements of pain **such as fear, existential distress** may also become more prominent……	Thank you for your comment. This has been amended.
Palliative Care Pharmacists Network (PCPN)	Full	155	39	No comma needed after 'sedation'	Thank you for your comment. This has been amended.
Palliative Care Pharmacists Network (PCPN)	Full	155	6	'important' used twice in same sentence	Thank you for your comment. This has been amended.
Palliative Care Pharmacists Network (PCPN)	Full	155	7	Typo 'putingt'	Thank you for your comment. This is been amended.

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Palliative Care Pharmacists Network (PCPN)	Full	156	29 table 44	Population: the order of the symptoms is different from that of the review question Interventions: both muscarinic and muscarinic acetylcholine receptor antagonists are listed – duplication Some of these listed are in the singular when the bulk are in plural – needs to be consistent Outcomes: the order of the symptoms is different from that of the review question	Thank you for your comment. The list of interventions has been amended. Additional outcomes are listed in the protocol and we feel no change is required to the review question.
Palliative Care Pharmacists Network (PCPN)	Full	156	8-12	We feel the sentence is too long and needs to be broken down	Thank you for your comment. This has been amended.
Palliative Care Pharmacists Network (PCPN)	Full	161		In trade off between clinical benefits and harms there is no reference to referral to specialists for help with pain management	Thank you for your comment. This has been added into the other considerations section.
Palliative Care Pharmacists Network (PCPN)	Full	162		We do not feel there is evidence for diamorphine still being widely used. Problems with access to the drug are historical but there have been no problems post 2004 although the cost is much higher than previously	Thank you this has been amended,
Palliative Care	Full	173	5	Bronchodilators if evidence for reversible airways obstruction	Thank you for your comment. The Committee have recommended to identify and treat reversible causes

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Pharmacists Network (PCPN)					of breathlessness. No evidence was found for the use of bronchodilators
Palliative Care Pharmacists Network (PCPN)	Full	176-182	general	General comment – there is no general guidance at all – the statement that an individualised approach is an essential part of caring for dying adults does not offer help to generalists	Thank you for your comment. The Committee have made general recommendations on nausea and vomiting, but do not recommend specific drugs as there was no evidence to recommend one anti-emetic over another.
Palliative Care Pharmacists Network (PCPN)	Full	193		Prostate not prostrate (Clark et al study column – population)	Thank you for your comment. This has been amended.
Palliative Care Pharmacists Network (PCPN)	Full	208		Incorrect information - Hyoscine hydrobromide is licensed as a pre-operative medication to control bronchial, nasal, pharyngeal and salivary secretions. It is not licensed for use in palliative care	Thank you. This has been amended.
Palliative Care Pharmacists Network (PCPN)	Full	209		Management of pharyngeal secretions in patients with MND – we feel at this stage, the problem would be better managed with the SC route and not with drops for sublingual use. Healthcare professionals would not be looking at this document for symptom control although this would be appropriate earlier in the disease trajectory.	Thank you for your comment. This is guideline is for non-specialists and the Committee are unable in the absence of evidence to comment on specific diseases or conditions.

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Palliative Care Pharmacists Network (PCPN)	Full	210		None of the current published guideline textbooks mention only trialling a pharmacological treatment for 12 hours then switching or stopping if ineffective. The palliative care books advocate dose titration which by virtue of using a 24hr CSCI would be a minimum of a 24hr review period and several days to titrate to maximum effective and accepted dose	Thank you for your comment. The Committee recommend trialling treatment for 12 hours and then switching based on the evidence review that indicated that these drugs may be clinically effective at 12 hours. The group did not want symptoms to remain unresolved for a longer time period as the prognosis in these people is very short. The group note that clinical judgement should be used to support consideration of a longer trial in those in whom death is anticipated outside this time frame. We would expect the findings of this evidence review to inform an update of current guideline textbooks in due course.
Palliative Care Pharmacists Network (PCPN)	Short	13	1	Specify IR morphine e.g. Oramorph liquid or morphine injection (doses specified in table 2 on page 28)	Thank you for your comment. We do not have evidence from our review to support this change. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, the prescribing tables are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Palliative Care Pharmaci	Short	13	3	Add nebulised bronchodilator for reversible airway obstruction/asthma and anti-muscarinic/bronchodilator if COPD	Thank you for your comment. The recommendation s drafted reflects the evidence considered. For more detail please see chapter 9, (section 9.9) of the full

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sts Network (PCPN)					guideline
Palliative Care Pharmacists Network (PCPN)	Full	Sect. 10.8		Recommendations and link to evidence ideally include this recommendation Specify: • Indication for use • Dose or dose range plus the volume of medication (of solution) which equates to dose or dose range • Route • Minimum time between doses Maximum number of doses to be given in 24 hours	Thank you for your comments had provided these in the prescribing tables. However, because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Palliative Care Pharmacists Network (PCPN)	Full	Sect. 10	General	We suggest the addition of these points: • Every person undergoing EoLC in all care settings should have input from a specialist palliative care team • Good communication between specialist palliative care teams, prescriber and community pharmacies can facilitate medicine availability (examples in e.g. Macmillan Glasgow project) Back up of medicines available fro the hub palliative care centre is sometimes available and can be advantageous	Thank you for your comment. The Committee have made recommendations to seek specialist advice where necessary. There are also recommendations on communication and shared decision making. The availability and specific arrangements for the provision of medications were beyond the remit of this guideline.
Palliative	Full	66		Subgroups – delivery system	45. Thank you for your comments on the

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Care Pharmacists Network (PCPN)				Orodispersible is the correct term for 'melt' Add RIG to PEG tube Sublingual. Buccal, dissolving tablet - this needs clarifying	prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Palliative Care Pharmacists Network (PCPN)	Full	67		Population: adult people in the last days of life who are 'nauseated' not nauseous – again, vomiting is not mentioned	Thank you for your comment. We are unable to answer as the page you refer to does not mention nausea.
Palliative Care Pharmacists Network (PCPN)	Full	67	general	Vomiting is not mentioned – only nausea	Thank you for your comment. We are unable to answer as the page you refer to does not mention nausea.
Palliative Care Pharma	Full	214		Under other considerations "The GDG agreed that a syringe pump should be considered if requiring more than 2-3 prn doses within 24hrs" Should read 'than'	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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cists Network (PCPN)					symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Palliative Care Pharmacists Network (PCPN)	Full	217-220	General	It is clear from the introduction to these tables that the recommendations are for starting doses, however should a generalist clinician use the tables in isolation from the text it perhaps could be clearer that these are starting doses. The doses quoted in syringe driver section in particular could be misunderstood as the recommended range beyond which they cannot prescribe.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Palliative Care Pharmacists Network (PCPN)	Full	218		Continuous subcutaneous infusions Diclofenac may be used by SC infusion but not ibuprofen Paracetamol is not given by SC infusion The table is not fit for purpose as it is confusing and there is no guidance for calculating rescue doses References to oral or IV administration are probably inappropriate	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This

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					important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Palliative Care Pharmacists Network (PCPN)	Full	218	3	Clonazepam injection via s/c route – this product is no longer marketed in the UK so although it is still sometimes used the cost of importing it and the evidence-base for its use may make it less appropriate	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Palliative Care Pharmacists Network (PCPN)	Full	219	3	Subcutaneously or intravenously levomepromazine 2.5 5 up to mg12 hhourly needs re-formatting	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Palliativ	Full	220	3	Comment as in 32 above	Thank you for your comment on the prescribing

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e Care Pharmacists Network (PCPN)					tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Palliative Care Pharmacists Network (PCPN)	Full	222		Hyoscine hydrobromide is unlicensed (see 5) Recommend removing reference to 12 hourly switch (see 7)	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Parkinson's UK	Full	24	7	The wording should be strengthened from 'can be initiated' to 'should be initiated' to urge that preparations for end of life care for people with Parkinson's begin early enough, before cognitive problems take hold. This demands that non-palliative care professionals, at any phase of the condition,	Thank you for your comment. As this is introduction text we are unable to state anything stronger, but have made several recommendations in this area. We are unable to make specific recommendations related to the needs of people with Parkinson's disease as this is general guidance for care at the

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				are skilled and confident enough to broach discussions around advance care planning in an appropriate way. Loss of capacity to communicate end of life wishes is a high risk for people with Parkinson's, as up to eight out of 10 people who have Parkinson's for more than 10 years develop dementia. (Perez et al, Risk of dementia in an elderly population of Parkinson's disease patients: A 15-year population-based study, 2012). The advanced phase of the disease lasts, on average, 2.2 years. (Richfield et al, Palliative care for Parkinson's disease: A summary of the evidence and future directions, 2013). In a 2008-2011 UK Study, 90 per cent of patients with Parkinson's had not discussed their wishes with a health or legal professional or written them down. (Walker RW, End Stage Disease in Parkinson's, Presentation to Autumn 2013 British Geriatrics Society meeting) The guideline should encourage professionals to ensure that where someone has not made their wishes known in advance, the principles of good practice in assessment of mental capacity for a specific decision and best interest decision making	end of life Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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				apply. They are: • involvement of key professionals and loved ones • respect to previous wishes (if known) • some idea of how they lived their life and therefore how this might be reflected in their end-of-life care • trying to understand from the person with loss of capacity something of what they value in life or makes them feel happy/settled/safe. So for example if being away from home is very distressing for the person then this may indicate it is in their best interest to remain at home even in the case of deteriorating condition – particularly if their deterioration is likely to be irreversible.	
Parkinson's UK	Short	3	19	We strongly urge that the clinical features that herald the onset of end-of-life care in long-term neurological conditions are included, these are: • Swallowing problems • Recurrent infections • Marked decline in physical function • First aspiration pneumonia • Cognitive difficulties • Weight loss • Significant complex symptoms	Thank you for your comment. All of the clinical features you list were included in the review. After careful consideration the Committee have re-grouped the list into 3 categories: signs, symptoms and functional observations. The examples given are from the evidence review, but are examples only. Further detail is given in the Linking evidence to recommendations' section of the chapter. Thank you for providing references. After careful consideration it was decided that the references provided do not meet the inclusion criteria for any of our review protocols. We would note that the

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				The first episode of aspiration may be particularly pertinent in Parkinson's where pneumonia is the commonest cause of death. (Pennington S, Snell K, Lee M, et al. The cause of death in idiopathic Parkinson's disease. *Parkinsonism Relat Disord* 2010; 16: 434–437.) (See also Richfield EW, Jones EJS and Alty JE, Palliative care for Parkinson's disease: A summary of the evidence and future directions *Palliat Med* 2013 27: 805) There are additional triggers particular to Parkinson's that may indicate the person is reaching their last year of life and particularly an inability to tolerate adequate dopaminergic medication as well as psychiatric problems. The results of physiotherapy assessments including mobility and balance can also predict mortality. (Gray WK et al, *Physical assessment as a predictor of mortality in people with Parkinson's disease: a study over 7 years*.Mov Disord. 2009 Oct 15;24(13):1934-40. doi: 10.1002/mds.22610). Weight loss in males can also be highly predictive of mortality (Walker, BGS, 2013). The guideline should clearly reference that there is	inclusion criteria for our reviews is last days of life.

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				no single sign that death is imminent in Parkinson's. However a combination of factors - a pattern of significant decline including increased secondary complications (falls, pneumonias, other infections, weight loss, bowel impaction etc.) combined with reduced benefit from Parkinson's medication, increased cognitive problems, poor swallow, reduced mobility and increased rigidity indicate that the person is entering the end of life phase.	
Parkinson's UK	Short	3	19	The guideline should reference that it is difficult to know whether the deterioration is due to a reversible acute illness (infection) or an inevitable and irreversible deterioration of the person's Parkinson's. It requires an understanding of the individual pattern and phase of the person's condition. The guideline should reference that having a Parkinson's specialist involved in the person's care as part of their multi-disciplinary team is crucial.	Thank you for your comment. We note your comments on the specific issues linked to Parkinson's and understanding that the patterns and phases relevant to this long term condition are important to recognizing dying. We have been keen to ensure that our recommendations enshrine the importance of gathering information on the person's medical history and the clinical context as part of this process. Our recommendations and the principles we outline are relevant to all people who may be dying and are intended to be especially helpful to the less specialized practitioner. Reversible causes are discussed in the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8).
Parkinson's UK	Short	4	21	The guideline should note that if the person with Parkinson's is unable to take adequate dopaminergic medication because of poor swallowing (a common symptom in advanced Parkinson's) they have a high risk of severe	Thank you for your comment. This guideline is aimed at non-specialists and we are unable to make comment about specific diseases or conditions.

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				complications and rapid decline.	
Parkinson's UK	Short	4	26	It is important that the guideline notes that in the case of very complex care needs at the time of dying, it is vital there is a clear pathway for the person to be able to access specialist palliative care. Success criteria for sharing expertise across disciplines (e.g. between palliative care and Parkinson's specialisms) include: Good working relationships, including a clear understanding of when the condition is in the palliative phase and of the role of the palliative care specialist; good routes of communication – being able to access each others' advice quickly; mutual education and service development; a shared vision, enthusiasm and compassion; mutual respect.	Thank you for your comment. After careful consideration the Committee felt that no change was required, as there are recommendations on information gathered from the multiprofessional team and chapters on communication and shared decision making.
Parkinson's UK	Short	6	4 - 7	We would urge the guideline references the complicated nature of medically managing Parkinson's with dementia. Getting the right balance of medication to improve movement can greatly exacerbate psychiatric problems. Early advance care planning and expert advice to family members at the time of dying, from a professional who understands the trade-off between the different drugs, should help to achieve the best possible balance of movement and thinking capabilities, in line with the person's wishes and best interests.	Thank you for your comment. This guideline covers all adults and all conditions. For guidance related to palliative care for Parkinson's please see NICE Guideline CG35 entitled: Parkinson's disease. More information can be found at the following link: http://www.nice.org.uk/guidance/cg35. The focus of the guideline is on the clinical care of the dying adult in the last 2-3 days of life. The committee recognize it is important to do advance care planning as early as possible. We have made amendments to a number of recommendations to clarify that the important information of relevance

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					includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Parkinson's UK	Short	5	17-25	The guideline should include a statement about accurate prognosis being difficult to establish in advanced Parkinson's. We suggest that the guideline also references the importance of the professional's skills to include conveying uncertain news sensitively, in order to help people with Parkinson's, their families and carers to manage uncertainty.	Thank you for your comment. More specific guidance regarding palliative care for Parkinson's disease can be found in the NICE guideline CG35 entitled: Parkinson's disease. More information can be found at the following link: http://www.nice.org.uk/guidance/cg35. Regarding conveying prognosis to the dying person, the Committee has recommended that the most appropriate and available healthcare professional should be identified to lead these discussions and of course agree that this should be done with sensitivity. The committee feel it important to recognize that the most appropriate person may be the person with the most experience of having these conversations. This does not always equate to seniority Please note that it has also been recommended that the multiprofessional team should be supported by experienced staff at all times and have the ability to seek further specialist advice if additional support is required. We are unable to make references to specific groups or conditions
Parkinson's UK	Short	8	6 - 8	The average time from identification of dying to death for people with Parkinson's has been shown to be 8.3 days (range 2-23 days) compared with 29	Thank you for your comment. The remit and scope of this guideline did not cover this area. This guideline focussed on the needs of the dying person

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				hours across all diseases (MCPCI 2012) (Adams D et al – Poster Presentation BMJ Support Palliative Care 2014;4:A107 doi:10.1136/bmjspcare-2014-000654.307) Healthcare professionals therefore need to be skilled at enabling families to acknowledge and manage the emotions and physical strain involved in this prolonged dying process. To make sure families get the support they require at this difficult time the guideline should outline how professionals should try to provide or arrange access to support that enables them to cope. While there is a great focus on people dying at home – and this is often presented as the ideal place of death, and may be/have been the preference of the dying person, it can be distressing for some members of the person's family as they may be emotionally or practically unprepared. In this case the guideline should state that it might be appropriate to diverge from an Advance Care Plan preference by offering hospice/community hospital admission. Where it is in the person's best interests to die at home, preparation can alleviate the stress e.g. making sure all necessary resources and back up support is in place (link to palliative care service, injectable medication, care package, equipment etc).	and has not reviewed the evidence around support for carers or those important to the dying person. For palliative care in Parkinson's Disease, please see NICE CG35 entitled: Parkinson's disease. More information can be found at the following link: http://www.nice.org.uk/guidance/cg35. NICE is currently developing guidance in palliative care service delivery and the issue of staff roles may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799

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				The unpredictable disease trajectory makes planning for the terminal event particularly difficult and most patients die in hospital rather than at home. Many people with Parkinson's have no opportunity to access hospice care. Research reports that only 2.7 per cent of people with Parkinson's died in a hospice (Snell K, Pennington S, Lee M, Walker R The place of death in Parkinson's disease. Age Ageing. 2009 Sep;38(5):617-9. doi: 10.1093/ageing/afp123. Epub 2009 Jul 23.) It is important that the guideline states that it is vital that the multidisciplinary practices of best hospice care are available in all settings. Given that dying at home can be prolonged and stressful in Parkinson's, people with the condition and their families should have access to the full range of places to die. In planning for and supporting the death of someone with Parkinson's, it is important to be very mindful that in many cases family carers are themselves older, with their own health issues, and they are often isolated.	
Parkinson's UK	Short	5	10	It is important the guideline notes that half of Parkinson's patients are unable to make or communicate decisions in the last month of life - 68% had difficulty communicating and 47% were confused. (Fleming, A., Cook, K. F., Nelson, N. D., &	Thank you for your comment. The guideline is aimed at non-specialists and we are unable to comment on specific conditions and diseases. The Committee feel that the recommendations made under communication are relevant and note that they

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				Lai, E. C. (2005). Proxy reports in Parkinson's disease: Caregiver and patient self-reports of quality of life and physical activity. Movement Disorders, 2011), 1462–1468 cited in Walker, BGS, 2013) Parkinson's can present very specific and complex communication challenges at the end of life. People with the condition often develop 'mask like features'. Their inability to show non-verbal signs of pain, as well as problems with speaking (weak voice) and communication because of confusion/dementia may obscure distress. This makes it even more important to ensure they receive dopaminergic medication, and effective pain relief, safely and adequately. It highlights that health and care staff must facilitate the person with Parkinson's expression and recording their end of life care preferences while their communication and cognition are intact. It would be helpful to make these points explicitly in the guidance, particularly the need for this to happen much earlier than current practice.	recommend seeking specialist advice if additional support is needed.
Parkinson's UK	Short	7	25	The discussion should enable the person with Parkinson's and/or their family to instruct on how they would like to control the delivery or discontinuation of routine care tasks, such as	Thank you for your comment. This guidance is for non-specialists and we are unable to make comment on specific diseases or conditions.

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				washing or turning, if these are too disturbing in the final hours before death.	
Parkinson's UK	Short	9	1	The guideline should note that difficulties with swallowing (choking and aspiration) are common at end of life in Parkinson's. Decisions about intubation need to take into account. Research that shows that tube feeding, though common, does not generally prolong life or improve outcomes in patients with advanced dementia and itself involves risks including aspiration, infection and aspiration pneumonia (Rhodes R, annals of Long-Term Care, Vol 22, Issue 9, September 2014) 79% of people with Parkinson's in a recent UK study indicated a desire for comfort care only for the last month of life, whereas a quarter of Parkinson's patients had a feeding tube and similarly a quarter had breathing support in the last month of life (Walker, 2013)	Thank you for your comment. Nutrition is beyond the remit and scope of this guideline. . In addition the references you provide are not specific to the last days of life and therefore do not meet the inclusion criteria for our review questions.
Parkinson's UK	Short	8	13 - 17	The guideline should state that good practice in supporting someone dying with Parkinson's who has swallowing problems will include expert advice from a Speech and Language Therapist, modified diet/drinks, appropriate positioning and carer support.	Thank you for your comment. The guideline is for generalists and we are unable to provide guidance for specific diseases and conditions. We believe clinical judgment should guide decisions appropriate for specific conditions.
Parkinson's UK	Short	10	26 - 28	The guideline should state that the priority when someone with Parkinson's is dying is to find ways to safely administer a safe dose of dopaminergic medication when swallow is lost or poor. The best	Thank you for your comment. The administration of dopaminergic medication in adults with Parkinson's at the end of life was outside the scope of this guideline. This guideline is focussed on making

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				ways to address this are by a topical patch or administering dispersible Madopar. There are serious risks and the consequences of suffering are high for the individual if dopaminergic medication is stopped - reactions could include; neuroleptic malignancy syndrome, severe rigidity/contractures, dopamine withdrawal syndrome. Management of dopaminergic medication in advanced Parkinson's is complicated and requires considerable expertise. The strategy for "wearing-off" phenomena is focused on prolonging the effect of individual L-Dopa doses without increasing the pulsatile dopaminergic stimulation. Strategies may include fragmentation of dosing, with more frequent administration of lower doses, and use of COMT inhibitor (entacapone and tolcapone), MAO inhibitor (selegiline and rasagiline), and use of dopamine agonists. Adjunctive therapy with a COMT inhibitor extends the duration of the L-Dopa effect, hence ameliorating wearing off, by blocking the COMT enzyme in the peripheral catabolism of L-Dopa. Potential adverse events, however, may arise from the COMT inhibitors. Increasing synaptic dopamine levels may also be associated with dyskinesia and increased L-Dopa toxicity leading to worsening of dementia and psychosis. (Varanese S et al.,	recommendations for non-specialists and we are unable to make specific recommendations for specific conditions or diseases. Thank you for submitting a reference, after careful consideration we are unable to include this in our evidence reviews as it does not meet our inclusion criteria.

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				Treatment of Advanced Parkinson's Disease, Parkinsons Dis. (2010) Article ID 480260, 9 pages). The pros and cons of all the different medications must be weighed and the regime optimised (in some cases, simplified) to best meet the needs of the dying person.	
Parkinson's UK	Short	10	26	The guideline should note that standard drugs often included in anticipatory drugs are contraindicated in Parkinson's because of the risk of severe side-effects, e.g. haloperidol, metoclopramide and levomepromazine (Richfield et al, 2013) There are suitable alternatives for people with Parkinson's; they include cyclizine, ondansetron and domperidone.	Thank you for your comment. The Committee recognised from their clinical experience that antipsychotic medication can results in patients with Parkinson's experiencing severe side effects and commented on this in the 'Linking evidence to recommendations' section in the pharmacological management of agitation, anxiety and delirium section of the full guideline. Thank you for submitting a reference, after careful consideration we are unable to include this in our evidence reviews as it does not meet our inclusion criteria.
Parkinson's UK	Short	11	10	It would be useful for the guideline to reference that administration of medication to combat parkinsonism is problematic in the dying phase and rigidity is a common problem. For patients unable to swallow in the terminal stage, medication can be administered subcutaneously as needed or continuously using a syringe driver. Medication can be given, if necessary, to relieve specific symptoms as follows:	Thank you for your comment. The Committee acknowledge your concerns that patients may not be able to take or tolerate oral medication in the last days of life, and recommended in 1.5.5 that if this is the case an alternative route should be prescribed. The Committee discussed the importance of considering the side effect profile of medication when making prescribing conditions and chose to make a recommendation reflecting this in 1.5.3.

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				• Midazolam for fear or agitation • Hyoscine butylbromide for drooling or chesty secretions • Morphine for pain If pain is present, a sufficient dose of morphine should be used to relieve it but without causing undesirable opioid side effects. Constipation is already a significant problem for many people with advanced Parkinson's and opioids can cause night terrors. (Campbell CW, Jones EJS and Merrills J, Palliative and end-of-life care in advanced Parkinson's disease and multiple sclerosis, Clin Med June 1, 2010 vol. 10 no. 3:290-292)	**Thank you for submitting a reference, after careful consideration we are unable to include this in our evidence reviews as it does not meet our inclusion criteria.**
Parkinson's UK	Short	12	14	The guideline should note the variety of pain assessment scales.We know more work is needed to validate these scales as there is limited evidence about their reliability, validity and clinical utility, so there is no ultimate tool that can be recommended for all circumstances. (Lichtner V et al, Pain assessment for people with dementia: a systematic review of systematic reviews of pain assessment tools, BMC Geriatrics 2014, 14:138 doi:10.1186/1471-2318-14-138)	Thank you for your comment. The Committee recognised that good pain assessment is important for all adults in the last days of life and made a recommendation that those who are unable to effectively verbally communicate will require a validated behavioural pain assessment (recommendation 1.5.14). The Committee were aware from their clinical experience that there are assessment scales that can be used to aid this in conditions such as dementia, but as the evidence for these was not reviewed, the Committee were unable to make a specific recommendation around this.
Parkinson's UK	Short	14	8	The guideline should include a reference to the two thirds of people with late-stage Parkinson's who suffer sleep disorders that include: insomnia,	Thank you for your comment. The Committee recognise that adults in the last days of life may experience anxiety due to a number of causes, and

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				parasomnias (REM sleep behaviour disorder, vivid dreams) and excessive daytime sleepiness and sleep attacks. (Walker RW, Presentation given on 16 September 2013 in Accra). Staff need access to appropriate expert input to reduce the anxiety associated with parasomnias.	chose to make recommendation 1.5.24 to prompt exploring possible causes with the dying person. Thank you for submitting a reference, after careful consideration we are unable to include this in our evidence reviews as it does not meet our inclusion criteria.
Parkinson's UK	Short	11	10-12	The guideline should note that swallowing difficulties are common in end-stage Parkinson's. In order to maintain the necessary dopaminergic therapy, skilled practitioners can use topical dopamine agonist medication (rotigotine patch) and may also use innovative delivery systems e.g. madopar paste rubbed into gums or injectable midazolam to reduce stiffness. Use of nasogastric or gastrostomy tube to administer dopaminergic medication in a dying patient is generally regarded as inappropriate as they carry risks (ockages, infections) and are invasive/uncomfortable. The 'cost' for someone in last few hours/days of dying is not outweighed by the benefit.	Thank you for your comment. We are unable to give further detail as an evidence review was not prioritised in this area. The Committee have discussed this further in the full version, 'Linking evidence to recommendations' section of chapter 9 (9.34).
Parkinson's UK	Short	12	5	The guideline should note that pain is common in Parkinson's and may not be explicitly volunteered by a patient – especially one with communication problems or dementia. A UK study found that overall pain in Parkinson's is	Thank you for your comment. We agree and have a specific recommendation on assessing pain in those who are unable to effectively communicate verbally (recommendation 1.5.13). In addition there is further detail in the 'Linking evidence to recommendations' section in the full guideline (chapter 9).Thank you for

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				present for 85 per cent of people. 63 per cent of people had Parkinson's pain and 64 per cent had non Parkinson's pain. Most Parkinson's pain is intermittent and non-Parkinson's pain is generally more severe. Pain does not get worse with disease progression. Analgesic use suggests that pain is under-treated (Lee M, Walker R, Hildreth A, Prentice W. A survey of pain in idiopathic Parkinson's disease. Journal of Pain and Symptom Management 2006; 32(5): 462-469). Staff need to respond to possible nonverbal indices of pain e.g. groaning, agitation and tearfulness. (Goy ER, Carter JH and Ganzini L: Parkinson's Disease at the End of Life – Caregiver Perspectives, Neurology August 7, 2007 vol. 69 no. 6 611-612)	providing a reference. After careful consideration it was decided that this does not meet the inclusion criteria for any of our review protocols.
Parkinson's UK	Short	12	8	We would urge the guideline to reference that the management of pain in Parkinson's needs to be specific relating to the type of pain. The most important intervention is dopaminergic medication, which means that health staff need to be particularly alert to the timing of pain related to time of day and administration of dopaminergic medication – as well as other drugs. Dosage regimes may need adjusting and this medication must be given on time. Management of pain needs to be specific relating to the type of pain:	Thank you for your comment. This guideline is for non-specialists and we are unable to make specific recommendations for specific conditions or diseases. Thank you for submitting references, after careful consideration we are unable to include this in our evidence reviews as it does not meet our inclusion criteria.

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				• Musculoskeletal pain – ache around joints, limbs. Muscle rigidity and cramps • Radicular-neuropathic – pain, numbness or weakness in the area of a nerve root as a consequence of nerve or root compression • Dystonic pain – dystonic spasms • Central pain – tingling, pricking, shooting pain • Akathitic discomfort (akathisia) – subjective restlessness or the painful impulse to move continually • Restless leg syndrome Pain management needs to reflect the fact that people with Parkinson's can have difficulty in localizing their pain symptoms and that many near death will have symptoms of dementia, including confusion and hallucinations, and thus be unable to communicate easily about their experience of pain. (**Fil** A et al, Pain in Parkinson disease: A review of the literature, Parkinsonism & Related Disorders, March 2013, vol 19 issue 3 285-294)	
Parkinson's UK	Short	14	17	It is crucial the guideline states that even though hallucinations are a common feature of Parkinson's dementia, the use of antipsychotics for patients with Parkinson's is contraindicated because of the risk of neuroleptic sensitivity.	Thank you for your comment. We are unable to give this level of detail for specific conditions or diseases.
Paul	Full	Gen		Communication. Although the guidance does	Thank you for your comment. As you state, we have

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Sartori Foundation – Pembrokeshire Hospice at Home		eral		include this, we feel there could be more emphasis on the need to establish a patient's willingness to engage in potentially distressing conversations, and the degree of information they wish to hear. The main motivation for this is that that it offers patients choice, but it also has the merit of avoiding time being wasted on an unwanted conversation - time that could be better spent talking to a patient who needs fuller and more detailed information	addressed this and agree that there is a need to establish a patient's willingness to engage in potentially distressing conversations. Please see recommendation 7 where we feel we have addressed this issue in particular,
Paul Sartori Foundation – Pembrokeshire Hospice at Home	short	7	12	We work closely with social care staff (and indeed are registered as a domiciliary agency ourselves). Although the term 'multi-disciplinary' should include social care staff, this is often overlooked. We would suggest that their inclusion is made more specific	Thank you for your comment. The introductory text for the guideline has been amended to indicate that the guideline is for health and social care professionals.
Paul Sartori Foundation – Pembrokeshire Hospice at Home	short	7	4	We would welcome an explicit suggestion that the most appropriate key worker in an individual case might be a voluntary sector professional	Thank you for your comment. The guideline is for anyone delivering NHS care and we are unable to make recommendations for the voluntary sector.
Paul Sartori Foundation –	short	8	26	The mention of oral hygiene sponges is likely to raise objections in Wales where their use has been discontinued	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.

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Pembrokeshire Hospice at Home					
Paul Sartori Foundation – Pembrokeshire Hospice at Home	short	14	14	In our experience, it is not unusual for a full bladder to be missed as a cause of agitation. Although it is mention in the previous point, it could also be added to the list of examples here. We would also like to see a full rectum specifically mentioned as a possible cause of agitation, as we believe this, too, is sometimes overlooked	Thank you. This has been added.
Paul Sartori Foundation – Pembrokeshire Hospice at Home	short	15	3	We would welcome an explicit suggestion of position changes, with advice to ensure that analgesia is sufficient to cover this.	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Paul Sartori Foundation – Pembrokeshire	short	16	General	We would welcome more advice throughout on prescribing analgesia than can be given by family and social care staff. For example: sublingual lorazepam and buccal prochlorperazine	Thank you for your comment. Our recommendations are made for health and social care staff to implement although it is clear that prescribing remains the remit of the appropriately trained professionals (doctors/nurse prescribers). We do not feel it is the role of this guideline to provide advice

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Hospice at Home					about the administration of medications by the family.
Paul Sartori Foundation – Pembrokeshire Hospice at Home	short	16	General	In our experience, syringes, needles and diluents are often overlooked when patients are transferred from hospital to the community and we would suggest a specific reminder about this	Thank you for your comment. We do not feel it would be appropriate to raise this issue in this guidance as we feel it remains the responsibility of the prescriber and the staff administering the medication to provide the relevant equipment to allow timely administration of the medication.
Paul Sartori Foundation – Pembrokeshire Hospice at Home	short	17	8/9	We anticipate that the biggest challenge will be with regard to communication skills. We feel that the biggest need is for very practical advice that will give specific suggestions for (eg) useful opening lines, how to structure a conversation etc. The advice needs to acknowledge the extremely limited time available for these conversations in many settings.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Pembridge Palliative care Centre	Short	General		No renal or hepatic failure guidance and so some generalists may feel this doesn't apply to their patients at all.	Thank you for your comment. Palliative care for specific diseases is covered in several NICE guidelines and these are listed in the 'related guidance' sections of both the short and full versions of the guideline. We would argue that this guideline provides general recommendations in many areas that are of relevance to all dying people regardless of their condition.
Pembridge Palliative	Short	General		We commented overall that separate sections for end of life in different conditions would be better as can have an opportunity to give clear specific advice	Thank you for your comment. Palliative care for specific diseases is covered in several NICE guidelines and these are listed in the 'related

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care Centre				on specific diseases i.e COPD guidance with an EoL section, MND guidance with EoL section, Cancer …..	guidance' sections of both the short and full versions of the guideline. We would argue that this guideline provides general recommendations in many areas that are of relevance to all dying people regardless of their condition.
Pembridge Palliative care Centre	Short	General		Given the paucity of evidence, it would be better to be clear what advice is based on evidence and what advice is not i.e. differentiating between recommendations (evidence based vs not) and this differentiation may lead to a conclusion that the creation of a consensus statement based on best practice in the absence of evidence may be more beneficial.	Thank you for your comment. It is not NICE policy to highlight consensus based recommendations. However, where recommendations have been drafted based on the consensus of the Committee, this is discussed in the 'Linking evidence to recommendations' statements of the relevant chapter.
Pembridge Palliative care Centre	Short	4	10/11/14/15	It is not clear where the evidence for these have come from especially as we feel it would be challenging for generalists as they are not specific to end of life and could be taken out of context. We also note that lack of radial pulse was discussed in the study (evidence) but not included here.	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. The list of signs and symptoms are examples only, and although they reflect the evidence, are not inclusive. The Committee considered the other examples given to be more appropriate. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline.
Pembridge	Short	4	21	We feel recovering is a misleading/widely open to interpretation. Would suggest using "improving".	Thank you for your comment. The Committee discussed the bullet points in the recommendation

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Palliative care Centre				Also suggest that section should mention trend or reversibility in some way as the message.	and decided to amend these to state: nearing death, deteriorating, stable or improving.
Pembridge Palliative care Centre	Short	4	22	We would suggest adding "senior" review to help teams implement this (with or without palliative care team support) but acknowledge that daily review with the required sensitive conversations should be led by someone senior.	Thank you for your comment. The guideline Committee considers that this recommendation applies to all healthcare professionals delivering care. There is a separate recommendation (1.1.5) that prompts staff to seek advice from colleagues with more experience of providing end of life care if there is uncertainty.
Pembridge Palliative care Centre	Short	6	3-9	We feel this would be challenging to place in the same category as would cause confusion. ACP and Mental capacity assessment are two different concepts although linked in some ways. The MC assessment also only touches on 2 aspects of the necessary criteria. Consider referring to separate guidance when talking about Mental Capacity.	Thank you for your comment. We agree that Advance Care Planning and Mental Capacity assessments are two different issues. However, the recommendation is drafted to ensure that healthcare professionals consider both issues when communicating with the dying person and those important to them during the last days of life. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare Further discussion is provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on Mental Capacity. We have also made further additions to the guideline to provide clarity and to direct

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					professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Pembridge Palliative care Centre	Short	5	23	We would suggest replacing accurate with "clear" as would be easier for generalists to implement and understand.	Thank you for your comment. The Committee believed that 'accurate' was more suited to this situation and do not see this as a hindrance to implementation.
Pembridge Palliative care Centre	Short	7	4	Named lead healthcare professional is too vague and the responsibilities laid out seem quite limited. I think phrasing their responsibility as ensuring the care plan is understood is unmeasurable. Better to say should endeavour to ….	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. The Committee recognises that there may be challenges to its implementation, but that is an aspirational recommendation.
Pembridge Palliative care Centre	Short	General		Our unit commented that the common thread of involving patient and those important to them is good to see, specifically around checking in with which belief system they hold and appreciating that this may impact on how patient's make decisions about their care.	Thank you for your comment.
Pembridg	Short	Gen		We felt that no mention of DNACPR or reference to	Thank you for your comment. We recognise that

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e Palliative care Centre		eral		it was disappointing and in need of mention. We feel it could be added to short version pg 7 line 18 as well as listing ceilings of management/care.	CPR and DNAR decisions are an important area in care of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas are more likely to have a wider impact on clinical practice. DNAR discussions will not be included in this guideline.
Pembridge Palliative care Centre	Short	General		On topic of clinically assisted hydration- too vague and not clear to professionals if there is any evidence to support benefit or harm. Better to say that there is no clear evidence if none exists and to balance that with patient and family expectations vs clinical situation (i.e pulmonary oedema/renal failure/ascites)	Thank you for your comment. The Committee considered the evidence presented (despite being of limited quality) to them to show equivalence in efficacy and adverse events between clinically assisted hydration and usual care or placebo and therefore considered clinically assisted hydration as a valid option, with the caveat that risks and benefits should be discussed and other factors such as level of consciousness and swallowing difficulties are taken into account. Further details are available in the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
Pembridge Palliative care Centre	Short	27	Table 1	Refers to maximum dose of opioids- we feel this is misleading and needs to be omitted as subjective!	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be

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					made available on the NICE website.
Pembridge Palliative care Centre	Short	30	Table 3	No mention of Ondansetron in end of life esp for those in cancer setting	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Pembridge Palliative care Centre	Short	30	Table 3	You mention in the full guideline that cyclizine is over prescribed, however list it first in the anti-emetic list thus risking it's continued over subscribed use.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Pembridge Palliativ	Short	General		Prescribing section- because it it trying to encompass all diseases at the end of life, it is impossible to give clear advise on what to prescribe	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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e care Centre				for which situation therefore better to list the 5 most common symptoms encountered (as per Irene Higginson's work therefore can be evidenced) and suggest users refer to local palliative care prescribing guidelines with or without formal support.	symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Pendleside Hospice	Full version	General	General	Otherwise, comments on long version same as on corresponding sections of short version	Thank you for your comment and for participating in the consultation process.
Pendleside Hospice	Short	General	General	This is long, and non-specialists are unlikely to read it. A shorter summary would be helpful.	Thank you for your comment. Several versions of the guideline are produced at publishing. The short guideline which includes the full list of recommendations, the full guideline and appendices which contains all evidence reports related to the topics covered and an 'Information for Patients' document that explains the recommendations in lay-speak and clarifies what dying people and those important to them could expect from the service at the end of life.
Pendleside Hospice	Full version	General	General	The evidence appears weak and the recommendations do not fully reflect that.	Thank you for your comment. The Committee have drafted their recommendations in line with guidance provided in the NICE guidelines manual which can be found at the following link: http://www.nice.org.uk/article/pmg20/chapter/1%20Introduction%20and%20overview. The manual states

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					in section 9.3.3 that some recommendations may be made with more certainty than others depending on the evidence. Our recommendations are constructed accordingly.
Pendleside Hospice	Short version	3	3	Question 1: This recommendation does not specify who (which grade or role) should be involved in making the decision that a person is dying. This leaves ambiguity and will lead to variation; clarification would help guide practice better.	Thank you for your comment. These recommendations apply to all healthcare professionals delivering care and may be different in each setting. NICE is currently developing guidance in palliative care service delivery and the issue of staff grade/role/seniority may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Pendleside Hospice	Short	9	10	Clinically assisted hydration – we are concerned that this recommendation concentrates on providing information about the possible benefits of CAH on relieving symptoms without information or consideration of the risks and side effects. The evidence is weak in promoting CAH, the recommendation sounds stronger than the evidence would suggest, so this seems potentially harmful.	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given. The order of the recommendations reflects the Committee's decision that the dying person should

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					be supported to drink by oral means first if they wish and are able to before clinically assisted hydration is considered. Further detail is given in the full version of the guideline under 'Linking evidence to recommendations'.
Pendlesi de Hospice	Short Appen dix A	27	Table 1	A prompt to consider alternatives in renal failure is missing. This is an area we struggle with in education, and a specified recommendation would help, particularly in terms of opioids.	Thank you for your comment. An evidence review undertaken during this guideline did not identify any evidence for choice of opioids in patients with renal failure in the last days of life. The Committee agreed that this is a difficult clinical issue but felt unable to make a specific recommendation given the paucity of evidence. In the introduction to this section it is suggested that specialist advice should be sought if there are uncertainties including renal impairment. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, the prescribing tables are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Pendlesi	Short	27	Table	Question 2: If the non-opioid section is felt	Thank you for your comment on the prescribing

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de Hospice	Appendix A		1	necessary, including this as an additional appendix as something to consider would seem more appropriate and leave a clearer recommendation.	tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Pendleside Hospice	Short Appendix A	27-28	Tables 1 and 2	"consider increasing the dose up to the maximum" is not a phrase that makes sense for opioids. This would be difficult to educate about.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Pendleside Hospice	Short Appendix A	32	Table 5	There are several drugs mentioned as options, reducing these for example by having levomepromazine as an oral or subcutaneous option for delirium would help clarity.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Pendleside Hospice	Short Appendix A	33	Table 6	Most literature refers to the dose of glycopyrronium as 200 micrograms SC PRN (not 400micrograms)	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Pendleside Hospice	Short	27	Table 1	Question 1: The non-opioid section appears confusing particularly by being at the top of the chart. The evidence appears to be weak particularly for NSAIDs. The inclusion of rectal measures and intravenous infusion of paracetamol seems more likely to be something that a select few patients might find more beneficial than burdensome. Including information about NSAIDs via continuous subcutaneous infusion seems unnecessarily complicated, and suggesting something quite risky that might be of benefit in few rather than many; the	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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				evidence to support this particularly is poor. We would find this challenging to implement in education, mainly due to the complexity and the need to provide clear information for practitioners who do not care for dying patients all the time.	
Pendlesi de Hospice	Short	Gen eral	Gener al	The prescribing tables are concerning and the provisos need to be made extremely clear and obvious to avoid the generic prescription of drugs rather than an individually tailored approach.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Pendlesid e Hospice	Short	16	8	Question 1: Prescribing anticipatory medication as early as possible can lead to problems, for example for unwell patients who may need assessment before these drugs would be appropriate to give (e.g. if on chemotherapy and at risk of neutropenic sepsis). This could be addressed by detailing circumstances in which it would or would not be appropriate to administer prescribed drugs.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.

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Phyllis Tuckwell Hospice	Short	general	general	This is a good guideline which will help the delivery of good quality terminal care for non-specialists and specialists alike. It will create a consistent evidence based approach but still allow for the individualisation of care plans for patients.	Thank you for your comment and for participating in the consultation process.
Phyllis Tuckwell Hospice	Short	18	8	The text talks about the multi-professional team judging the patient to be in the last few days of life, is this more a medical and nursing decision? I have often questioned whether all the members of the multi-professional team are trained to recognise dying. For example are our chaplaincy, physiotherapy or occupational therapy team members trained to recognise the signs of a dying patient; especially as part of this assessment relies on understanding the person's medical history and clinical context.	Thank you for your comment. The multiprofessional team would include all healthcare professionals caring for people who are dying, in particular those working in primary care, care homes, hospices and hospitals. This may include physiotherapy or occupational therapy staff who deliver NHS care. We do recognize that there are a number of care providers, not necessarily 'senior' level who are skilled, experienced and competent in recognizing dying. It will be important not to de-skills this group of care providers by always requiring senior input however we do make reference to the requirement to seek specialist advice where there is uncertainty.
Phyllis Tuckwell Hospice	47. Short	48	49.	50. The signs and symptoms that suggest a person is entering the last days of life appears as a fairly randomly grouped collection of objective signs and more subjective nebulous signs. I wonder whether these need better grouping as Cheyne-Stokes breathing is almost pathognomonic of dying whereas fatigue can occur early in disease, perhaps many	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8).

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				months before death.	
Phyllis Tuckwell Hospice	Short	general	general	The guideline seems not to acknowledge that most dying people are semi-responsive or unconscious and therefore they are unable to take part in the discussions, to the level the guidelines suggest. Whilst it is best practice to involve the person in all decisions relating to their care, it is important to acknowledge that this may not be possible or as in depth as one would like it, ideally. Not only is conscious level a limiting factor but also fatigue can hinder thorough communicating.	Thank you for your comment. The committee noted that people are not always semi-responsive or unconscious as they enter the last days of life and wished to make clear that, if possible and appropriate, dying people should always have their care options discussed with them. Further detail has been added to the 'Linking evidence to recommendations' section of chapter 7.
Phyllis Tuckwell Hospice	Short	8		Maintain Hydration: A review of the patient's hydration status on a daily basis is suggested but not how to do this. Given that blood tests are unlikely to be taken at this late stage of the illness and the patient is likely to be unconscious with a number of anti-muscaric drugs drying the oral mucosa what is best practise in assessing hydration? Would it be worth commenting on this? Similarly in 1.4.8 how one monitors whether a therapeutic trial of clinically assisted hydration is successful or not. (Section 1.4.4)	51. Thank you for your comment. We are unable to comment on methods of hydration status as a review was not prioritised in this area. However, the 'Linking evidence to recommendations' section of the full details states that as hydration status can be assessed clinically, performing blood tests in the last days of life may not provide benefit. We would anticipate that assessing hydration status would be part of clinical judgment skills and as such does not warrant separate comment. Further detail for monitoring benefits and harms of clinically assisted hydration is given in the 'Linking evidence to recommendations' section of the full guideline.
Phyllis	Short	11		Is it realistic that for a dying patient with learning	Thank you for your comment. An evidence review

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Tuckwell Hospice				difficulties being able to take part in using a validated behavioural pain assessment tool, given that they are likely to be unconscious as well as struggling cognitively at the best of time. (Section 1.5.3)	was not conducted on the use of pain assessment tools in the last few days of life, however the Committee chose to make a recommendation about their use based on their own clinical experience. The Committee were particularly concerned that pain may be undertreated in a dying person who cannot effectively verbally communicate and that other signs and symptoms that may be a sign of pain, may be treated inappropriately with sedatives rather than analgesics. Further detail has been added to the 'Linking evidence to recommendations' section of this chapter in the full guideline.
Phyllis Tuckwell Hospice	Short	12 14 22	7 12 4	**Inconsistencies in terminology** the guideline uses the term "full bladder" whereas elsewhere in the guideline it refers "bladder retention" and in one other page it refers to the same problem as "urinary retention"	Thank you for your comment. We believe that there are subtle difference in the intentions behind these terms and do not feel it appropriate to use one term.
Phyllis Tuckwell Hospice	Short	13		Under the heading of "Nausea and Vomiting" is it worth suggesting that the pre-dying antiemetics should be continued where possible and the route discussed and altered as needed.	Thank you for your comment. The Committee feel that this is covered under the general pharmacological recommendation about medicines reconciliation and considering route of administration.
Phyllis Tuckwell Hospice	Short	general	general	Symptom control for the dying patient should be considered as an emergency situation, because in common with other more classical emergencies such as a ruptured triple aortic aneurism, there is a lack of time in which the doctor or clinician has to act	Thank you for your comment. We do recognize that there are very difficult issues to address for some individuals as they approach the end of their lives. We believe our recommendations on anticipatory prescribing which recommend a tailored,

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				within. Getting it wrong within the short time frame, for both the dying patient and the ruptured triple aortic aneurism has tremendous adverse consequences.	individualized approach to prescribing would address these issues. We have provided further detail in section 10.8 of the full guideline.
Phyllis Tuckwell Hospice	Short	general	general	Mostly through the guideline the term "syringe pump" is referred to rather than the term "syringe driver". The main manufacturer of syringe drivers refers to the whole class of device as a "syringe driver" and the particular model that is mostly used as a syringe pump. It is therefore more accurate to call the device a "syringe driver" and more familiar to staff as well	Thank you for your comment. The Committee discussed the terminology of pump versus driver and reached a consensus decision to use pump. This has been detailed in the full guideline glossary.
Phyllis Tuckwell Hospice	Short	27		In the table for prescribing of pain relief, increasing the dose of analgesia to the maximum dose if the dying person is still in pain but this does not make sense in the context of opioids as there are no ceiling doses for many of the strong opioids. Also in this table there is no dose reference for Diclofenac in a syringe pump. Nor was I aware that there was any evidence that Paracetamol can be given by a subcutaneous infusion.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Phyllis Tuckwell Hospice	Short	30		I feel the table for the management of nausea and vomiting needs a foot note about Metoclopramide being contraindicated in Parkinson's Disease-in a	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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				similar manner to the foot note about caution use of Cyclizine in heart failure and Domperidone and Metoclopramide in bowel obstruction.	symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Plymouth Community Healthcare CIC	Full	Whole document		Overall There are a range of issues the guidance does not cover including people still engaging in high risk behaviours whilst in the last weeks of life (i.e. drinking/drugging) and working effectively within the guidance with hard to reach individuals including travelling communities/ homeless and roofless etc.	Thank you for your comment. The guideline focusses on the clinical care of the dying adult in the last 2-3 days of life. The guideline has not been able to address all issues relevant to the care of the dying adult. This issue is beyond the remit and scope of this guideline. Reference is made in the document to the issues for homeless people/travellers in the last 2-3 days of life. They are also discussed in the Equalities Impact Assessment form that accompanies the guideline.
Plymouth Community Healthcare CIC	Full	79 81	8	Recognising someone entering the last days of life The ECOG and Zubrod scores seem quite simple and may not help in the determining if someone entering last days of life, I would expect clinicians to have more of an understanding of changes to individual patient's condition. Should other changes to patients such as skin change at end of life (SCALE) rather than just mottled? As recommended by EPUAP	Thank you for your comment. The Committee recognise that other functional observations may be useful, but give examples here based on the evidence identified. After careful consideration the example of ECOG has been removed from the recommendation and replaced with: Functional observations, for example deteriorating performance status, social withdrawal, changes in communication. Further detail has been added to

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				http://www.epuap.org/scale-skin-changes-at-lifes-end/	the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8).
Plymouth Community Healthcare CIC	Full	108		Shared decisions Some CCG's have policies in place which keep tight financial control on the budget for end of life care packages, this has not been mentioned as part of the decision making process No mention of shared care plans handover of documentation, this would be best practice and ensure continuity of care.	Service delivery, including resource implications for palliative care was outside the remit and scope of the guideline. NICE is currently developing palliative care service delivery guidance that may address this issue. Please note that more detail about this work can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799. The committee agree that handover of documentation is important, but feel that this is standard good practice and was not prioritized for discussion in this guideline on clinical care in the last days of life.
Plymouth Community Healthcare CIC	Full	86		Communication There was no mention of treatment escalation plans, or the use of IT systems such as Adastra to inform or communicate with other health care services such as paramedics, 111, 999, out of Hours District Nurses, who may attend a patient in an emergency situation. This is an approach used with Devon facilitated by the Devon Doctors Service.	Thank you for your comment. Service Delivery, including communication systems, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Plymouth Com	Full	223	26	Anticipatory medication In some areas there is use of a "Just In case bag" which is a small selection of drugs available	Thank you for your comment. The Committee noted that this was the case in some parts of the country. The Committee discussed the potential benefits and

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munity Healthcare CIC				if a palliative patient has a deterioration in clinical condition then at end of life "anticipatory medication plus syringe driver" available,(JICB removed) the guidance was slightly confusing in respect to this.	harms of this type of approach but did not feel there was sufficient evidence to make specific recommendations about this. We have made a research recommendation to address this evidence shortfall. This can be found in section 10.9 of the full guideline
Public Health Agency	Short	Page 10	1.5.1 Line 19	We would have concerns about the practical implementation , particularly on ward round if family are not present at that time and patient not taken medication need to stop/ review/ anticipatory prescribe at that point not postpone as moment maybe lost and patient suffers.	Thank you for your comment. Our guidelines are intended to be very individually focused and the unavailability of those important to the dying person will not delay the standards of care supported by the draft recommendations. Healthcare professionals are encouraged to engage and include those important to the dying person where appropriate, and whenever possible.
Public Health Agency	Short	Page 18-19		We support the extension of the guidance to beyond the last days of life and believe that earlier planning can enhance good quality of life throughout a person's journey, whilst leaving planning until the end of life can run the risk of impacting vital issues such as capacity of decision making and availability of resources such as drugs and equipment.	Thank you for your comment. The guideline has purely focussed on the clinical care required in the last days of life as this was felt to be an area where guidance was lacking following the withdrawal of the Liverpool Care Pathway. The Committee recognises that for many areas included in the guideline (including for example communication, shared decision making and advance care planning), care should be initiated or planned for long before the last days of life but we are unable to extend the guideline beyond its remit and scope.

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Public Health Agency	Full	Comment		We would request that the status of this guideline needs to be made clear in terms of where it sits with other national and local documents/ guidance focused at improve Care of the dying adult. Care of the dying adult could be compromised if clinicians do not have a clear steer on this as a matter of urgency.	Thank you for your comment. NICE provides national guidance and advice to improve health and social care. Guidelines are evidence based and may sit alongside national policy but are developed independent of it. They may be used to inform national and local documents and guidance.
Public Health Agency	Full	Comment		We would suggest to support the implementation of the Guidance, there should be consideration within the guidance on adequate resourcing, training, education, and support required for health and social care staff for the Dying Adult Patient.	Thank you for your comment. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Public Health Agency	Full	comment		Palliative Oedema It is disappointing that palliative oedema not referenced in the guidance document. This would be an area that should be considered for inclusion in future guidance. Simply recognition that swelling at end of life is mostly related to hypoproteinaemia rather than lymphoedema	Thank you for your comment. This issue is beyond the remit and scope of this guideline.
Public Health Agency	Full	General		We welcomed the guidance which was very positively received by the staff that reviewed and commented. Professor Sam Ahmedzai and his colleagues have clearly invested a great deal of time and effort in compiling the Guideline and they	Thank you for your kind comment and for participating in this consultation process.

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				deserve to be commended for their hard work	
Public Health Agency	Full	General Page 34-38		We acknowledge that training, workforce planning and service delivery fall outside the scope of this guideline; however, we would like to emphasise that high quality care for all cannot become a reality without them. We look forward to working with NICE and sharing our experiences of best practice in the future to make sure the second guideline on improving supportive and palliative care, including service delivery, is as robust as possible and has wider applicability to those in the dying phase of their life.	Thank you for your comment. Please note that more detail about the development of the service delivery guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Public Health Agency	Full	General		We suggest palliative oedema could be referenced in the guidance document. This would be an area that should be considered for inclusion in future drafts of the guidance. Simply recognition that swelling at end of life is mostly related to hypoproteinaemia rather than lymphoedema.	Thank you for your comment. This issue is beyond the remit and scope of this guideline.
Public Health Agency	Full	General		We suggest the Guidelines provide reference to the training needs of the staff who will implement them, and also make recommendations for how the Guidelines should be audited.	Thank you for your comment. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link:

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					http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799. The RCP undertakes an annual audit of end of life care and we would hope that that audit if funded further would measure implementation against our recommendations.
Public Health Agency	Full	General		Lack of holistic assessment We suggest the Guideline provides useful information for those working in the community in terms of the practicalities and drug treatments for common symptoms. The Guideline does not appear to relate to the other non-physical factors which contribute to symptomatology nor distinguish between the potential contributions which non physical factors can make to symptomatology and to the treatment of the same. Part of the core curriculum in General Practice is to always ensure that a patient's symptom is assessed holistically, and this is particularly relevant in end of life care	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult.
Public Health Agency	Full	General		We suggest consideration and reference to carer's pre and post bereavement needs	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult.
Public Health Agency	Full	General		We suggest consideration to include information situations where post mortem may be required	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult.

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Public Health Agency	Full	General		We are concerned that a barrier to implementation here will be the availability of experienced professionals or specialist palliative care professionals to provide advice, particularly at weekends and out of hours.	Thank you for your comment. Service Delivery, including availability of specialist palliative care advice out of hours, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Public Health Agency	Full	General		Northern Ireland clinicians through the Regional Palliative Medicine Group have developed Guidance for the Management of Symptoms in Adults in the Last Days of Life which have been endorsed for use in Northern Ireland. We would be willing to submit the Guidance for the Management of Symptoms in Adults in the Last Days of Life to the NICE shared learning database. Contact Dr Kiran Kaur Consultant in Palliative Medicine Belfast Trust (Royal Hospitals) and Northern Ireland Hospice Working Days Mondays, Wednesdays, Thursdays	Thank you for your comment. NICE guidelines do not make reference to other guidelines but we will ensure that this information is passed to our implementation colleagues at NICE.

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				(NI Hospice) & Fridays Elliott Dynes Rehab Unit, Royal Hospitals Grosvenor Road Belfast BT12 6BA Contact no: 028 9063 5311 or 4409 or (Hospice) 028 9078 1836 EMAIL: Kiran.Kaur@belfasttrust.hscni.net	
Public Health Agency	Full	General		Northern Ireland are currently engaging with service users and carers to begin the process to develop public facing supporting information in order to prepare for the implementation of the NICE guidance. We would be willing to submit the supporting information to the NICE share learning data base or for it to form part of the NICE public supporting information.	Thank you for your comment. We will ensure that this information is passed to our implementation colleagues at NICE.
Public Health Agency	Full	General		We would like greater reference made to advance care planning including DNACPR.	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult. This issue is beyond the remit and scope of this guideline.
Public Health Agency	Full	General		We would suggest the current layout would benefit from reformatting. Accessibility to the key considerations which need to be made by clinicians to improve care of the dying adult are at risk of being lost due to the current level of detail included in this draft guideline. Suggest consideration of other methods to present	Thank you for your comment. The full guideline to which you refer is intended to be the detailed document providing information about methods, evidence reviews and Committee discussions that inform the recommendations. A shorter version of the guideline is available (the NICE guideline) which reproduces the recommendations only.

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				information as such e.g in a flow chart /charts format.	
Public Health Agency	Full	General		We welcome research focus within the document . Research into palliative and end of life care has historically been under-funded and there is a need for greater attention in this area.. Topics which are particularly relevant to the scope of this guideline and may warrant consideration or mention in this section of the guideline include: assessing and treating pain and discomfort for people with cognitive impairment or communication difficulties at the end of life; ensuring continuity for patients at the end of life, and how best to listen to and incorporate patient preferences in care planning.	The process for formulating research recommendations is outlined in section 9.5 of the NICE guidelines manual which can be found at the following link: http://www.nice.org.uk/article/pmg20/chapter/1%20Introduction%20and%20overview. Further detail is also provided in section 4.4.1 of the full guideline. The Committee have only been able to formulate research recommendations in areas where evidence reviews have been undertaken. The Committee have prioritized three recommendations for further research further to their review of the evidence. These are linked to recognizing dying, agitation and delirium and noisy respiratory secretions. Full discussion is provided in Appendix O.
Public Health Agency	Full	General		We would ask why does the guidance not cover clinically assisted nutrition?	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult. This issue is beyond the remit and scope of this guideline.
Public Health Agency	Short	Page 3	1.1.2 line 19	We suggest the alphabetical listing of signs and symptoms is open to misinterpretation. Some of these symptoms relate to understanding of disease progression/ increased frailty over time e.g. weight	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to

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				loss; others are signs of imminent death e.g. mottled skin; still others are indicative of nearness to death only with specific contextualisation e.g. social withdrawal. Taken out of context it can be suggested that people could be taken to be dying on little evidence. – reported in the lay press already. These points need better contextualisation (as in the full guideline).	provide clarity. Further detail has been added to the Linking evidence to recommendations' section of the full guideline.
Public Health Agency	Full	General		We suggest clarify on who is responsible for diagnosing that someone is dying.	Thank you for your comment. The Committee consider these recommendations to be applicable to whoever is responsible for delivering care for people who may be entering the last days of life. We recognise that in many cases the setting could be one where the dying person does not have immediate access to the full range of clinical staff including senior doctors. We are keen to ensure that all staff caring for people at the end of their life should have the ability to recognize dying (or their potential for recovery) with access to more senior or specialist support as required. Similarly, the need to recognise the potential for dying could occur 'out of hours' when senior medical staff are not always available. Therefore we did not think it appropriate to define only one group and a specific level of seniority, expecting also that many nurses, GPs and medical trainees in the front line of care should possess these skills, but also should have access to more senior staff and specialists in care of dying

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					people as part of the multidisciplinary decision-making and review process.
Public Health Agency	Full	General comment on Page 54-85	Recognising when a person is in the last days of life section	We welcome the focus on the much earlier recognition of 'dying' in the document . When it comes to 'recognising dying' there is an acknowledgement that as a patient's condition changes, many changes that may be seen weeks before the person could be said to be in the 'last days', should be triggers for discussions and decision making that may lead to changes in care and treatment- this may prompt earlier discussions with patient and family about the future. The guidance is a subtle reminder that while the LCP focused on last days and hours (a vitally important time) it is also very important to be aware that there will often be changes in a patient's condition much earlier that would allow communication and care planning in advance of a person's last hours, and that health professionals should be able to read and act on these signs.	Thank you for your comment. The remit of this guideline is last days of life so we are unable to comment on earlier time points, but have made reference to changes occurring in the last weeks in the introduction to the chapter.
Public Health Agency	Short	Page 4	1.1.3	We suggest this section is expanded beyond 'nearing death or recovering' and includes an assessment on whether or not the state of decline is based on anything which is clinically reversible eg infection, hypercalcaemia. Then appropriateness of treatment should be clinically ascertained	Thank you for your comment. The Committee discussed the bullet points in the recommendation and decided to amend these to state: nearing death, deteriorating, stable or improving.

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Public Health Agency	Short	Page 4	Line 22	We would have concerns about the practical implementation for monitor every 24hrs Particularly in a community setting if no syringe driver and asymptomatic especially at weekends	Thank you for your comment. The Committee consider the recommendations equally applicable to hospital and community settings and believe that implementation is manageable after careful discussion on the matter
Public Health Agency		Page 7	1.3.5 Line 18	We welcome the guidance on producing individual care plans. We believe that further information could be included on the form this should take to encourage best practice in documenting people's wishes and facilitating ease of accessibility and use amongst professionals and different settings, e.g. when transitioning from community to hospital care or for providers of out of hours care.	Thank you for your comment It has not been within the remit of this guideline to address appropriate documentation. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Public Health Agency	Full	General		We would suggest it would be helpful to mention of communicating with GPs etc	Thank you for your comment. We consider that GPs are part of the multi-professional team and as such our recommendations are applicable to GPs.
Public Health Agency	Full	comment		We would suggest that shared decision making, could be referred to as shared goal setting to increase the partnership working balance with patients. Clinician's should follow the patient's lead when it comes to goal setting supporting the patient to set SMART goals and revisiting resetting goals as patient condition dictates	Thank you for your comment. This guideline is for the last few days of life. While the Committee shares your view on the importance and value of goal setting it does not quite convey the activities covered by end of life care delivery.

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Public Health Agency	Full	General comment on page 86-108.	Communication section	We welcome that while it is important to discuss prognosis with the dying person and their family, it has been acknowledged that not all dying people wish to be informed of their prognosis. The section could be enhanced if written in more facilitative language rather than current information giving language, drawing and promoting the use of advanced communication skills in the guideline.	Thank you for your comment. The Committee believes that the need for the strategies mentioned in your comment would emerge, when the communication needs of the dying person have been assessed and explored. Recommendation 7 acknowledges that not all people wish to be made aware of their prognosis and this is discussed in the 'Linking evidence to recommendations' section 6.6 of the full guideline.
Public Health Agency	Full	General		We suggest that it could cause confusion between use of terms such as advance care planning and individualised plan of care.	Thank you for your comment. We have added definitions in the guideline's glossary about advance care planning, advance statements and advance decisions on refusal of treatment. The recommendations have also been amended to clarify the terms used in the process of advance care planning.
Public Health Agency	Short	Page 5	1.2.2 line 13	We suggest that the statement about discussion with significant others should have some clarity that discussions could take place in the patient's best interest if the patient is unconscious / lacking capacity.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental

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					capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Public Health Agency	Short	Page 6	1-2	We suggest specifically providing details of members of the team who could support the dying person such as the Chaplain and Social Worker.	Thank you for your comment. The Committee agrees that this is important. Recommendation 2.2.1 encourages healthcare professionals to establish the communication needs and expectations of people who may be entering their last days of life, taking into account any cultural, religious, social or spiritual needs or preferences that should be considered. Further detail has been added to the 'Linking evidence to recommendations' section for this chapter in this regard (see section 7.6).
Public Health Agency	Short	Page 7	1.3.3 Line 4	We welcome the inclusion of a named lead healthcare professional. We know that a lack of information, consistency, coordination of services and help to navigate the complex health system is a considerable problem and cause of stress for people and their families in the last day of life.	Thank you for your comment.
Public Health Agency	Short	Page 7	1.3.5 Line 26	We suggest there should be inclusion to severity of symptoms – perhaps implying that all symptom management is unnecessary. Last bullet point – "needs for care after death, if any are specified"- a guideline should help providers recognise issues that they were not aware of- this needs to be reformulated so that providers will enquire about needs.	Thank you for your comment. The Committee preferred to capture preferences for symptoms management within this recommendation and any detail about severity would be captured by this. Further amendments have been made to this recommendation in relation to symptom management. This now reads: current and anticipated care needs and preferences for symptom

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					management Care after death was outside the scope of this guideline.
Public Health Agency	Full	Page 150	Rec. 25	We think this recommendation will be a challenging to implement in practice because of the training re, staffing and equipment required, particularly in a community setting.	The Committee intend this recommendation to apply to all settings, including the community, but note that there may be challenges to its implementation. NICE is currently developing guidance in palliative care service delivery and the issue of resources and training may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Public Health Agency	Full	Page 151		Some LMDM members support those GDG members view that clinically assisted hydration is another intervention which is invasive. Based on the available evidence presented for the clinical benefits and harm within the guidance, we would be suggest that recommendation 25 stating that '*clinically assisted hydration be considered preferably on a daily basis'*, may be too prescriptive and may have implications for implementation of the guidance.	Thank you for your comment. The order of the recommendations reflects the Committee's decision that the dying person should be supported to drink by oral means first if they wish and are able to before clinically assisted hydration is considered. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and have changed 'unlikely' to 'uncertain' whether providing clinically

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					assisted hydration will prolong life or the dying process or hasten death if it is not given. The recommendation to which you refer reminds practitioners to review the possible need for clinically assisted hydration and then only to provide a therapeutic trial to assess benefit. Further details have been added to the full version of the guideline under 'Linking evidence to recommendations'.
Public Health Agency	Full	Page 151	Rec. 26	We would suggest that from the evidence and statements presented in the document it is difficult to outline the risks and benefits of as opposed to no clinically assisted hydration, therefore having discussions with patients and their carers may prove challenging.	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and have changed 'unlikely' to 'uncertain' whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given. The full guideline 'Linking evidence to recommendations' statement in section 8.6, gives further details, including adopting an individualized approach and considering existing co-morbidities.

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Public Health Agency	Full	Page 153		We would advise that the use of wet oral hygiene sponges are use are in line with the advice of the Medical safety alert -foam heads of oral swabs may detach from the stick during use, which may present a choking hazard for patients. (MDA/2012/020)	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline
Public Health Agency	Full	Page 153		We would have concerns that the statement *other measures of hydration can be used if aspiration of fluids is problematic such as ice chips* could imply that ice chips were a reduced risk option for those who are at risk of aspiration.	Thank you for your comment. This has been amended.
Public Health Agency	Full	Page e150		We are concerned that this recommendations on page 150 may not reflect strongly enough the statement on Page 153 *The GDG was keen to note that the management of hydration in the dying person should always be individualised and, wherever possible, be by oral means. They felt it important to make a recommendation that indicated that this should be encouraged.*	Thank you for your comment. The Committee aimed to reflect the preference for oral hydration where possible in the order of the recommendations. In addition recommendation 29 has been amended to state: Consider a therapeutic trial of clinically assisted hydration if the person has distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium and if oral hydration is inadequate.
Public Health Agency	Short	Page 9	1.4.6 Line 8	We suggest that there should be reference to the potential harms of assisted hydration in the short document as per the full version- see page 153 main document re the need better to inform patients and relatives.	Thank you for your comment. Unfortunately this is a limitation of the short guideline and we are unable to provide more detail. As you state, detail is provided in the 'Linking evidence to recommendations' statement in section 8.6 in the full guideline.

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Public Health Agency	Short	Page 10	1.5	We suggest consideration should include as a general concept the potential value of having "as required" medication available	Thank you for your comment. The Committee agree and have made several recommendation on anticipatory prescribing – see section 1.6.
Public Health Agency	Short	Page 10	1.5.12 Line 10	We would suggest that the documents need to include if the patient can actually receive medication via that route – this needs to be assessed as well as preference.	Thank you for your comment. The Committee agree that the route of administration is an important consideration and this is detailed in recommendations 1.5.4 and 1.5.5.
Public Health Agency	Short	Page 11	1.5.3 Line 5	We suggest that the document needs to reinforce discussing cultural views re symptom management – need to check not making cultural assumptions but individual informed choice.	Thank you for your comment. The Committee agree that this is an important issue. Please also see the chapters on communication and shared decision making for additional information.
Public Health Agency	Short	Page 11	1.5.8 Line 25	We would suggest that it could be challenging assessing patients symptoms daily. In the interest of producing a document that can be used in community as well as hospital / care homes – this is a retrograde step that reduces the assessment of potentially difficult symptoms to once daily.	Thank you for your comment. The Committee consider these recommendations are applicable to all settings and expect that dying people would have symptoms assessed daily in the last days of life when medications are being administered to ensure that they may be titrated effectively or other medications prescribed that may be more helpful.
Public Health Agency	Short	Page11	1.5.6 Line 17	We would suggest that the statement is confusing re Syringe drivers. These have specific uses. However if a patient requires multiple PRN doses in 24 hours – they may need commencement/ review of longer acting medication not necessarily syringe drivers.	Thank you for your comment. This recommendation is a "consider" recommendation, which reflects its weaker strength and that there is some uncertainty around the evidence behind this recommendation. However, the Committee considered that it is a useful option in some cases.

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Public Health Agency	Short	Page 25	Line 20	Alphabet listing is confusing - the most commonly prescribed drugs should be listed first, following the same principle of the order of the symptoms in the point above.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Public Health Agency	Short	Page 27	Table 1	<u>Prescribing for the management of pain in adults in the last 1 days of life</u> 1) Table format can be improved as difficult to follow - suggest flow chart format instead. THIS APPLIES TO ALL THE TABLES. 2) RECTALLY - This route is very rarely used in practice - perhaps a footnote can be added that this route may be considered if necessary 3) Diclofenac and Ibuprofen continuous subcutaneous infusion - Ibuprofen is not available as an injectable form - Parecoxib can be used if needed but this would not be initiated as first line. Would normally prescribe low doses of opioids in this	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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				situation if patient unable to take oral drugs and in pain 4) Orally opioid analgesics: There is no maximum dose for opioids, hence this statement is confusing. 5) Morphine sulphate 1.25-2.5mg: Would not use decimal points unless unavoidable. This is to reduce errors in prescribing .THIS APPLIES TO THE REST OF THE DOCUMENT ALSO. Suggest 2mg and 1-2mg here. 6) Continuous subcutaneous infusion of morphine sulphate 10-20mg as starting dose: Would prescribe lower doses - 5-10mg.	
Public Health Agency	Short	Page 28	Table 2	<u>Prescribing for management of breathlessness in adults in the 1 last days of life</u> 1) Points 1, 2,4 and 5 as above 2) If still breathless with opioid (despite dose increases and switching), consider adding a benzodiazepine: Benzodiazepines are added for anxiety related to breathlessness	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This

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				and is not a treatment for breathlessness per se. 3) Continuous subcutaneous infusion - Clonazepam : Currently, Clonazepam injection does not have a UK marketing authorisation. Would not start Midazolam above 10mg unless patient was already taking regular oral benzodiazepines. 4) Midazolam 5 - 20mg over 24 hours continuous subcutaneous infusion : Would normally start at lower dose of 5-10mg 5) Midazolam Buccally - not commonly used route for breathlessness; recommend adding "up to" 4 times a day.	important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Public Health Agency	Short	Page 30	Table 3	<u>Prescribing for the management of nausea and vomiting in 1 adults in the last days of life</u> 1) Buccal route if patients not able to take oral route for nausea and vomiting – usually not appropriate if patients not able to take oral route, especially in last few days of life	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This

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				2) Proclroperazine – Not commonly used, suggest insert buccal preparation in this column rather than "If unable to take oral drugs" column 3) Levomepromazine 6 – 6.25mg : Suggest 6mg or 6.25mg 4-6 hourly (as 6-6.25mg implies dose range between 6 and 6.25mg.) 4) Subcutaneously or *intravenously* Levomepromazine 2.5 – 5 up to mg 12 hourly – intravenous route not used, suggest Levomepromazine 2.5-5mg 4-6 hourly up to ?50mg daily. 5) Note b) at bottom of page – cyclizine and site reactions – suggest : Should be used with" Water for Injections" as diluent to minimize site reactions	important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Public Health Agency	Short	Page 31	Table 4	<u>Prescribing for management of anxiety (with or without 1 agitation) in adults in the last days of life</u> 1) Maximum dose of anxiolytic medication – difficult to determine what this dose is 2) Midazolam 5 - 20mg over 24 hours starting dose: 20mg is a rather high starting dodose especially if this is aimed at generalist staff, suggest 5-10mg	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Public Health Agency	Short	Page 32	Table 5	<u>Prescribing for management of delirium (with or without 1 agitation) in adults in the last days of life</u> 1) Maximum dose of antipsychotic is difficult to determine what this is 2) Olazepine and Risperidone - Both these drugs are not commonly initiated in the last days of life; also has implications for dose adjustments in liver and renal failure. Levomepromazine not used intravenously	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Public Health Agency	Short	Page 33	Table 6	<u>Prescribing for the management of noisy respiratory secretions 1 in adults in the last days of life</u> 1) Glycopyrronium doses - 1200 micrograms of glycopyrronium equivalent to 2400	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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				micrograms of hyoscine, which is the maximum dose. For consistency, starting dose should be 600 micrograms for continuous subcutaneous infusion 2) Note a) - Monitor for unwanted sedation and other side effects - Due to unwanted sedation and other side effects, Glycopyrronium is used first line.	implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
RCGP Wales	Full	11-19		When presented in this format, they recommendations are difficult to read. They are not categorised, it is not always clear what topic area they apply to, and they are repetitive in their language. As this overall summary list may be the first place readers come across the recommendations the format and presentation needs to be clearer in terms of the topic area each recommendation applies to.	Thank you for your comment. Sub headings will be added to the final versions of this guideline, for improved clarity.
	13	18-25		There is no suggestion or guidance on who the lead Health care professional responsible for shared decision making should be. This may lead to conflict between professionals and a delay in decision making. It may be helpful to emphasise that whist one person should take the lead and ensure shared decision making takes place, there is a collective responsibility on the whole mdt . In other	Thank you for your comment. We agree that there is a collective responsibility for ensuring effective and shared decision-making. Other recommendations place the emphasis on all members of the multiprofessional team having responsibility for ensuring that the wishes and needs of the dying person are addressed. They felt it important, however, to ensure that one specific

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				recommendations there has been an emphasis on the fact that who takes the lead may be influenced by whom is most involved with or has the best rapport with the patient.	individual should be responsible for leading the discussions linked to decision-making to avoid the situation of other providers thinking someone else had provided that function, when in reality, no-one had prioritized this issue.
	General			The recommendations around artificial hydration seem sensible and pragmatic and reflect the evidence presented. In a hospital setting, this may result in decreased IV hydration. However there is not currently consistent access to artificial hydration in the community setting which may affect the options that can be offered. Non specialist health care professionals may feel compelled to offer artificial hydration which may lead to an inability to carry out care in the community setting due to lack of resource. Although the recommendations on this topic are quite clear and helpful, this is the area that is most likely to result in change in practice. Perhaps a decision support tool designed to support both patients/carers and professionals would be helpful	Thank you for your comment. Strategies to maintain hydration in all settings are provided in the recommendations. The importance for maintaining hydration is the aim of all of our recommendations and we believe this may be achieved by oral or clinically assisted hydration. The Committee noted the importance of maintaining hydration as a priority in the last days of life and that any decision to provide clinically assisted hydration should be based on individual needs and circumstances. We would disagree that this means there may be decreased clinically assisted hydration in hospitals. We agree that there may be some challenges in providing clinically assisted hydration in the community settings but the Committee had experience of this being effectively provided in this setting. The other recommendations in this section outline the issues to be considered when assessing the need for such support and do not feel any further decision support tools are required.

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	11	27		Due to a general lack of familiarity with ECOG scoring, it's inclusion as an appendix may be helpful, or a summary chart of factors to consider when assessing whether someone is dying (a visual tool or guide similar to more medium term prognostic indicator guides)	Thank you for your comment. We have added further detail on ECOG scoring to the glossary of the guideline and have added a hyperlink to direct the reader who requires further information on this criteria.
Full	General			Multiple references are made to 'non-pharmacological measures' for managing symptoms. Whilst for pharmacological symptom control a summary table has been included, there is no detail or suggestions for non pharmacological measures. This implicitly suggests that pharmacological benefits may be more effective, regardless of the level of evidence.	Thank you for your comment. We are unable to comment specifically on non-pharmacological measures for managing symptoms as we did not undertake an evidence review in these areas as it was beyond the scope and remit of this guideline. As such no specific evidence reviews on non-pharmacological interventions for symptom management at the end of life were undertaken and specific recommendations were not made as the evidence base for them was not evaluated. The Committee recognize their importance and value as part of care and have made a number of consensus recommendations. Examples, however, are provided in the relevant 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
RCGP Wales		16	17-21	As is highlighted in other parts of the document, octreotide is difficult to source in the community setting and there are issues around storage. This might mean that this recommendation is discounted in the community setting.	Thank you for your comment. The Committee recognised that there may be challenges in accessing Octreotide as a treatment option for Nausea and Vomiting, but, chose to recommend it as a second line therapy as it is a valid treatment

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					option. Further information on the Committee's discussions in this area can be found in section 9.13 of the full guideline. The Committee intend this recommendation to apply to all settings, including the community
RCGP Wales		218	3	There is no reference to the need to calculate appropriate doses when converting from one opioid to another (both type and route). There ideally should be some reference to this as it affects dose choices.	Thank you for your comment. It is not possible for the guideline to outline all clinical actions to be undertaken, especially as part of prescribing practice. This guideline assumes that prescribers, regardless of setting or specialism, will follow standardised prescribing principles and relevant professional guidance, for example as outlined in the British National Formulary or by the General Medical Council.
Resuscitation Council (UK)	Short and full	General		An evidence-based guideline of this nature with a limited scope is best regarded as one of many possible sources of information to be used by those who have the responsibility of providing high-quality end-of-life care. There is a danger that people will regard adherence to the contents of this guideline as all that they need to do to deliver high-quality end-of-life care. Good clinical reasoning is an essential component of good clinical care, allowing an HCP to allow for the interactions between the different pieces of evidence that have been assessed separately, and to recognise and take into account how those pieces of evidence and their interactions may or may not apply in each individual person at any specific time.	Thank you for your comment. This guideline responds to a need for an evidence-based guideline for the clinical care of the dying adult throughout the NHS. It is focussed on care needed when a person is judged by the multiprofessional clinical team to be within a few days of death. The aim of the guidance is to provide a set of recommendations to guide healthcare professionals to recognise better when a person is dying, how to communicate and share decisions respectfully with the dying person and those important to them, and how best to manage difficult symptoms in order to maintain comfort and dignity without causing unacceptable side effects. This has effectively addressed the three main areas of concern highlighted by users of the LCP. This

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				This guideline cannot be regarded as a replacement for the LCP, as has been implied in the media.	has been highlighted in the introductory text of all versions of the guideline. . Healthcare professionals are expected to take NICE guidance into account as part of clinical care. But it is acknowledged that professionals should always base decisions on the person or population they are working with.
Resuscitation Council (UK)	Full	11	6–7	Most strokes, subarachnoid haemorrhages and myocardial infarctions are acute, not subacute events. The use of 'subacute' here is likely to mislead people.	Thank you for your comment. This has been amended, 'subacute' has been removed from the text.
Resuscitation Council (UK)	Full	11	7–8	Surely this guideline would apply to anyone whose death within a few days is regarded as inevitable. People who have suffered, for example, catastrophic traumatic injury with no prospect of recovery, should have access to the same level of high-quality care as those with conditions that you have included here.	Thank you for your comment. This has been amended, as the guideline does apply to people in the populations you mention.
Resuscitation Council (UK)	Full	11–19		Please see the above comments (1–13) on corresponding text in the 'short' guideline.	Thank you for your comment.
Resuscitation Council (UK)	Full	21	15–19	Better wording and punctuation needed here: Question: In people considered to be in the last few hours and days of life, are antisecretory antimuscarinic drugs (used alongside standard nursing interventions such as repositioning and oropharyngeal suction) better than nursing interventions alone at reducing noisy respiratory	Thank you for your comment. This section has been reworded.

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				secretions and patient, family and carer distress, without causing undesired side effects?	
Resuscitation Council (UK)	Full	Glossary		A considerable number of the definitions in the glossary are badly written or overtly incorrect. For example: • 'Analgesia'. This 'definition' is nonsense. • 'Hypoxia' is a state of reduced oxygen concentration or saturation, not a 'relatively complete absence of oxygen' (whatever that means!). • 'Intravenously' is an adverb that may refer to a route of administration of drugs or fluid. It is not only applicable to the administration of fluid, so your definition is incorrect. • 'Subcutaneously' is an adverb that may refer to a route of administration of drugs or fluid or the site of implantation of a device. It is not only applicable to the administration of fluid, so your definition is incorrect. • 'Stridor' is an abnormal noise heard only during inspiration, so your definition is incorrect. • 'Dying person' is a person who is dying! • End of life means the end of life (i.e. death). When used as an adjective, end-of-life refers to events or actions (such as care) that take place during the last days, weeks or months of a person's life. There are many other incorrect or poorly worded	Thank you for your comment. These have now been amended.

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				definitions. The glossary should be rewritten with much better attention to accuracy and in correct, plain English.	
Resuscitation Council (UK)	Short	3	11-18	If this guidance is to be truly patient-centred these bullet points should be presented in a different order, with the person's goals and wishes as the first bullet point. 'Current clinical signs and symptoms' is very medical. Current symptoms are the priority in a patient-centred document, but it is important to record current clinical signs also.	Thank you for your comment. This recommendation has been further edited for greater clarity and has now re-grouped the factors under separate headings for signs, symptoms and functional observations.
Resuscitation Council (UK)	Short	3–4	19 (3)–21 (4)	These recommendations don't give people any practical help to recognise ('diagnose') when a person is dying. There is no mention of balancing the person's clinical condition, its reversibility and the potential treatments available in order to assess the probability of the person dying or recovering. The examples seem to be a muddled collection of symptoms or signs or changes, some of which are highly non-specific (e.g. fatigue) and some of which are highly likely to be predictive of impending death (e.g. Cheyne-Stokes breathing)	Thank you for your comment. Reversible causes are discussed in the 'Linking evidence to recommendations' section of the full guideline (Please see section 5.8). . After careful consideration the Committee have rewritten recommendation 1.1.2 and separated out the list into signs, symptoms and functional observations to provide clarity. The Committee discussed the bullet points in recommendation 1.1.3 and decided to amend these to state: nearing death, deteriorating, stable or improving. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (Please see section 5.8).
Resuscitation	Full	112	1–23	We wonder whether more extensive information may have been obtained from searches that included	Thank you for your comments. Given time and resource constraints, we were unable to prioritise

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Council (UK)				more specific elements of end-of-life care. For example, there is substantial literature on the attitudes and experiences of patients and HCPs to anticipatory decisions about CPR and decisions about deactivation of implantable cardioverter-defibrillators and on related barriers to good communication and good clinical practice.	multiple review questions in this area and this includes DNACPR. The qualitative evidence identified from the review question that the committee identified as a priority area was considered applicable by the committee and identified many themes they had expected. It helpfully informed their recommendations.
Resuscitation Council (UK)	Full	118		We were surprised that misunderstandings about their condition or about the purpose of their treatment for it were not identified as significant factors relating to patients. This is common in clinical practice and there is published evidence to support this, so it may be that the structure of the literature search used did not include specific detail that might have picked this up.	Thank you for your comment. The review protocol for this question is detailed in the appendix of the full guideline together with the themes extracted (see table 5). The committee did not feel the issue of misunderstanding or purpose of treatment as key areas to include in their recommendations. We would note that our recommendations on communication may address some of these concerns particularly, recommendations 7 and 11 (2.2.2 and 2.2.6).
Resuscitation Council (UK)	Full	111	33–37	There is no mention of ADRT and the distinction (again under the MCA 2005) between this (which is legally binding) and an advance care plan or similar advance decision record (which provides clinical guidance to support later decisions but is not legally binding).	Thank you for your comment. "…advance decision to refuse treatment" has been added to recommendation 14 (2.3.2.) We have made further amendments to the guideline 'Linking evidence to recommendations' section (7.6) to provide context as to the requirements of the Mental Capacity Act recognizing that the intention of our review question in this chapter was to understand how the dying person, their loved ones and their multiprofessional team could best work together to ensure that decisions made considered

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					and met (where possible) the dying person's wishes (please see 7.1 for further information behind the intention of the evidence review that informed these recommendations). We have not undertaken a review of capacity or 'best interests' as these issues are defined in law.
Resuscitation Council (UK)	Full	111	3–5	Whilst we recognise that NICE guidelines focus on clinical excellence, there is a need also for them to address what practice is and is not lawful. There is a clear legal requirement for a presumption in favour of involvement of patients in the process of decision-making towards the end of life, for example in relation to decisions about cardiopulmonary resuscitation. The nature of that involvement will depend on the individual circumstances (please see 'preliminary statement' at https://www.resus.org.uk/dnacpr/tracey-v-cuh-and-secretary-of-state-for-health/).	Thank you for your comment. We wished to understand how the dying person, their loved ones and their multiprofessional team could best work together to ensure that decisions made considered and met (where possible) the dying person's wishes (see 7.1 for further information behind the intention of the evidence review that informed these recommendations. We have not undertaken a review of capacity or 'best interests' as these issues are defined in law. DNACPR was outside the scope of this guideline.
Resuscitation Council (UK)	Full	26 27 28 also 134– 135	21–41 1–40 1–14	Whilst we recognise and endorse the more generic recommendations made in 7.6, a major cause of concern is that the scope made no provision for including guidance on the importance of specific elements of decision-making (to try to avoid subjecting the dying person to indignity and harm), such as • anticipatory decisions about CPR and • making decisions to deactivate implantable cardioverter-defibrillators.	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult and DNACPR or decisions to deactivate implantable cardioverter-defibrillators were not prioritised for inclusion in the scope. We have added some text to the 'Linking evidence to recommendations' section in chapter 6 around the management of implantable cardioverter defibrillators at the end of life,

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				These are an integral part of good-quality care towards the end of life, including in the last few days – especially if such decisions have not been addressed earlier. This concern was expressed by several of us who attended the stakeholder meeting to consider the draft scope. We are concerned that this failure to include such decisions in this guideline (or even to mention that they have been deliberately excluded and why) is a clear risk to its clinical credibility. Whilst many such decisions may be considered in the context of 'shared decision-making' some such decisions are clinical decisions that require sensitive explanation in the context of effective communication. These and other decisions that may be made about a person's care towards the end of life must be made lawfully, with due regard to the laws concerning capacity, equality and human rights, yet there is published evidence of inconsistent compliance National guidance on '**Decisions relating to cardiopulmonary resuscitation**' is published by the British Medical Association, Resuscitation Council (UK) and Royal College of Nursing and available at www.resus.org.uk. In addition **NICE-accredited guidance** from the Resuscitation Council (UK), British Cardiovascular Society and National Council for Palliative Care, '**Cardiovascular implanted**	We acknowledge the importance of the issues you raise in relation to DNACPR and implantable cardioverter defibrillators, however, the guideline has not been able to address all issues relevant to the care of the dying adult. Given time and resource constraints, these topics were not prioritised for this guideline as other review areas were considered more likely, during scope development, to have a wider impact on clinical practice.

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				electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death', also available at www.resus.org.uk, is highly relevant to the provision of good-quality care in the last few days of life and should be referred to in this guideline, at the very least as related guidance.	
Resuscitation Council (UK)	Full	86	3	The use of the word 'vital' (literally meaning necessary to the continuation of life) is inappropriate when referring to a dying person. We suggest changing to 'crucial'.	Thank you for your comment. This has been amended.
Resuscitation Council (UK)	Short	6 + 7	12(6) + 28(7)	There is some inconsistency here. Is 'record of care' intended to mean the same as 'medical records'?	Thank you for your comment. We have amended the recommendations to consistently refer to 'record of care'. We believe this will be inclusive of other types of record beyond the medical records.
Resuscitation Council (UK)	Short	5–6	1(5)–15(6)	This section on communication is good. Some people may be uncertain about what is being recommended in 1.2.7. It would be helpful to add a statement clarifying that withholding information from a person's about their condition or their care is not usually appropriate (or lawful) unless they express a clear wish not to discuss or receive that information.	Thank you for your comment. This recommendation has now been removed although discussion on this issue remains in the Linking evidence to recommendations section of chapter 6.
Resuscitation Council (UK)	Short	7	18–26	This is good. However, it is important to identify a person's **needs** for symptom management as well as their preferences.	Thank you for your comment. This has been amended, the list now includes 'preferences for symptom control'
Resuscitation Council	Full	111	15	Typo: person, not persons	Thank you for your comment. This has been amended.

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(UK)					
Resuscitation Council (UK)	Full	111	19	Typo: hours not ours	Thank you for your comment. This has been amended.
Resuscitation Council (UK)	Full	111	34–36	Rewording is required here. The sentence 'They may have appointed someone to have enduring power of attorney. In some instances, people with reduced mental capacity may also have an Independent Mental Capacity Advocate (IMCA).' is not correct/fit for purpose and does not reflect the different laws on capacity in the four nations of the UK. An Enduring Power of Attorney predates the introduction in October 2007 of the Mental Capacity Act 2005 in England and Wales and confers only power to deal with financial matters. A Lasting Power of Attorney for Health and Welfare may be given (in England and Wales only) to people under the MCA 2005. Similarly an IMCA is a provision of the MCA 2005. Health professionals have a responsibility to involve an IMCA for people who do not have capacity and do not have anyone else to speak for them. The IMCA has no power to make decisions for a patient but can provide observations or information that may help the senior responsible clinician to make a best-interests decision on behalf of a patient who has lost capacity.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Resuscit	Full	111	36–37	Again the word 'vital' is inappropriate here. We	Thank you for your comment. This has been

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ation Council (UK)				suggest 'crucial'.	amended.
Resuscitation Council (UK)	Full	111	36–37	We question also the appropriateness of the term 'wards' here. This has specific legal definition but its use here appears intended to imply a broader meaning.	Thank you for your comment. This has been amended.
Resuscitation Council (UK)	Full	111	36–37	This sentence appears to conflate inappropriately the role of those with legal power to make decisions on behalf of a person who has lost capacity (e.g. Welfare Attorney or equivalent) and those who have no decision-making power but should be involved in discussions to support the senior clinician in making a best-interests decision for a person who has lost capacity (e.g. family members or IMCA). It is CRUCIAL that NICE clinical guidelines present clear guidance that reflects the law accurately, which the current wording fails to do.	Thank you for your comment. This has been amended.
Resuscitation Council (UK)	Full	111	5	Again, the use of the word 'vital' (literally meaning necessary to the continuation of life) is inappropriate when referring to a dying person. We suggest changing to 'crucial'.	Thank you for your comment. This has been amended.
Resuscitation Council (UK)	Short	6–7	23(6)–3(7)	The first priority is to establish the dying person's goals and wishes. The second priority is to identify cultural or religious etc beliefs that need consideration. An advance care plan or ADRT only becomes relevant if the person loses capacity. If they have already lost capacity, the advance care plan or ADRT will be one of the means of	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these

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				establishing their goals and wishes. If they haven't lost capacity it is important to talk to them and check that their previously expressed wishes and goals have not changed. It would be helpful for the guideline to explain the interaction with capacity.	issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Resuscitation Council (UK)	Short	8	1–11	This is good.	Thank you for your comment.
Resuscitation Council (UK)	Short	10	5–8	Clinically assisted hydration should also be stopped if there is no evidence of benefit to the dying person. It reduces dignity at the end of life as well as using resources to no useful purpose, so on ethical grounds absence of benefit is a clear indication to stop clinically assisted hydration. Parenteral therapy is likely to require re-cannulation at intervals,	Thank you for your comment. The Committee consider the most important reasons for reducing or stopping clinically assisted hydration to be signs of possible harm or if the person no longer wants it. They do not wish to be so prescriptive to add further detail, but consider that clinical judgment guides further decisions as outlined in recommendation 2.4.10. Further detail has been added to the 'Linking evidence to recommendations' statement in section 8.6 in the full guideline.
Resuscitation Council (UK)	Short	9	17–20	This recommendation requires clarification regarding the person's capacity and rewording regarding the role of an advance care plan. If clinically assisted hydration is being considered now and the person has capacity they are able to make a	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking

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				contemporaneous shared decision about whether or not to have it. If there is an agreed advance care plan not to use clinically assisted hydration and the person has lost capacity, that plan should guide clinical decision-making. However the decisions in an advance care plan are not irrevocable and a person with capacity should not be deprived of the opportunity to change their mind.	evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We agree that people with capacity should always be make decisions about their care (see recommendation 2.3.2)
Resuscitation Council (UK)	Full	173 (–175)	5 onwards	See also comment 8 above. Even those who are hypoxaemic should not be given oxygen unless there is good reason to believe that the benefit will outweigh the harms (dry mouth, loss of dignity, cost etc). This concept is mentioned in the GDG notes on page 175 but has not been communicated in the guideline recommendation. Giving oxygen to a dying person because 'if I take it off her saturations drop' was a recent experience illustrating the importance of promoting good clinical reasoning high priority in the delivery of good-quality nursing and medical care, tailored to the individual needs of each patient at any moment in time..	Thank you for your comment. The evidence review was unable to show whether oxygen was beneficial or not for the management of breathlessness in the last few days of life, however the consensus of the Committee was that oxygen may be beneficial to people who are symptomatic with known or suspected hypoxia based on their clinical experience. The recommendation has been amended to state "Only offer oxygen therapy to people known or clinically suspected to have symptomatic hypoxaemia" and additional text has been added to the 'Linking evidence to recommendation' section (9.9) of the full guideline.

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Resuscitation Council (UK)	Short	11	19	'…are needed', not '…is needed'.	Thank you for your comment. This has been amended.
Resuscitation Council (UK)	Short	11	20–22	This wording doesn't make sense. The whole point is to start with the lowest recommended dose to avoid adverse effects, but as there is uncertainty whether that will be effective for the individual, the dose must be increased if it proves not to be effective.	Thank you for your comment. We agree and state "start at the lowest effective dose". Further detail is given in the 'Linking evidence to recommendations' section of the full guideline (please see 9.34).
Resuscitation Council (UK)	Short	12	23–25	Please see also comment 8. The recommendation 'Only offer oxygen therapy to people known or clinically suspected to have hypoxaemia' will tend to encourage use of oxygen to treat oxygen saturations rather to treat patients according to their individual needs. It would be better to recommend the use of oxygen as part of end-of-life care only when it appears to provide symptom relief and does not cause discomfort (from the equipment use to deliver it or from drying of the mouth and/or nose).	Thank you for your comment. The evidence review was unable to show whether oxygen was beneficial or not for the management of breathlessness in the last few days of life, however the consensus of the Committee was that oxygen is may be beneficial to people who are symptomatic with known or suspected hypoxia based on their clinical experience. The recommendation has been amended to state "Only offer oxygen therapy to people known or clinically suspected to have symptomatic hypoxaemia" and additional text has been added to the 'Linking evidence to recommendations' section of the full guideline (9.5).
Resuscitation Council (UK)	Short	8	18–23	It is also important to avoid inappropriate delivery of oxygen to dying people. This causes drying of the mucus membranes of the mouth and/or nose and increases the need for frequent mouth and lip care, in addition to the discomfort and reduced dignity	Thank you for your comment. The evidence review was unable to show whether oxygen was beneficial or not for the management of breathlessness in the last few days of life, however the consensus of the Committee was that oxygen may be beneficial to

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				imposed by the mask or 'nasal spectacles'. You may feel that this would be covered by 1.5.1 or 1.5.16 but, sadly, many doctors and nurses do not regard oxygen in the same way as other prescribed drugs, and do not always recognise the harm that it may do during end-of-life care.	people who are symptomatic with known or suspected hypoxia based on their clinical experience. Additional text has been added to the 'Linking evidence to recommendations' section of the full guideline to state that "The Committee discussed that oxygen is considered a drug and that as for any medications used in the last few days of life, prescribing decisions should be made on a case by case basis weighing up the risks and benefits for any given individual."
Resuscitation Council (UK)	Full	215	20	Spelling error : 'licensed'	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Resuscitation Council (UK)	Full	215	11	BNF is not a 'prescribing principle'.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Resuscitation Council (UK)	Short	24	15	BNF is not a 'prescribing principle'.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Resuscitation Council (UK)	Short	24	26	Spelling error: licensed	Thank you for your comment on the prescribing tables. We have edited this item. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE

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					website.
Resuscitation Council (UK)	Short	28	Table 2	Failure to show '4' in superscript after 'diazepam' could cause confusion.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Richard von Abendorff	Full	general		1. Apologies for poor editing: done in haste and after 4 years campaigning for better end of life care, without the editing skills of my burnt out wife Oona 2. Context for submission-advocacy by Professor Rob George and also reference from Dr Frances Healey NHS England I make this submission after Twitter exchange with Professor Rob George (Director St Christopher's and Chair of Association of Palliative Medicine) in the last few days where he publically urged me to raise many of the issues I do below. I have made some points to Dignity in Dying but their remit and focus is limited , I have not been able to see their submission and my case study of failings causing 'iatrogenic suffering' as Professor George confirmed	Non-registered stakeholder. No response required. However detail provided for the NICE team only: Thank you for your comment. We are unable to respond to the specific issues related to your mother's care although we recognize the issues raised. It has been the intention of this guidance to minimize the number of instances where there is variation in the quality of care provided to people in the last 2-3 days of life. The Committee has made recommendations that prioritize an individualized approach to patient care.

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				my mother's coroner , I believe needs taking account of in your guidance feedback. Prof George urged I comment on Mental Capacity Act and family consultation and also agreed issues around palliative services levels, pain as a medical emergency and opiates fear, as he had noted these systemic issues in his report about my mother's case. His report is attached. I have recently heard from Denise Charlesworth who has registered as a stakeholder direct but I did not know this was an avenue for me. I am a patient safety campaigner having spoken at a recent MHRA/NHSE Patient safety conference for medication safety officers on the back of a national patient safety alert I was instrumental in getting. You can contact Dr Frances Healy, Deputy to Dr. Mike Durkin at NHSE Patient Safety if you need a reference for me. Case study and context-general comments I am giving you feedback having seen my mother's iatrogenic suffering in her last three days of life. This was due to a lack of adequate pain control in turn to multiple fallings in palliative care the Trust concerned could not deny (the (PHSO is doing a third investigation over 4 years on) including: lack of assessment of palliative medication; lack of use of palliative care expertise; lack of awareness of core palliative issues (especially confusion about opiates double effect and risks; opiate titration; opiate	A number of our recommendations have been drafted with the non-specialist care provider in mind to try to maximise some understanding and acknowledgement of the issues required around appropriate, safe prescribing in the last days of life. The Committee particularly focussed on the requirements to avoid unwanted sedation while considering interactions with other medications and appropriate titration. We have been keen to ensure that our recommendations ensure individualized care for the dying person with loved ones and others of importance to the dying person being closely involved as appropriate. We have made further amendments to the guideline linked to provide better links to the requirements of the Mental Capacity Act. We make direct reference (recommendation 1.5.9) to the need to seek specialist palliative care if symptoms do not improve promptly. We do need to assume within the context of this guideline that prescribers are following relevant professional guidance (for example the General Medical

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				toxicity diagnosis and management), lack of empowered palliative services to act; lack of consultation of family and failure to follow Mental Capacity Act (all despite clear advance directive and care plan supplied by family) ; lack of nursing and medical resources; lack of priority to pain control . While number of these issues are there hidden away in the many many pages of three reports of guidance none I believe are made nearly clearly enough nor adequately emphasized. I am convinced that even if guidance was available at the time of my mother's death and read very recently by treating doctors it would have made no difference to iatrogenic suffering my mother experienced nor prevented the serious of errors and neglect my mother suffered. I centre my comments and the gaps particularly around pain relief and mental capacity rights where I believe it is seriously deficient. None of this guidance substitutes in any way for accessible expert palliative input yet as Professor George says in his attached report expert direct input (not merely advisory) for some cases is essential else a service is not fit for purpose. Guidance doesn't emphasise the role of expertise. There is even lack of adequate attention when to escalate. Yet much specialist palliative guidance on drug use (in my mother case use of fentanyl and use of naloxone) refers on many occasions to getting that expert input-this cannot be	Council's document on Good Practice in prescribing and managing medicines and devices: http://www.gmc-uk.org/Prescribing_guidance.pdf_59055247.pdf) and take full responsibility for their decisions including the management of uncontrolled pain. NICE have already developed quality standards for end of life care and we assume that this will be updated in light of this guideline and a number of others currently in development to support measurement of care provided in settings where NHS care is provided. Finally, we would respond that we feel strongly that colleagues working on this Committee either as full members or as expert advisors have been able to add significant value to the interpretation of the evidence base considered. All our members are passionate about and committed to providing high quality end of life care and have been selected subject to a rigorous and transparent recruitment process.

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				ignored. A recent NHSE patient safety alert highlights this issue(see below) -this general and event specific issue cannot be ignored Yet the experience of my mother and high profile cases like Charity Bagwell(see webpage below) and Joanne Fowler show the serious disastrous and traumatic consequences of this reality being not understood nor acted upon to this day. Also see all recent reports showing end of life care in acute hospital settings is not improving. In the context of cuts to already inadequate services revealed by Channel 5 research recently (, link below), is very concerning. Guidance should set some standards and suggest how to provide safe end of life care which reports have found to be failing too many in hospitals and a problem which has not improved over the last 7 years as the National Audit Office informed me. Moreover meeting pain relief wishes is a fundamental right, a core to a dignified death. There is also the issue about listening to patient and family advocates (George report mentions). Ensuring respect for patient wishes also needs to be raised, addressed and challenged. I have profound concerns about guidelines, they do not provide the role model they should at this time of acknowledged failing. There even appear some	

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				errors (e.g. there is no 'maximum' opiates doses-see George report). I also have profound concerns and criticise the whole process by which 'experts by experience' have been consulted and are consulted in pulling together this needed guidance. More Issues and concerns as bullet points • in acute hospital emergency situation, where most people die, (and a context where end of life care is not improving) while earlier discussion about death is ideal, in most cases this discussion will include the need to act on what known at that time-current medications and history, wishes, consulting family if patient lacks capacity, especially as set out in advance directives. In my mother's case 'best interest' was used to override her wishes or even consult me yet then mental capacity act guidance was breached-this legislation and how to implement it has to be at the core of any guidance. As you know this is a national concern as raised in recent Parliamentary Commission and none more so in dying people when it is the final chance to get it right and be implemented • it lacks any standards-e.g. out of control pain in dying patient is medical emergency-see George report--just reassessing at least every day is not an adequate timeline-and misleading. The cases of Bagwell and Fowler are a perfect illustration	

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				of the horrific reality of this being implemented in a way that does not recognise pain in a dying patient as a medical emergency	
Robert Common City Hospitals				I'm surprised the development group doesn't have an end of life care facilitator. I have being doing this role for 5 years, have a MSc in End of Life Care and have been pivotal to improvements in end of life care in my region (North East). End of life care facilitators are the pivotal staff trying to improve and embed good end of life care daily. I'd be happy to offer any help	Non-registered stakeholder. No response required.
Robert Murphy South Bank University	Full	149	General/Re: Clinically assisted hydration.	Regarding clinical assisted hydration. The following are comments from my experience in palliative care and are subjective and are mostly observational from a clinical perspective. I think that the below areas need further exploration and guidance as it is a very grey area for practitioners. For example; -Cultural/Spiritual beliefs, could this be expanded on as some religious groups and indeed individuals themselves who are dying may want to continue to take fluids regardless of medical condition i.e. overloading -Regarding Level of Consciousness and the Dying. Some individual's who are dying remain unconscious for weeks. Some families find this	Non registered stakeholder. No response required.

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				distressing and can't understand (regardless of explanations) why there is a total withdrawal of fluids/hydration. And in similar scenario, some individuals remain unconscious for long periods and wake up and eventual return to baseline. (This tends to be, the end stage dementia groups). Some families can't understand why there was a total withdrawal of fluids, even though fluids may have been contra-indicated by the medical team at the time. Also, some patients maybe unconscious for long periods/days/weeks and then some fall into and out of semi-consciousness periods. During this period, it is difficult to assess swallow. Yet, they maybe thirsty and request a drink.	
Rotherham Hospice	Full	General		General It was felt that there wasn't anything which is surprising or significantly different when compared with guidance / reports that have gone before. However there were some general comments in summary as follows. General feedback: Not enough information or involvement of community care and outreach services. Emphasis is on individual organisations rather than on integration and care coordination. It is (of course) about end of life care but avoids discussions about "The pathway" Many of the older medications and procedures	Thank you for your comment. Service Delivery, including how services work together, are arranged, integrated and coordinated, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799 We have not described a pathway in our guidance as we believe our recommendations focus on the need to individualize care for the dying person.

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				suggested for symptom management are still scientifically unproven. Research and innovation What are the new ideas? Is this the section where the coordination and strength in multidisciplinary working could have been explored? What's Missing? Peer review and multi-disciplinary team working in general Implications of DoLS including further advice to coroners re referral and inquest	We have performed a systematic review of the evidence linked to the pharmacological management of some of the more common symptoms in the last days of life. We agree that there is limited evidence and have made a number of research recommendations in this area. Whilst it was not in the remit of our guideline to address the issues linked to Deprivation of Liberty, the Committee agree that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the Linking evidence to recommendations section of the relevant chapters in the full guideline on these issues. We have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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Rotherham Hospice	Short		1.1.2	Are 'investigation results and radiological imaging' signs and symptoms of dying?	Thank you for your comment. The Committee agree that unnecessary investigations should be avoided, but that if available may provide useful information. Available investigation results have been moved to the stem of the recommendation to avoid confusion with other signs or symptoms of recognising dying.
Rotherham Hospice	Short		1.1.3,	The choice of 'nearing death' or 'recovering' strange. If someone was recovering why would you think they were dying? Do they mean 'potential to recover'/'likely to recover'?	Thank you for your comment. The Committee discussed the bullet points in the recommendation and decided to amend these to state: nearing death, deteriorating, stable or improving.
Rotherham Hospice	Short		1.1.4	– who should be monitoring the patient every 24 hours? The recent National Audit seemed to indicate this should be the lead or deputy. Though ideal, I think this is unrealistic – A GP, cons or reg is not going to be readily available to review every pt at end of life every day whether they are in hospital or community. I think for some of the time the task needs to be delegated to a competent nurse or junior doctor especially at weekends.	Thank you for your comment. The Committee consider these recommendations to be applicable to whoever is responsible to delivering care. We are unable to comment on team structures or leadership as we have not undertaken a review in this area. NICE is currently developing guidance in palliative care service delivery and the issue of seniority or team structures may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Rotherham Hospice	Short		1.3.4 –	I am unsure why this is under shared decision making	Thank you for your comment. The Committee's intention behind this recommendation is to include the dying person and those important to them in all decisions related to their care in the last few days of

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					life. We have also introduced an additional heading that means this recommendation now sits within a section entitled 'Individualized care planning'.
Rotherham Hospice	Short		1.4 -	53. I wonder why they have chosen to tackle hydration but not nutrition issues. With regards to hydration, there is no onus from the document to provide it clinically assisted, but I do wonder what impact the recommendation may have in non hospital settings where administration becomes less of an easy option and whether there is the possibility this will shift more end of life care back into acute settings so that a pts wish to have eg parenteral hydration can be met. No-one wishes a patient to be dehydrated but is it unethical to provide other pharmacological ways of managing symptoms if artificial hydration cannot be practically implemented, eg antipsychotics for delirium rather than an IVI? Also there appears to be no recommendation on how to proceed with artificial hydration if there is no benefit but equally no harm – the guidelines only give us a choice if there is benefit (continue) or harm (stop). The default may therefore be that fluids are continued, potentially an easier option than discussions and attempts to remove once started, which again may lead to more people receiving artificial hydration in circumstances where it will be challenging to provide and where the overall	**Thank you for your comment.** Nutrition is beyond the remit and scope of this guideline. The Committee intend this recommendation to apply to all settings and are aware that clinically assisted hydration may take place in the community, but note that there may be challenges to its implementation. Further detail has been added to the 'Linking evidence to recommendations' section. NICE is currently developing guidance in palliative care service delivery and the issue of resources and training may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799 Additional detail has been added to the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce

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				outcome or symptom burden will not be changed.	other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given.
Rotherham Hospice	Short		In section 1.5.31 /.32	it mentions treating the side effects of drugs given for secretions. If I had a patient on Hyoscine Hydrobromide for example suffering cognitive SE I'd be more likely to change the antisecretory than add an antipsychotic as a first line measure. Surely we are looking to keep pharmacological intervention as simple as possible? I think the tables of drugs for administration provide a range of decent options. The dose of Paracetamol iv is weight dependent for adults under 50kg (and we do see some tiny, frail individuals in pall care) – this isn't reflected in the tables, but may be thought to not be relevant	Thank you for your comments on the prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Rotherham Hospice	Short		Section 1.5.3 –	Aren't the recommendations here simply part of what should be generic, safe prescribing? Do they need to be separately spelled out? Why do we have the recommendations 1.5.19 and 1.5.21 for nausea and vomiting and not for the prescribing of medications for any other symptom management?	Thank you for your comment. These recommendations are for non-specialists and the Committee felt it important to give this level of detail. Recommendation 1.5.3 provides overarching advice but the recommendations you refer to capture detail specific to the treatment of nausea and vomiting (e.g. sedative effect of anti-emetics

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Rowcroft Hospice	Short	20	8	What is GDG?	Thank you for your comment. For clarity we have explained the acronym where it appears first in each chapter. GDG refers to the guideline development group. However, NICE's processes have changed during the course of development and this group is now referred to in our consultation responses and future edits of the guideline, as 'Committee'.
Rowcroft Hospice	Short	17	1	We suggest it would be helpful to give the example of 'repositioning', after non-pharmacological measures to manage respiratory sections	Thank you for your comment. Non-pharmacological management of symptoms is beyond the remit and scope of this guideline and as such we are unable to provide detailed recommendations in these areas. The Committee acknowledge the importance of such approaches and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Rowcroft Hospice	Short	17	13 & 20	In community settings we suggest 24hrs review period would fit with the 24hrs syringe pump change, and is more realistic to achieve.	Thank you for your comment.
Rowcroft Hospice	Short	18	31	It would also be helpful to include a prompt to prescribe 'sufficient' quantity of anticipatory medications to manage symptoms out of hours.	Thank you for your comment. We do not believe it is necessary to make reference to this issue in the introductory text.

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Rowcroft Hospice	Short	21	39	We are concerned about the outcomes of the review of the research evidence in relation to the use of anti-muscarinics which leaves a sense of ambiguity about whether they should be prescribed at all. In practice they do work for some patients, but not for all. We are concerned GP's may not prescribe these medications if they follow this guidance, preventing some patients from benefiting.	The recommendations on noisy respiratory secretions state to first look for likely causes, consider non-pharmacological measures and then consider a trial of medication. The evidence review is limited and the GDG based this recommendation largely on consensus of their expert opinion and it is expected that clinical judgement will be used when making prescribing decisions.
Rowcroft Hospice	Short	5	17 -21	We suggest that section 1.2.3 be more appropriately positioned before 1.2.2	Thank you for your suggestion. This has been amended.
Rowcroft Hospice	Short	11	27	We are concerned that as this guidance is for general staff it will be challenging to use the Eastern Cooperative Oncology Group status tool. Previously the Karnofsky functional tool has been advised for use by the NHS. If the decision remains that ECOG is to be recommended we suggest this tool be added to the appendices	Thank you for your comment. This has been amended to state "Functional observations, for example, deteriorating performance status". Additional detail is given in the 'Linking evidence to recommendations' section 9.34.
Rowcroft Hospice	Short	11	34	We are concerned that the mention of 'progressive weight loss' could imply that patients should be weighed. As this guidance is specifically aimed at care in the last days of life we believe this is unhelpful and unnecessary	Thank you for your comment. This was identified by the evidence review and the Committee consider it a valid example.
Rowcroft Hospice	Short	11	40	We are concerned the term 'recovering' will be unhelpful and could lead to misunderstandings in communications with patients and their families. The word implies people can recover from dying, whereas in practice it is about misdiagnosis of dying. Could the words 'requires acute intervention' be	Thank you. We agree and this has been amended to state "nearing death, deteriorating, stable or improving."

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				used instead?	
Rowcroft Hospice	Short	12	41	We are concerned that the placement of 'anticipatory prescribing decisions' in this section implies they are patient initiated rather than clinical decisions.	Thank you for your comment. These recommendations are intended for healthcare professionals and are intended to provide an individualised approach. Further detail is in the Linking evidence to recommendations section in the full guideline (please see chapter 10).
Rowcroft Hospice	Short	13	18	We are concerned that in practice to have a one lead professional is unrealistic when care is organised in teams.	Thank you for your comment.
Rowcroft Hospice	Short	13	28	Re- the sentence "…assistance from an organisation" – for what? It seems there should be something added here.	Thank you for your comment. We recognize that support or assistance may vary and have not been prescriptive in this area.
Rowcroft Hospice	Short	14	14	In relation to 'frequent sips of fluid' we are concerned that if the person has lost there swallow reflex this could do harm	Thank you. We agree and this recommendation should be read with the others within the section on maintaining hydration which detail checking for difficulties in swallowing problems.
Rowcroft Hospice	Short	14	18	We are concerned about the emphasis placed on clinically assisted hydration when this is only realistically possible in hospital or hospice. As we are trying to enable more home deaths this is at odds with this objective, and may drive inappropriate admissions for a 'trial' of fluids.	Thank you for your comment. The Committee consider this recommendation to apply to all settings, but have noted potential implementation needs in the 'Linking evidence to recommendations' section. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Rowcroft	Short	15	20	In community settings in the last days of life the	Thank you for your comment. The Committee

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Hospice				suggested use of Octreotide is unrealistic in practice	recognized that there may be challenges in accessing Octreotide as a treatment option for Nausea and Vomiting, but, chose to recommend it as a second line therapy as it is a valid treatment option. Further information on the Committee's discussions in this area can be found in section 9.13 of the full guideline. The Committee intend this recommendation to apply to all settings, including the community.
Rowcroft Hospice	Full	217 - 221		Having medications in alphabetical order is unhelpful for busy GP's and clinicians, who may just pick the first drug on the list. We are also concerned that many of the medications listed are not in keeping with local/regional practice and are not part of our recently agreed local formulary. We would suggest instead that clinicians are advised to refer to their local palliative care formularies or the Palliative Care Formulary for prescribing advice.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Royal College of Emergency Medicine	short	General		Overall this document is quite wordy, the guideline may be brilliant (it is very thorough!) but far less people will use it if it is too long. I think there is scope for keeping most of the recommendations but shortening the way it is written. There is also a danger that some of the recommendations are obvious and part of common practice.	Thank you for your comment. The short version of the guideline is designed to condense the research down to include the full list of recommendations, explain the research recommendations. We are pleased to hear that the standards of care we seek to establish and outline in our guideline are obvious and common practice for your organisation. The Committee was not convinced that there was a

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				I think your recommendations for the short guideline should be much briefer and seek to raise standards rather than describe common practice	common standard of practice across the UK and therefore in order to ensure that the same levels of service are available throughout the NHS and in all settings where NHS services are provided, they felt it was imperative that these recommendations were made within the guideline.
Royal College of Emergency Medicine	Short	General		I think NICE should be recommending training for all healthcare professionals dealing with dying patients – e.g. all nursing home qualified nurses, community matrons etc.	**Thank you for your comment. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about this work can be found at the following link:** http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Royal College of Emergency Medicine	Short	General		Do we need a short section on reviewing the patient's current location and determining if the right care can be given there as well as looking at resources and carers that are needed? This is hinted at in 1.3.4	Thank you for your comment. This issue was considered by the Committee during the discussion of evidence and this has been made clearer in the other considerations section of the 'Linking evidence to recommendations' of section 5.8 of the full guideline. The Committee feels that all of its recommendations should be relevant to the care of people in the last days of life regardless of setting.
Royal College of Emergen	short	4	16-21	Ditch this section as there is no need for it, section 1.1.4 is sufficient. Make 1.1.4 more directive**. The patient should be reviewed daily by an experienced nurse or doctor.**	Thank you for your comment. The Committee have strengthened recommendation 1.1.3 and feel that it has value.

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cy Medicine					
Royal College of Emergency Medicine	Short	6	1-3	A specific task should be to **explore whether the patient or family would like support from a member of clergy or religious leader and help them to organise this if needed.**	Thank you for your comment. We have amended recommendation 2.2.1. to include the following: take into account any cultural, religious, social or spiritual needs or preferences that should be considered. We have also added further text to the 'Linking evidence to recommendations' section of chapter 6 (section 6.6) to highlight this issue.
Royal College of Emergency Medicine	Short	7	27-29	**Share the care plan with community and acute services using the electronic palliative care record if possible**. (The best laid plans are made in the community but fall apart and the patient lands in the Emergency Department (ED) and we start again!)	Thank you for your comment. We have amended the recommendation to encourage people providing end of life care to share the care plan with the dying person, those important to them and all members of the multiprofessional team. We are unable to make further comment on the electronic palliative care record as this has not been subject to any formal evidence review as part of this guideline.
Royal College of Emergency Medicine	Short	General		There is no mention of recording a DNACPR anywhere, are you waiting for the national DNACPR form to be published?	Thank you for your comment. We recognise that CPR and DNAR decisions are an important area in care of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas are more likely to have a wider impact on clinical practice. DNAR discussions will not be included in this guideline.

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Royal College of Emergency Medicine	Short	8	18-23	Too much detail for the summary / short guideline, put in full guideline	Thank you for your comment. This recommendation has been amended for clarity.
Royal College of Emergency Medicine	Short	9	8-14	This section should come first in this section about clinically assisted hydration. **Clinically assisted hydration should probably be defined somewhere.**	Thank you for your comment. We have carefully considered the order of the recommendation and feel that no change is required. Clinically assisted hydration is defined in the glossary of the full guideline.
Royal College of Emergency Medicine	Short	12	14-17	Re word as **"If a patient is unable to communicate verbally to indicate their pain, take advice from those close to the patient as to what behaviour may indicate pain"**	Thank you for your comment. Your point is covered within the 'Linking evidence to recommendations' section of the full guideline (please see section 9.5).
Royal College of Emergency Medicine	Short	13	16-17	Such as??	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.

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Royal College of Emergency Medicine	Short	16	2-30	Reword whole section in more succinct manner. I would emphasize more the concept of a tailored approach for each patient by recommending that blanket prescribing of many prn meds should be avoided and anticipatory prescriptions include clear guidance as to when medicines should be started. The medicines prescribed should be available immediately if needed.	Thank you for your comment. Our recommendations encourage health care professionals to prescribe as early as possible and individually. The Committee considered this to be important and these discussions are reflected in the 'Linking evidence to recommendations' table In this Chapter (please see section 10.6).
Royal College of Emergency Medicine	Short	General		The prescribing tables are excellent.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Royal College of General Practitioners	Full	11-19		When presented in this format, they recommendations are difficult to read. They are not categorised, it is not always clear what topic area they apply to, and they are repetitive in their language. As this overall summary list may be the first place readers come across the recommendations the format and presentation needs to be clearer in terms of the topic area each	Thank you for your comment. Headings have been added to this section for clarity.

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				recommendation applies to.	
Full	General			Multiple references are made to 'non-pharmacological measures' for managing symptoms. Whilst for pharmacological symptom control a summary table has been included, there is no detail or suggestions for non pharmacological measures. This implicitly suggests that pharmacological benefits may be more effective, regardless of the level of evidence.	Thank you for your comment. The non-pharmacological management of symptoms is outside the scope of the guideline. As such, the Committee have not been able to provide detailed guidance in this area within the main body of the guideline. The Committee acknowledge the importance of such approaches and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline. Thank you for your comment.
Royal College of General Practitioners	Full	11	27	Due to a general lack of familiarity with ECOG scoring, it's inclusion as an appendix may be helpful, or a summary chart of factors to consider when assessing whether someone is dying (a visual tool or guide similar to more medium term prognostic indicator guides)	Thank you for your comment. After careful consideration the example of ECOG has been removed from the recommendation and replaced with: Functional observations, for example deteriorating performance status, social withdrawal, changes in communication. Further details have been added to the 'Linking evidence to recommendations' section of the full guideline.

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Royal College of General Practitioners	Full	13	18-25	There is no suggestion or guidance on who the lead Health care professional responsible for shared decision making should be. This may lead to conflict between professionals and a delay in decision making. It may be helpful to emphasise that whist one person should take the lead and ensure shared decision making takes place, there is a collective responsibility on the whole mdt . In other recommendations there has been an emphasis on the fact that who takes the lead may be influenced by whom is most involved with or has the best rapport with the patient.	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform who the most appropriate person is to encourage shared decision making. The Committee feel that this person may be a clinician or nurse or any relevant person delivering NHS care. Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section.
Royal College of General Practitioners	Full	General		The recommendations around artificial hydration seem sensible and pragmatic and reflect the evidence presented. In a hospital setting, this may result in decreased IV hydration. However there is not currently consistent access to artificial hydration in the community setting which may affect the options that can be offered. Non-specialist health care professionals may feel compelled to offer artificial hydration which may lead to an inability to carry out care in the community setting due to lack of resource. Although the recommendations on this topic are quite clear and helpful, this is the area that is most likely to result in change in practice. Perhaps a decision support tool designed to support both	Thank you for your comment. Service Delivery is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.

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				patients/carers and professionals would be helpful	
Royal College of General Practitioners	Full	16	17-21	As is highlighted in other parts of the document, octreotide is difficult to source in the community setting and there are issues around storage. This might mean that this recommendation is discounted in the community setting	Thank you for your comment. The Committee recognises the issues you outline and have provided further detail in the 'Linking evidence to recommendations' in section 9.13 of the full guideline. For the reason you outline below the recommendation prioritized hyoscine butylbromide as a first line therapy, however, they did not wish to preclude the use of Octreotide where it was considered possible and appropriate.
Full	218	3		There is no reference to the need to calculate appropriate doses when converting from one opioid to another (both type and route). There ideally should be some reference to this as it affects dose choices.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Royal College of Nursing	Full	General	General	There is an over emphasis on one identified link healthcare professional. There should always be a deputy to respond in case of sickness, shift changes etc. The same identifying criteria should apply.	Thank you for your comment. We believe that the lead health care professional should be the link to direct shared decision-making. This does not impact on the need to coordinate and lead care more generally. We would assume that in the case of sickness or shift change, alternative leads should be

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					identified.
Royal College of Nursing	General	General	General	The Royal College of Nursing (RCN) welcomes this draft guideline consultation. The guideline is useful and timely.	Thank you for your comment and for participating in the consultation process.
Royal College of Nursing	General	General	General	The RCN invited members working in this area to review the document. Comments below include the view of our members.	Thank you for participating in the consultation process.
Royal College of Nursing	Full	23	40	The guidance states that it is 'specifically targeted at those working in primary care or in care homes'. The language of the short guidance does not seem to reflect this. The language seems to be targeted for acute care. As it is, the guidance does not seem helpful to those providing care to those spending the last days of their lives in their own homes, most likely cared for and attended by non-professionals (informal carers), social carers, with NHS staff 'dipping in' once a day (for example community nurse) and the senior health care professionals (for example the patient's GP) less frequently. Guidance on subjects that have proved sensitive in the debate around the Liverpool Care Pathway such	Thank you for your comment, we have amended the contextual text in the NICE guideline to reflect that the recommendations are equally pertinent to people dying at home or in a setting where NHS care is provided outside the hospital. The Committee discussed access to a trial of assisted hydration in a community setting and considered it possible to support. Further discussion is provided in the 'Linking evidence to recommendations' section of Chapter 8

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				as hydration, need to be thought through in terms of their appropriateness to primary care. The introduction of a guideline stating that clinically assisted hydration is to be discussed as a possible intervention (on a trial basis even?) including with patients who wish to die at home and those close to them, is too rigid and may lead to loss of confidence that managing to die at home (in a non-medical environment without 24 hour medical and qualified nursing support) is possible.	
Royal College of Nursing	Full	General	General	In focussing on the patient, the needs of family and friends are under emphasised – signposting to appropriate services and engagement in decision making are key. The identification of people with Lasting Power of Attorney should be made at an earlier stage.	Thank you for your comment. We have not reviewed the evidence linked to the role of Lasting Power of Attorney as it was not in the remit or scope of this guideline. This guideline provides evidence based recommendations on the clinical care of the dying adult in the last days of life. We feel that we acknowledge the role and needs of those important to the dying person while focussing on the individual needs of the person in the last days of life.
Royal College of Nursing	Full and short	General	General	The importance of private time for family and friends and an opportunity of physical intimacy might also be added.	Thank you for your comment. We do not feel it has been appropriate within the context of the evidence reviewed to provide this level of detail.
Royal College of	Full and short	General	General	Overall these guidelines are helpful, however, there is insufficient emphasis that these are merely guidelines which offer some useful advice and information, but which may be limited. Care of the	Thank you for your comment. It is acknowledged that NICE guidance is provided to guide practice but it does not take the place of care professionals using their clinical judgement in practice based on

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Nursing				dying, one size most emphatically does not fit all!	individualized need.
Royal College of Nursing	Full and short	General	General	Our members suggest the use of some texts that reminds intending users of the guideline of the individuality of each patient. More emphasis on the importance of regular and frequent review is also required.	Thank you for your comment. We believe we have sufficiently addressed the issue of individualized care and monitor and review throughout our recommendations where relevant.
Royal College of Nursing	Full and short	General	General	Our members also consider that the guidance tends to focus on physical care, which is of high importance, but should be considered in conjunction with the psychological, spiritual and social needs of the individual patient, their family and those important to them.	Thank you for your comment. The focus of our guideline has been on the clinical care of the dying adult in the last days of life and so has a strong physical component. However, the Committee have always considered the importance of the psychological, spiritual and social needs alongside physical care and have made a number of recommendations where this is referred to explicitly.
Royal College of Nursing	Full and short	General	General	Overall the use of the words 'NHS setting' can be misleading and seems to focus on provision within a building rather than peoples' own homes and the care home sector. The intention that the guidance is to be used and applicable across settings should be acknowledged and made overtly visible in this guidance to support effective implementation.	Thank you for your comment. The remit of NICE guidelines generally is to provide guidance to NHS and social care providers. We have been pleased to be able to make reference to the broader settings in which NHS care is provided. This is especially important in this context where we are aware that end of life care is often provided within the hospice and charitable care settings.

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Royal College of Nursing	Short	1	5	'Who is it for?' People who are dying their families and carers are important to them' – Our members consider that if the intention is that the guideline would be used by families and carers, it would need to be cleared of healthcare jargon.	Thank you for your comment. NICE guidelines are available in different formats. A separate document entitled 'Information for the public' will be published alongside other versions.
Royal College of Nursing	Short	18	12	The guidance talks of healthcare professionals, much of the care in the community and in care homes is provided by social care staff this needs to be explicit.	Thank you for your comment. We acknowledge the role of social care providers throughout the document where we refer to health and care providers. As the guideline's focus is on the clinical care of the dying person in the last days of life, addressing some recommendations to social care providers is considered to be inappropriate although we recognize that many of the guideline recommendations such as those linked to recognizing dying, communication and shared decision making will be of key importance to this group of care providers.
Royal College of Nursing	Short	18	13	The guidance talks of 'NHS settings', surely we consider that this guidance would be useful for all settings not just the NHS?	Thank you for your comment. We have made some amendments to this section to incorporate other settings.
Royal College of Nursing	Short	3	19	We note that assessing for signs and symptoms is set out in alphabetical order. Our members consider that it would be helpful to reorder and group the signs and symptoms, for example group changes in communication and social withdrawal together, list	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the

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				first, for ease of reference?	'Linking evidence to recommendations' section of the full guideline (please see section 5.8).
Royal College of Nursing	Short	4	21	The word *'recovering'* here could imply that the person may make a full recovery, if this is not the intention perhaps the word should be 'making temporary improvement'?	Thank you for your comment. The Committee discussed the bullet points in the recommendation and decided to amend these to state: nearing death, deteriorating, stable or improving.
Royal College of Nursing	Full and short	General	General	In considering advance care planning, the notion of "final pleasures", music, special food, fragrance etc. might also be included.	Thank you for your comment. The committee has, through its recommendations, encouraged health care professionals to explore with the dying person and those important to them whether the dying person has made any advance statement and to respect the dying person's articulated goals, wishes and needs as far as possible.
Royal College of Nursing	Short	6	3-9	Much of this may have been established already. If it has, it would be appropriate to refer to these plans, ensure they are still valid. This would save time. Going over old ground may be an unnecessary duplication and potentially distressing.	Thank you for your comment. The Committee have drafted these recommendations to ensure that a framework exists to best support the dying persons who may not have put an advance care plan in place or considered advance decisions to refuse treatment. The committee feels it is important to have these discussions with the dying person and to also offer an opportunity to individuals who have an articulated care plan to revise this is their needs, wishes and goals have changed. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to

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					refuse treatment and lasting power of attorney for health and welfare.
Royal College of Nursing	Short	6	4	This needs to include legally binding Advance Directives, Lasting Power of Attorney etc.	Thank you for your comment. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Royal College of Nursing	Short	5	1	Our members consider that the absence of the word 'listening' from the section on communication (possibly the entire document?) is notable, there is a great emphasis on information - giving and advice.	Thank you for your comment. The guideline encourages the multidisciplinary team to provide the dying person and those important to them with opportunities for further discussion if needed and the committee feels this supports mutual exchange among the healthcare team, the dying person and those important to that person. We agree that listening is important. **A**s a guide, the committee relied on guidance provided in the NICE guidance entitled, Patient Experience in the adult NHS services. A cross reference to this guideline has been included. More information on this guideline can be found at: https://www.nice.org.uk/guidance/cg138.
Royal College of Nursing	Short	6	8/9	Suggest consider rewording this sentence. The language used here sounds like the dying person has to pass a test /an exam.	Thank you for your comment. We have amended the recommendation. Healthcare professionals are asked to explore with the dying person and those important to them, 'whether the dying person has understood and can retain the information given

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					about their prognosis'.
Royal College of Nursing	Short	7	1-3	It would be helpful if this is considered earlier and integrated into the process of ongoing communication.	Thank you for your comment. This has been added to recommendation 2.2.1.
Royal College of Nursing	Short	7	14	Suggest include ongoing assessment of the patient's need as needs will fluctuate.	Thank you for your comment. The Committee agrees and have drafted recommendation 2.3.7 which states: Continue to explore the understanding and wishes of the dying person and those important to them, and update the care plan as required. Recognise that the dying person's ability and desire to be involved in making decisions about their care may change as their condition deteriorates or as they accept their prognosis.
Royal College of Nursing	Short	7	14	Suggest include the assessment of the needs of those caring for the dying person and include offering available resources to them where appropriate.	Thank you for your comment. Service Delivery, including carer and bereavement support, are outside the remit of the guideline.
Royal College of Nursing	Short	5	13	It would be helpful to provide clarity on whose duty it is to discuss prognosis, and also include the need to share this with the multiple disciplinary team (MDT), if consent is given.	Thank you for your comment. The Committee agrees that this is an important issue and have sought to address this in its communication recommendations. As the multidisciplinary team would vary according to patient need, care setting and across Trusts, the Committee thought it best to recommend that 'the most appropriate available' multiprofessional team member be identified to

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					explain the dying person's prognosis' (see recommendation 2.2.3).
Royal College of Nursing	Short	5	13/14	The suggestion is that the person may not want to discuss issues, what if they are not conscious or lack capacity?	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Royal College of Nursing	Short	6	10	This should also include the person's wishes not just the prognosis.	Thank you for your comment. The Committee has recommended that an individualised plan of care should be created and that this plan should include the dying person's personal goals and wishes.

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Royal College of Nursing	Short	6	13-15	This needs to be more specific about the rights of the patient, the don etc. and explaining this to family etc., if necessary.	Thank you for your comment. This recommendation has now been removed although discussion on this issue remains in the Linking evidence to recommendations section of chapter 6.
Royal College of Nursing	Short	6	20/21	Our members consider that it would helpful to define what is meant by 'honesty' and 'transparency' in this context.	Thank you for your comment. We believe that these are principles that most professionals would understand and do not feel it necessary to provide any further clarification in this regard.
Royal College of Nursing	Short	7	28	Needs to include other types of professional records and not exclusively medical records, it should not be assumed that it is only the medical team that is involved.	Thank you for your comment. We have amended the recommendation to encourage people providing end of life care to share the care plan with the dying person, those important to them and all members of the multiprofessional team. We agree that this is not exclusively medical records. This recommendation has been amended to capture this.
Royal College of Nursing	Short	7	28	Add share 'also with the patient and those important to them'.	Thank you for your comment. We have amended the recommendation as suggested.
Royal College of Nursing	Short	7	4	As with above comment, this also needs to come earlier.	Thank you for your comment. In an attempt to respect the goals and wishes of the dying person and to continually strive to deliver individualised care, the Committee felt it was best to first establish the dying person's wishes related to shared decision making, ahead of all other considerations. This is reinforced by recommendations on shared decision-making in NICE's guideline on patient experience in adult NHS services.

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Royal College of Nursing	Short	8	6-8	It may be necessary to deal with any 'fall-out' arising from this.	Thank you for your comment. The 'Linking evidence to recommendations' section has been edited to explain the circumstances when it may not be possible to meet the needs of the dying person.
Royal College of Nursing	Short	7	2	The word 'should' is used, this should be 'must'	Thank you for your comment. We are unable to use the word 'must' as in terms of terms of NICE guidelines this refers to a legal duty to apply a recommendation.
Royal College of Nursing	Full and Short	General	General	Our members consider that neither the full nor the short document adequately addressed the right of an unresponsive patient to be heard through their Lasting Power of Attorney for personal care, and in the absence of this being in place, the right to be heard through their next of kin/appointed spokesperson.	Thank you for your helpful comments. We have amended our recommendations to reflect the outputs of any advance care planning process in terms of advance statements, advance decision to refuse treatment and proxy spokesperson and lasting power of attorney roles. We intend that these issues inform the development of an individualized care plan.
Royal College of Nursing	Short	8	13	*Supporting the dying person with hydration* - in Primary Care, with the person dying at home, who does this? The guideline needs to be more explicit about the need for conversations with the patient and informal carers about their understanding, and the patient's wishes.	Thank you for your comment. The Committee intend this recommendation to apply to all settings and can be done by anyone delivering NHS care. We feel we have provided the level of detail you suggest in subsequent recommendations in this section.
Royal College of Nursing	Short	8	18-23	See line 19, professionals' roles is to support the informal and/or social carers who may provide this care as described.	Thank you for your comment, the contents of which are noted.

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Royal College of Nursing	Short	8	23	Our members have indicated that this does not apply to Primary Care. The NHS professionals supporting the patient dying at home will not be delivering this care. Their role is facilitative, educational as described in 24-27.	Thank you for your comment. The Committee intend this recommendation to apply to all settings and all carers as appropriate.
Royal College of Nursing	Short	9 10	1-29 1-13	Our members consider that this section on clinically assisted hydration is not helpful to NHS professional supporting a person wishing to die at home. Whereas the subject of hydration needs to be broached and informal carers' questions and concerns need to be addressed, the implications of introducing clinically assisted hydration (on a trial basis?) into the discussions will require more thought.	Thank you for your comment. Recommendation 2.4.5 does state that risks and benefits are discussed with the dying person and those important to them and the Committee expect this to include any concerns. See also the recommendations in communication and shared decision making chapters. The Committee intend this recommendation to apply to all settings and are aware that clinically assisted hydration may take place in the community, but note that there may be challenges to its implementation and that this is an aspirational recommendation.
Royal College of Nursing	Full and short	161 Full 12 Sh	14-17 Short	Our members are concerned that there appears to be a confusing discrepancy here between the full and the short versions. In the full version it states that observational pain assessment tools *"can be used if thought to be helpful",* and in the short version it states *"Ensure that a dying person who is unable to effectively verbally communicate…..has a validated behavioural assessment to inform their management".* The evidence shows that in order to properly assess pain in an unresponsive patient, a behavioural assessment tool (such as "PAINAD") MUST be used, as recommended in the short	Thank you for your comment. The full version of the guideline gives further detail on assessing pain in those who are unable to communicate effectively. In addition it refers to the NICE guideline on Dementia that covers this issue too: https://www.nice.org.uk/guidance/cg42. Amendments have now been made to the 'Linking evidence to recommendations' section of the full guideline in this area (please see section 9.5)

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		or t		version.	
Royal College of Nursing	Full and short	162 Full	17	The full version states that *"often people associate the use of opioids with death and incorrectly conclude that commencing opioids will speed up the dying process"*. Our members agree that this has been observed in clinical practice, a majority of nurses and junior doctors are of the same incorrect opinion, and their practice reflects this, possibly due to fear of litigation. Our members suggest that it would be very helpful if this was clearly highlighted in these guidelines. It is also backed up by the literature – that there is no evidence that the proper use of opioids hastens death, but there is a body of evidence that suggests that patients in pain are likely to die more quickly.	Thank you for your comment. We are unable to add this into a recommendation as we have not conducted an evidence review in this area. As you state, we have highlighted this in the 'Linking evidence to recommendations' section.
Royal College of Nursing	Full and short	General	General	Both documents mentioned *"unwanted sedation",* in several sections but have not specifically balanced this with by stating that many individual patients may have chosen to be sedated, as part of their Advance Care Plan. Without this balance, there is a danger of some healthcare professionals associating "sedation" with "unwanted".	Thank you. We agree and have commented on this in the 'Linking evidence to recommendations' section, particularly in the noisy respiratory secretion chapter.

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Royal College of Nursing	Short	10	19-23	Suggest include stopping to monitor for example blood glucose levels, blood pressure etc., if appropriate.	Thank you for your comment. As this chapter is specifically about medication we are unable to comment on other interventions. We also consider this if limited relevance in the last days of life
Royal College of Nursing	Short	11	17-19	In this scenario, it would appear that the dying patient would have experienced pain on at least three occasions in 24 hours which is unacceptable. Our members recommend that, having had one episode of pain, in which potential avoidable causes have been excluded (such as retention or constipation), the patient is started at that point on a syringe pump to avoid any future pain.	Thank you for your comment. This recommendation is a "consider" recommendation, which reflect the strength and level of uncertainty around the evidence base. The Committee feel that clinical judgement should also be used when deciding on whether to use a syringe pump. They were keen to avoid over medicalising this issue as some people may not have the symptom, or require continuous control medication.
Royal College of Nursing	Short	11 and 16	25-27 and 27-30	In any patient, a daily reassessment of pain is not sufficient, as it risks future pain over the next 24 hours. This should instead be undertaken at least 4-hourly.	Thank you for your comment. "At least daily" does not preclude more frequent reassessment. As no evidence review was conducted in this area the Committee are unable to be more prescriptive.
Royal College of Nursing	Short	12	10-13	The statement *"the management of pain in the last days of life should follow principles of pain management used at other times…"* may be misleading for prescribers; when prescribing for non-terminal patients, the prescriber has to consider long-term adverse effects of some medications, for example unwanted sedation in a post-operative patient who needs to be alert for physiotherapy, mobilisation etc. This is not the case for the dying patient, especially those who have expressed a wish to be sedated as they are dying. As evidence suggests that pain in the dying patient has	Thank you for your comment. After careful consideration we do not feel any change to our recommendation is required. The intention of this recommendation is to outline that similar considerations should be made when managing pain in the last days of life. This does not preclude an assessment of benefits and harms but these would be considered within this specific context. Recommendation1.5.3 outlines the need for prescribers to bear in mind the dying person's preferences for symptom management.

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				historically been poorly recognised and under-treated, we need a different approach, not the same approach.	
Royal College of Nursing	Short	12	26	Add 'if pharmacological management is appropriate'	Thank you for your comment. This is a "consider" recommendation and should be read with the other recommendations in this section including detail on non-pharmacological management and identifying and treating reversible causes of breathlessness.
Royal College of Nursing	Short	13	16	Non-pharmacological methods such as? It would be helpful to specify.	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Royal College of Nursing	Short	14	13	Suggest include considering non-pharmacological interventions, such as psychological interventions.	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full

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					guideline.
Royal College of Nursing	Short	3	11	Perhaps line 16 not should come before line 11?	Thank you for your comment. These bullet points are listed in alphabetical order.
Royal College of Nursing	Short	27	Table 1	Our members consider that this table could easily be open to misinterpretation by prescribers, as it could be interpreted that a dying patient who is not taking any analgesics can only be given diclofenac etc., and not moved quickly on to opioids if required. For a patient already on opioids, the dose of 1.25-2.5mg of morphine prn or 10-20mg in a syringe driver may be grossly inadequate.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Royal College of Nursing	Short	17	10	People who are dying and their families need assurance that they can access support in a timely way from competent staff. They do not want to have to explain things dozens of times. Shared records and use of interoperable information technology (IT) are vital to making this happen not just a care navigator/coordinator. Robust backup needs to be in place so that if key contacts are absent	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.

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				there are people able to take over. We are aware that Airedale Trust have implemented the use of IPads in care homes and peoples' own homes so they can Skype for advice and not necessarily wait for a visit.	
Royal College of Nursing	Short	17	8	If this guidance is to ensure that people receive care outside acute care there are significant implications for staffing in both the community and in the independent and care home sector. The current workforce is struggling to meet current need not just increased demand. There are also implications for the provision of education and training to ensure staff are equipped to provide good quality care.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Royal College of Physicians (RCP)	General	General	General	The RCP is grateful for the opportunity to respond to the NICE draft guideline on Care of Dying Adult. We have liaised with the RCP Committee on Ethical Issues in Medicine and wish to make the comments below. We would also like to endorse the responses from the Association for Palliative Medicine of Great Britain and Ireland, the Renal Association, the British Geriatrics Society, the British Thoracic Society and the Association of British Clinical Diabetologists. Our fellows and members felt that a six week consultation period was too short for a topic of this magnitude and cross-specialty nature. This was particularly problematic as those six weeks overlapped with the main holiday period.	Thank you for your comment. The dates for the consultation were available to stakeholders many months in advance of the consultation over the summer. We would point out that 6 weeks is the standard period for consultation on NICE guidelines.

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Royal College of Physicians (RCP)	General	General	General	The following comments have been based primarily on the Short Version of the Consultation Draft, although the reading is informed by reference to the Long Version. As a matter of style and presentation, it was felt that the draft was wordy and repetitious, in places. Given the importance of the area, and that it is the short version that most people will read, it is important to ensure that the Guidelines are as clearly and crisply presented as possible. There are a number of omissions in the draft guidance. There is no mention of or any guidance on, the crucial issue of whether or not the patient has capacity for relevant decisions and the different processes of decision-making that must be followed depending on whether the dying patient has or lacks capacity. For care in the last few days of life this issue is crucial, because in such clinical contexts a high proportion of patients will lose capacity for health care decisions (due to diminished consciousness, pre-existing dementia or delirium). The absence of explicit mention of the Mental Capacity Act, and of instruction to follow it, alongside	Thank you for your comment. The recommendations have been subject to a rigorous editing process before consultation by NICE editors and will be reviewed again in light of stakeholder comments. The guideline has not been able to address all issues relevant to the care of the dying adult. The implementation of a legal position in terms of the Mental Capacity Act was not prioritised as part of the scope. The Committee agree that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues. We have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. We would expect health and care providers to be aware of and cognisant of the implications of the Act when providing care to patients. The issue of DNACPR is beyond the remit and

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				the absence of the terminology of the Act, and the use instead of vague or out-dated terminology in the recommendations and the full guideline, is a serious and pervasive problem in the draft versions. There is not any guidance in the use of the normal consent process when the patient has capacity, as against the use the processes of the MCA, based on the patient's best interests, where the patient lacks capacity. The guidance repeatedly instructs that 'those important to the person' should be informed and included or involved in decision-making, but it does not give any guidance about their very different roles according to whether the patient has capacity (so it is the patient who is consenting to or refusing treatment options), or whether 'those important to the person' are involved in making best interests judgments because the patient lacks capacity for the relevant decisions. Another important omission is the absence of any mention or guidance on dealing with the issue of those necessary decisions, made in advance of foreseen cardiorespiratory arrest at the time of death, not to attempt cardiopulmonary resuscitation in the event of cardiorespiratory arrest. There is no mention of, or advice on, the implications of the Tracey judgment regarding discussions about DNAR decisions with the patient.	scope of this guideline which is focussed on the clinical care of the dying adult in the last 2-3 days of life.

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Royal College of Physicians (RCP)	Short	3	General	The order of recommendations is confusing, since many readers will expect the recommendations to flow in the order which would normally be followed in clinical practice. The third bullet point of 1.1.1 should come first, and might read: 'if the person's medical history, clinical context and underlying diagnosis indicate that the person may be entering the last days of life, then gather information on …' and then go to 1.1.2 'Assess for signs and symptoms and any change that may suggest a person is entering the last days of life, for example…….'. It is odd to consider the other bullet points of 1.1.1 , ie 'changes in the physiological, social, spiritual and psychological needs of the person, the person's goals and wishes, the views of those important to the person with respect to future care' *before* one has reached any considered judgment as to whether the patient is in the last days of life or is recovering. These other bullet points could be omitted from this section as they are made repeatedly in the next two sections.	Thank you for your comment. These points are in alphabetical order as each point is considered to have equal status. The order of the recommendations is to reflect gathering information, assessing the patient in light of this information and then using the knowledge gained to determine the person's status.

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Royal College of Physicians (RCP)	Short	3 - 8	General	In particular, the sections on recognising when a person is in the last days of life, communication, and shared decision making are repetitious and oddly structured, and so are more difficult to follow than they need to be. More care needs to be taken to identify and communicate clearly the key practical implications of the guidelines. Serious issues arise because of vagueness and almost complete absence of guidance to follow the ethically and legally necessary decision-making processes. Similar problems recur in other sections.	Thank you for your comment. We suggest that the full guideline may provide greater detail behind the recommendations and the structure of the recommendations, however we acknowledge that improvements can be made. Several edits have now been made to the recommendations to improve clarity. NICE is currently developing guidance in palliative care service delivery that may address your concern of implementation of this guideline. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area, however it is not for this guideline to re-interpret legal directives. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are

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					available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Royal College of Physicians (RCP)	Short	4	22 - 25	1.1.4 Is too wordy. The crux is the need to monitor at least every 24 hours for improvement or deterioration in clinical condition, and to update care plan accordingly	Thank you for your comment. This recommendation has now been edited.
Royal College of Physicians (RCP)	Short	6	3 - 7	1.2.5 instructs staff to explore with the dying person and those important to them: 'whether the person has an 'Advance Care Plan' or has stated preferences about their care in the last days of life'. What is meant by 'Advance Care Plan' should be clarified. Does NICE mean an Advance Statement, which is the term used in law and in the National End of Life Care Programme guidance on Advance Care Planning, and which refers to a recorded expression of the person's wishes/preferences to inform decision making in the event of loss of capacity in the future? Or does NICE mean some sort of individualised care plan to be implemented in the future but without specific reference to loss of capacity? In the Full guideline Glossary, 'Advanced care plan' is defined as a 'record of advance care planning	Thank you for your helpful comments. We have amended our recommendations to reflect the outputs of any advance care planning process in terms of advance statements, advance decision to refuse treatment and proxy spokesperson and lasting power of attorney roles. We intend that these issues inform the development of an individualized care plan. We have corrected the references to advance directives and enduring power of attorney and amended our definitions of advance care planning. The glossary now also includes definitions for advance statement, advance decision to refuse treatment and lasting power of attorney Further information on these issues and the implications of the Mental Capacity Act have also been added to the 'Linking evidence to

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				discussions'. The Glossary also defines 'Advanced care planning' but it unfortunately quotes only half of the National End of Life Care Programme guidance definition which it references. Thus the Glossary omits to mention that a record of an advance care planning discussion is an Advance Statement, and that another outcome might be appointment of someone as Lasting Power of Attorney for health and welfare decisions. It is unclear why the draft omits the second half of its chosen definition of advance care planning, especially given that it is equally as important as the first half. Instead, the full guideline on page 111, line 34, mentions 'Enduring power of attorney' which was actually replaced by the new Lasting Power of Attorney via the Mental Capacity Act 2005, so the full guideline is badly out of date and thus confusing/misleading to readers in England and Wales. The full guideline on page 136, 2nd paragraph, stipulates that 'Advanced Directives should be honoured according to legal requirements'. This also is confusing and misleading since the term 'Advance	recommendations' section of section 7.6 in the full guideline

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				Directive' (there is actually no 'd' on the end, another error) is poorly understood because it was superseded in the Mental Capacity Act 2005 by Advance Decisions to Refuse Treatment (the same spelling error recurs in the Recommendations for research, page 19, line 27 of the Short guideline version.) Why have outdated and thus poorly understood terms been used in the Full guideline, which readers might use in seeking clarification? Most readers will be in England and Wales, where the Mental Capacity Act applies. According to the draft glossary definitions, an Advance care plan is one which must necessarily result from an advance care planning discussion. However, in reality people may write Advance Statements without engaging in such discussions. Such statements are vitally important in making best interests judgments on behalf of dying people who lack capacity, so professionals are legally bound to take those Advance Statements into account in making best interests judgments. Therefore the use of the term and glossary definition of 'Advance care plan' is likely to lead to confusion and/or poor clinical practice in terms of law and ethics, since staff are not advised to seek out advance statements. In this context, it is unclear why the draft uses the term	

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				'Advance care plan', rather than 'Advance Statement'. If the person has an Advance Statement, surely staff need to be reminded to: ascertain where it is kept; ensure that the dying person (and those important to them) knows that it will be used only in the event of loss of capacity; ascertain whether the patient wishes to change any of it (if the patient still has capacity to do so). The draft guideline omits these essential actions for healthcare professionals.	
Royal College of Physicians (RCP)	Short	10 - 12	General	Problems arise because no distinctions are drawn between decision-making processes required where the dying person has capacity and where the dying person lacks capacity. 1.5.1 and 1.5.2 illustrate the problems that this brings	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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54. Royal College of Physicians (RCP)	55.	56	57.	58. 1.2.5 instructs staff to explore whether the dying person 'has understood and can remember the information given about their prognosis'. This issue would be properly covered if the guideline reminded staff to assess the patient's capacity - including ability to retain information - an essential clinical assessment where there is any reason to doubt the patient's capacity for relevant decisions. Some patients with functioning memory will 'forget' even carefully explained bad news when they cannot deal with it emotionally – surely we must allow them to do this?	Thank you for your comment. We have amended the recommendation. Healthcare professionals are asked to explore with the dying person and those important to them, 'whether the dying person has understood and can retain the information given about their prognosis'. Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Royal College of Physicians (RCP)	Short	7	10 - 13	1.3.3 Stipulates that 'The lead healthcare professional should ensure that any agreed changes to the care plan are understood by the dying person, those important to them …..' There is no mention here of the real possibility that the patient may be	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking

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				unconscious or confused so unable to understand such changes. Also, if the patient has capacity, surely it is the patient's understanding which is of primary importance, since it is the patient who will consent to or refuse treatment or care options.	evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. All recommendations encourage healthcare professionals to prioritise the needs, wishes and goals of the dying person and to maintain an individualised approach to delivering care.
Royal College of Physicians (RCP)	Short	5	13 - 16	1.2.2 Stipulates that one should 'discuss the dying person's prognosis with them (unless they do not wish to be informed) as soon as it is recognised that they may be entering the last days of life…' However, in clinical practice one's approach will very often need to be more nuanced than this, especially with patients who do not refuse or discourage information but have consistently formed an unrealistic and over-optimistic interpretation of information given.	Thank you for your comment. The Committee appreciates the challenges faced by the healthcare providers who deliver end of life care and have recommended that those responsible for shared decision making are able to seek specialist advice if additional support is required. For the difficult situation mentioned in your comment, it is also recommended that the multiprofessional team is supported at all times in all settings by experienced staff. Recommendation 1.2.4 acknowledges that information given should reflect uncertainty and avoid over-optimism for those who approach prognosis with unrealistic hope.

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Royal College of Physicians (RCP)	Short	5	17 - 21	1.2.3, about identifying the most appropriate available team member to explain the diagnosis/prognosis to the patient, should logically come before 1.2.2.	Thank you for your suggestion. This has been amended.
Royal College of Physicians (RCP)	Short	5	22 - 29	1.2.4 appears to repeat 1.2.2.	Thank you for your comment. The Committee's intention is to first ensure that a discussion takes place with the dying person, recommendation 1.2.4 that you refer to covers the provision of information and opportunities for further discussion. The committee sees all the elements described in each recommendation as a key to the communication process.
Royal College of Physicians (RCP)	Short	5	6 - 12	1.2.1 Directs staff to establish the person's 'current level of understanding that they may be nearing death', 'whether they would like a person important to them to be present when making decisions about their care', and 'how much information they would like about their prognosis'. Whilst there is a mention of establishing the patient's 'cognitive status', there is only mention of establishing 'specific speech, language or other communication needs'. There is no mention of assessing the patient's capacity to make any particular decisions (even as to how much information they want). In the last few days of life very many people are so unwell that their ability to communicate is severely impaired due to confusion or diminished consciousness and it is odd that this is not mentioned and so no advice is given.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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Royal College of Physicians (RCP)	Short	6	13 - 15	1.2.7 How does NICE think that requests from people important to the dying person to withhold information from the dying person about their prognosis should be 'sensitively addressed'? A recommendation as to how this should be addressed would be helpful. For example, one might say that there is a duty to answer in a sensitive manner direct questions from the patient (even if this causes others concern), or gently to enquire what the patient wishes to know, whilst there is no duty to inflict information that the patient is clearly indicating they do not want to know or hear.	Thank you for your comment. This recommendation has now been removed although discussion on this issue remains in the Linking evidence to recommendations section of chapter 6.
Royal College of Physicians (RCP)	Short	6	19 - 22	1.3.1 stipulates that staff should 'Establish the level of involvement that the dying person wishes to have in shared decision-making' but there is no mention of the possibility that the patient may lack capacity; where there is any doubt an assessment of capacity is essential. Also, if the patient has capacity then the patient's consent will be needed for treatment to proceed. Surely some guidance about the impact of the Montgomery judgment on information which professionals must now give the patient is needed here.	Thank you for your comment. The committee agree that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues. We have made further additions to the guideline to provide clarity and to direct professionals to additional guidance and legal imperatives in this area.

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				Full Guideline on 'Shared decision-making': 'They [the GDG] noted that if a person has reduced capacity, then their views expressed in advance care plans and Advanced Directives should be honoured according to legal requirements. The GDG noted that people with reduced capacity defined in the Mental Capacity Act may have other needs and requirements, and these too should be honoured.' (p.136.) Whilst there is here a reference to the Mental Capacity Act, what is stated is muddled or erroneous since the Act makes it clear that following a capacity assessment a person must be judged as either having capacity for a decision or lacking capacity. There is no such legal concept as 'reduced capacity'. Therefore there is no legally-sanctioned process for decision making on the grounds of 'reduced capacity'. This section of the Full guideline is likely to lead to confusion and possibly to practice outside the law. The fact that these errors occur in the Full guideline raises the question of whether the GDG had an adequate understanding of the Mental Capacity Act and its major relevance for care in the last few days of life. Further advice is therefore required on the Mental	

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				Capacity Act in reviewing this section of the Full guidance and the Recommendations of the Short version. Alternatively, the Act's Code of Practice 2007 is written in plain English and makes these issues very clear.	
Royal College of Physicians (RCP)	Short	6	23 - 26	1.3.2 Stipulates that 'as part of any shared decision-making process' staff should 'take into account whether the dying person or those important to them have any cultural, religious, social or spiritual preferences that should be considered'. This gives the impression that the preferences of those important to the patient have the same weight as the patient's preferences. This is not the case either in ethics or in law. If the patient has capacity then the patient will decide whether to accept or refuse options offered, via the consent process; if the patient lacks capacity then the decision must be based (ethically and legally) on the dying person's best interests (as the patient) and not on the interests of those important to the patient. Thus the draft guideline completely fails to give those reading it any clear guidance on the roles of dying persons, and those close to them, in the decision-making processes where the patient has capacity, or conversely lacks capacity.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. Regarding the role of dying person and those close to them in the decision making process, the Committee's intention is that all parties be included and their wishes, needs and goals considered in the decision making process although it is clearly not the

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					case that these override those of the dying person. We would of course expect care givers to be cognisant of the needs of those important to the dying person in terms of their cultural, religious, social and spiritual preferences.
Royal College of Physicians (RCP)	Short	6 - 8	General	(1) In this section there is no mention of the necessity for awareness of the distinct roles in decision-making of the dying person and those important to them, according to whether the consent process is being followed (because the patient has capacity), or the process of making best interests judgments is being followed as per the Mental Capacity Act (because the person lacks capacity). So it is not clear what NICE means by 'shared decision-making'. The Glossary definition of shared decision-making (SDM) in the Full guideline is: 'The process of making a selective intellectual judgment when presented with several complex alternatives consisting of several variables, and usually defining a course of action or an idea.' (2) But if this definition is used in this NICE guideline, who is making the 'intellectual judgment' (dying person, those important to them, or possibly even the professionals)?	(1) Thank you for your comment. The definition for Shared Decision Making in the full guideline has been amended and now states: A process in which patients, when they reach a decision crossroads in their health care, can review all the treatment options available to them and participate actively with their healthcare professional in making that decision. (2) The Committee recognised that shared decision making and the use of multidisciplinary teams to deliver care are standard across all medical specialities, but felt it is especially important in the last days of life to involve the dying person in decisions about their care if they so wished. The Committee believes these recommendations support this ideal. (3) The development of an individualised care plan is seen as a joint effort by the multidisciplinary team but the guidance also seeks to ensure that shared decision making can be supported by experienced staff at all times. (3) The roles and responsibilities of professional

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				How does the 'sharing' aspect of SDM come in - between who is it shared, and how? (3) Later, on page 19, lines 5 and 6, in the section on 'Context', the draft guideline states 'This guideline's aim is to provide a set of recommendations to guide healthcare professionals to recognise better when a person is dying, how to communicate and share decisions respectfully with the dying person and those important to them…'. Yet the guideline does not actually mention or describe the correct processes for 'shared' decision making, nor the roles and responsibilities of professionals, patients and those important to them in the different processes of decision making via consent, and via making best interests judgments where the dying person lacks capacity for the decision. So in this crucial respect the draft guideline fails to achieve its stated aim. (4) A main concern is that non-specialists in the care of the dying might be left seriously confused by the combination of the Glossary definition, the draft recommendations on SDM, and this later statement under 'Context' in this NICE draft guideline.	members of the multidisciplinary team may vary across different Trusts and indeed in the range of settings covered by this guideline and is therefore considered outside the remit of this guidance. We have added further detail of the implications of the Mental Capacity Act and we would assume that the appropriate and competent clinician would have a good understanding of these issues and how they impact on their practice. Our intention is to guide some of the approach and content of the discussion having undertaken an evidence review to identify the levers and barriers to this process. (4) We sincerely hope that the redrafted definition of Shared Decision making clarifies the issue for non-specialists, but wish to note that our guidance also stresses the importance of ensuring that further specialist advice can be sought if additional shared decision making support is required. We believe that colleagues are able to interpret the intent behind our recommendations whilst also being aware of the impact of legislation on their practice as outlined above.

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Royal College of Physicians (RCP)	Short	7	21 - 26	1.3.5 Mentions that the individualised plan should include the dying person's anticipated care needs, preferred care setting and preferences for symptom management, but omits to mention that the 'plan' should include how to manage symptoms that the dying person is suffering from now, i.e. immediate and urgent needs. More emphasis on care now would be most helpful, as opposed to focussing merely on preferences/needs for the future.	Thank you for your comment. The Committee agrees that ideally, the needs of patients would be best established during an earlier point in care. A number of other recommendations have been made in respect of symptom control However, the Committee also felt strongly that this recommendation was very key to delivering an individualised care plan to the dying person. The list now includes 'current and anticipated care needs and preferences for symptom management'.
Royal College of Physicians (RCP)	Short	7	27 - 29	1.3.6 There is no mention of asking the dying person's permission to record care planning discussions and resulting care plans in the person's medical records. In contrast, the National End of Life Care guidance on advance care planning (ACP) advises that the dying person's permission must be sought before recording ACP discussions/outcomes. This is to ensure that the patient agrees with what is written. Would the same apply to the 'individualised care plan'?	Thank you for your comment. The Communication and Shared Decision Making recommendations encourage healthcare professionals delivering end of life care to prioritise the personal goals and wishes of the dying person and this includes establishing their communication needs and expectations. Further detail has been added to section 7.6 of the full guideline in this regard.
Royal College of Physicians (RCP)	Short	7	18 - 19	1.3.5 States 'In discussion with the dying person, those important to them and the multiprofessional team, create an individualised plan of care.' [italics added] But with whom should that care plan be agreed (dying person or those important to them)? Whose preferences are most important (dying person or those close to them) and what ought	Thank you for your comment. This recommendation is about shared decision making between dying person, those important to them and multiprofessional team. Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and

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				professionals to do where there is conflict of preferences? NICE gives no guidance on this, even though such differences of preference occur quite frequently in this clinical context. Reminders of the consent process (where patient has capacity) and best interest processes (where patient lacks capacity) would give guidance to staff faced with this difficulty.	participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Royal College of Physicians (RCP)	Short	7	4 - 9	1.3.3 States that the lead 'healthcare professional should give their own contact details… to the dying person and those important to them'. This is not clear. Does NICE mean the professional's personal contact details (e.g. mobile phone number) here? If NICE does mean this, then there are serious implications for the work/life balance and perhaps emotional wellbeing of those responsible for the care of dying patients. Are such professionals not intended to be 'off duty'? Should there not be a line about clarifying with the patient and their family who will be the first point of contact if deterioration happens overnight and the patient is in an institutional setting?	The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section. The Committee agree and that next of kin contact details should be obtained, but considered this to be standard practice and applicable prior to the last days of life. They therefore chose not to specifically state this in the recommendation.

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Royal College of Physicians (RCP)	Short	8	1 - 5	1.3.7 State that staff should 'Recognise that the dying person's ability and desire to be involved in making decisions about their care may change as their condition deteriorates….' But still there is no mention of assessing the dying person's capacity. This same point instructs 'Continue to explore the understanding and wishes of the dying person and those important to them, and update the care plan as required.' But whose wishes are most important here: is the care plan to be changed according to the wishes of those important to the patient (rather than the patient's wishes) where the patient retains capacity?	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Royal College of Physicians (RCP)	Short	8	9 - 11	1.3.9. How do you identify the 'experienced staff' who are the specialist advisors?	Thank you for your comment. This may be determined locally and implies knowledge of local staff who are experienced in these processes. This may be more senior members of staff but may equally be experienced staff in end of life care such as GPs

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Royal College of Physicians (RCP)	Short	8	13 - 17	1.4.1 More emphasis should be given to the importance of dedicated efforts from appropriately experienced nurses to assist dying patients to drink – this is time consuming and requires skills, not least to assess if there is risk of aspiration.	Thank you for your comment. The Committee consider this to be part of basic caring skills and do not feel the need to provide further detail in this regard as this may be undertaken not only by nursing or care staff but by the dying person's loved ones with support.
Royal College of Physicians (RCP)	Short	9	1 - 3	1.4.4 States that 'the possible need for clinically assisted hydration in those not currently receiving it' should be reviewed, preferably daily, with people at the end of life, 'respecting their wishes and preferences.' It would be helpful if the guideline could acknowledge that it may not be possible to 'respect' the dying person's preference - for example, if that preference is to remain at home or in a care home but also to receive effective clinically assisted hydration to correct dehydration, via iv fluids or enteral tube (e.g. if an enteral tube has become displaced). 1.4.4 as it stands is likely to be imposing an impossible duty on professionals in such clinical circumstances.	Thank you for your comment. The Committee chose to state 'respecting their wishes and preferences' to capture discussions around culture and religion and also decisions stated in the advance care plan. The Committee chose 'respected' to mean that in some cases it may not be possible, but that they would always be considered and be taken into account. This has been added to the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
Royal College of Physicians (RCP)	Short	9	15 - 25	1.4.7 is more helpful, since it lists factors which professionals should 'take into account'; implying that the professionals have some real say in the decision, as opposed to simply having to 'respect the wishes and preferences' of the dying person, as implied by 1.4.4.	Thank you for your comment. The Committee believes that 'respect' coveys the concept of having due regard for someone's feelings, wishes and needs.

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Royal College of Physicians (RCP)	Short	9	26 – 28	1.4.8 advises professionals to 'consider a therapeutic trial' of clinically assisted hydration where distress may be caused by dehydration; it would be helpful if the guideline acknowledged that such a therapeutic trial would require a move to hospital/hospice, or remaining in such a location rather than being at home.	Thank you for your comment. The Committee intends this recommendation to apply to all settings and are aware that clinically assisted hydration may take place in the community, but note that there may be challenges to its implementation.
Royal College of Physicians (RCP)	Short	9	8 - 14	1.4.6 Is it not meant to be 'unlikely to prolong life *but may* prolong the dying process'. Or should it be left at 'may not prolong life' (full stop).	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given.
59. Royal College of	60.	61	62.	63. 1.4.4 to 1.4.8 Re Clinically assisted hydration, there is no mention of the fact that *effective* clinically assisted hydration requires either intravenous fluids or hydration via gastrostomy or other intestinal tube, especially if there is intent to reverse existing dehydration as mentioned in 1.4.8. Since intravenous (iv) fluids cannot be administered at home or in care home settings, it is very important that any guideline should remind staff that iv	Thank you for your comment. We are unable to provide this level of detail within the guideline although we are aware of fluids being administered successfully by sub cutaneous infusion. Please see the discussion in the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline. The Committee intends this recommendation to apply to all settings and are aware that clinically assisted hydration may take place in the community, but note that there may be challenges to its

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Physicians (RCP)				hydration will require a move to hospital or hospice, or not leaving such locations if the dying person is already there. Dying patients (and those important to them) do need to be informed of this fact, yet it is unfortunately omitted from this draft guideline. It is very unlikely to be appropriate to subject a patient to the insertion of a feeding tube (to provide hydration) in the last few days of life, since the burdens and risks are most likely to exceed the benefits – the guideline mentions only (in 1.4.9) whether hydration should continue via pre-existing tubes.	implementation. The Committee does recommend discussing the risks and benefits of clinically assisted hydration with the dying person and those important to them and if a move to hospital/hospice be required because this service is not available to them in their locality, it is expected that this be discussed.
Royal College of Physicians (RCP)	Short	15	21 - 26	1.5.32 Finally, the draft guideline advises to 'consider' stopping the medication if unacceptable side effects persist despite treatment of those side effects. Why not simply advise stopping the medication? In this context, how could you justify continuing it in terms of ethics and law, given lack of benefit and unrelieved adverse effects for the patient?	Thank you for your comment. The recommendation has been structured in line with NICE style. The first bullet point recognizes the limitations of the evidence in the area and after the consideration of a trial of medication for a period of 12 hours suggests stopping the medication if there is no benefit. Should any of the side effects occur and become unacceptable to the individual before that time, then the medication should also be stopped
Royal College of Physicians (RCP)	Both	10 - 15	General	Guidance on symptom control, including pain control, is relatively brief. Practically no attention is given to the problems of symptom control in patients with dementia. Nor is there any mention of, or guidance on, the management of diabetes	Thank you for your comment. No evidence was identified regarding dying adults with dementia and pain management and therefore no specific recommendations were made for this group. The Committee were aware of the complexities of

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				(especially insulin-dependent) in the last days of life, despite the high and increasing incidence of this disease. More generally, how to manage pain, fear of pain or acute discomfort and breathlessness are of great concern to patients and their carers. While the documents seek to follow a logical narrative, it might be better to bring these key messages closer to the front. The same goes for anticipatory prescribing. Given staff shortages there can be considerable delays, where chronic conditions associated with dying take second place to urgent matters of saving other people's lives. Where anticipatory provision is problematic, as it can be with opioids for example, then it would be helpful to see a specific reference to mechanisms for speedy access to analgesics, anxiety-relieving or antiemetic drugs.	managing pain in these patients and chose to make a consensus recommendation that in patients who are unable to communicate verbally such as those with advanced dementia, a validated behavioural pain assessment should be used to inform their management. This is further expanded on in the 'Linking evidence to recommendations' in this Chapter. Similarly, management of diabetes in the last days of life was outside the scope of this guideline. Service Delivery, including staffing and provision and access to anticipatory prescribing, are beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Royal College of Physicians (RCP)	Both	14 - 15	General	1.5.28 to 1.5.32 on the treatment of 'noisy respiratory secretions', are inherently problematic from the ethical and legal perspectives, since these treatments have side-effects and there is a 'lack of evidence of any beneficial effect to the patient or improvement in distress levels' as stated on page 21, lines 22 and 23, in the section on Recommendations for Research. Furthermore, on	Thank you for your comment. The Committee acknowledge the limited evidence in this area, but note that the evidence suggests that the medications were of equivalent efficacy and could therefore not prioritise one over another. Due to the low quality of the evidence the recommendation made is a "consider a trial of" recommendation, as detailed in the NICE guidelines manual

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				page 22 the draft guideline mentions the side-effects of these drugs and states: 'it is hard both morally and economically to justify their continued use when current evidence does not support them and treatment is usually aimed at minimising distress of people other than the patient.' So why does the draft guideline advise professionals to consider prescribing these drugs, especially where the stated justification according to 1.5.29 may be 'to reduce any distress in the dying person *or those important to them'*? [italics added] It is difficult to justify giving these drugs to patients on the basis of the dying person's best interests, which must be the ethical and legal basis since the overwhelming majority of patients in this context lack capacity re this decision. How can NICE then justify its statement that professionals should consider giving the dying patient these drugs to reduce distress *in those important to them*? The draft guideline (Short version) gives no justification for giving these drugs to patients, who will not benefit and may be harmed, merely in the hope that those important to the dying person will be less distressed. The draft guideline gives the clear impression that it is ethically and legally acceptable to give dying	(https://www.nice.org.uk/media/default/about/what-we-do/our-programmes/developing-nice-guidelines-the-manual.pdf) this reflects the strength of the evidence. The Committee has amended recommendation 1.5.30 and removed reference to the purpose of this treatment to reduce any distress in those important to the dying person. As there is uncertainty in this area the Committee have made a research recommendation. The order of recommendations reflects the Committee's intention of first considering non-pharmacological interventions. Further detail is given in the 'Linking evidence to recommendation' section 9.30 in the full guideline.

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				patients medications which will not benefit them and are instead likely to cause harm, merely in the interests of those important to the patient. This is a serious concern both ethically and legally.	
Royal College of Physicians (RCP)	Short	10	19 - 23	1.5.1 states that where a person may be entering the last few days of life, after discussion and agreement with the patient *and those important to them*, previously prescribed medicines should be stopped where 'they are not providing symptomatic benefit or may cause harm'. However, where the patient has capacity it is the patient's agreement which is required. For example, if the family want the medication continued and the patient agrees to it being stopped, then it is the patient's request to stop it (effectively a refusal to take it) which must be determinative. Where a patient lacks capacity, and the responsible doctor and multi-professional team agree that it is not in the best interests of the patient to continue a medication because it is harmful and/or of no benefit, then surely that medication should be stopped even if those important to the dying person do not agree. This is a matter of ethics and law, which are important considerations at the end of life.	Thank you for your comment. Reference to the Mental Capacity Act has been added and a link added to the shared decision making chapter where further information is detailed about this issue. We have clearly indicated the requirements of the act for clinicians in this area in the 'Linking evidence to recommendations' section of this guideline in case they were not aware. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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Royal College of Physicians (RCP)	Short	10	24 - 25	1.5.2 Mentions 'involving the dying person *and those important to them* in making decisions about symptom control in the last days of life' (italics added). The guideline fails to remind professionals that the 'involvement' of those important to the patient is of a different nature depending on whether the dying person has capacity or lacks capacity – in the former case it must be the patient's views which are determinative via consent or refusal of treatment offered, and in the latter case the role of those important to the patient is defined by the Mental Capacity Act whereby the basis of those decisions (responsibility for which usually lies with the healthcare professionals) must be the dying person's best interests.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We have made a minor amendment to this recommendation for clarity.
Royal College of Physicians (RCP)	Short	10	24 - 29	1.5.2 It would be helpful if the guideline could advise on the implications of the Montgomery judgment regarding information which must be given to patients (with capacity) regarding the burdens and risks of treatment options for symptom control.	Thank you for your comment. We have added text to the 'Linking evidence to recommendations' section of chapter 6 (6.6)

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Royal College of Physicians (RCP)	Short	12	14 - 17	1.5.13 Re pain control where the patient cannot communicate verbally, examples given being dementia or learning disabilities, what is meant by 'a validated behavioural pain assessment'? It would be helpful if such an assessment could be included in the Appendices. Many patients cannot communicate verbally due to confusion or diminished consciousness – does NICE advocate the use of validated behavioural assessments in these clinical contexts?	Thank you for your comment. This is discussed in more detail in the full guideline 'Linking evidence to recommendations' section (9.5), along with reference to the Mental Capacity Act. Cross reference is also given to the NICE dementia guideline. The Committee feel that clinical judgment should always apply in the context you outline.
Royal College of Physicians (RCP)	Short	14	13 - 15	1.5.24 advises 'Treat any reversible causes of agitation, anxiety or delirium' and lists as an example 'certain metabolic disorders'. However, some metabolic disorders causing delirium (such as hypercalcaemia in malignancy, or uraemia) would require invasive or burdensome treatment, necessitating hospital admission or renal dialysis in the case of uraemia. Since such treatments are unlikely to be appropriate for irreversibly dying patients in the last few days of life, it would be preferable for the NICE guideline to say 'consider treating', rather than the single instruction to 'treat' the reversible causes regardless of the burdens and risks of such treatment in this clinical context.	Thank you for your comment. The Committee are content with the recommendation as currently worded. We are aware that reversible causes may not be possible to treat, but expect healthcare professionals to use clinical judgment to explore these.

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Royal College of Physicians (RCP)	Short	15	14 - 20	1.5.31 advises that side effects (of the medications for noisy secretions) such as delirium should be treated. This would probably mean using an anti-psychotic agent or benzodiazepine, which are both likely to sedate the patient. Is adding an anti-psychotic agent or benzodiazepine really justifiable, simply to treat the delirium caused by the drug which itself is unlikely to benefit the patient, according to NICE? The draft recommendation does not adequately reflect the ethics or the legal implications here, and this recommendation should be reviewed.	Thank you for your comment. We feel that recommendation 1.5.32 which suggests stopping medication if unacceptable side effects persist is helpful in this regard. Our recommendations also create the opportunity for a trial of this medication. We feel it important to provide options and advice for when the clinician considers this a valid option for the dying person (given caveats about capacity to make decisions). The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Royal College of Physi	Short	16	28	1.6.5 Re anticipatory prescribing, on page 16 line 28 the draft advises 'monitor and review the dying person's symptoms and any side effects *daily*' (my italics). Surely monitoring should be	Thank you for your comment. We have made amendment to this recommendation which now reads "At least daily" .The Committee feels that this does not preclude more frequent reassessment. As

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cians (RCP)				more frequent than this, particularly in care homes, hospices and hospitals, because condition and symptoms can change rapidly in patients in the last few days of life. If medication is given, its effect should be reviewed (for example, to see if it relieved pain, breathlessness etc) more frequently than once per day – review only every 24 hours would be unlikely to alleviate symptoms successfully, let alone optimally.	no evidence review was conducted in this area the Committee are unable to be more prescriptive.
Royal College of Physicians (RCP)	Short Appendix A	24	15 – 21	Page 24, lines 15 to 21, re drugs recommended for indications for which they do not have a UK marketing authorisation, the guideline states: 'The prescriber should follow relevant professional guidance, taking full responsibility for the decision. The patient (or those with authority to consent on their behalf) should provide informed consent, which should be documented.' There are two problems with these statements. Firstly, in the last few days of life many patients will lack capacity to consent. In that case, according to the Mental Capacity Act, the only person who can 'consent on behalf of the patient' would be someone officially appointed as having Lasting Power of Attorney for health and welfare. Such appointments are still uncommon, so in the vast majority of cases decision making responsibility falls to the decision-	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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		25 8 - 9		making member of the health care team following the Mental Capacity Act processes – thus no-one 'consents on behalf of' the patient. Therefore, this sentence should be amended to reflect the most common situation. Secondly, does NICE really believe that extremely ill patients in the last few days of life must be told that the drugs recommended do not have UK marketing authorisation for that indication, in addition to having to be told all about the risks and burdens of those treatments? Would the Montgomery judgment actually mean that such imminently dying patients must be burdened with this information, in addition to all the other information they must receive in order to give valid consent? Re the Montgomery standard for giving information, in the last few days of life would a 'prudent person in the patient's position' really want this information about marketing authorisation? Page 25, lines 8 to 9, state 'Consider local prescribing preferences, *but the preferences of the dying person should be respected*.' [italics added] What does NICE mean by this, especially given that on the previous page it stated that the prescriber must take *full responsibility* for the prescribing	

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				decision? Surely if the prescriber has to 'respect' the patient's preferences, then that implies the prescriber must prescribe what the patient wants, whether or not the prescriber believes it to be clinically appropriate. How can the prescriber take 'full responsibility' in a situation where NICE indicates that the prescriber must prescribe according to the patient's preference – in that scenario the responsibility must logically pass to the patient, not the prescriber. The ethical and legal situation simply is more complex than the draft guideline statement that the dying person's 'preferences must be respected'; such complexity ought to be reflected in the NICE guideline, otherwise healthcare professionals, dying patients and those important to them are highly likely to be misled and/or confused. The relatively simple reality is that whilst a patient can refuse a medication offered, the patient cannot demand that a medication be given where the prescriber believes it to be clinically inappropriate – this must also apply where the drug would be prescribed outside its marketing authorisation.	

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Royal College of Physicians (RCP)	Prescribing table 1	27	Prescribing table 1	This contains no guidance on how to adjust the dose of the patient's current opiate medication when the patient is no longer able to take it orally and so it must be given by subcutaneous injection. For most opiates, the dose should be significantly reduced (e.g. halved) when changing from the oral to the parenteral route. The absence of such guidance is likely to lead to inadvertent opiate overdose and thus harm to dying patients. Why is the intravenous route mentioned as an option in the tables? It is impracticable outside hospital or hospice, gives a rapid rise and high peak in opiate level in the blood, and overall lacks advantage over the subcutaneous route in the great majority of cases. Does NICE really wish to retain this advice in the table, and if so, retaining this advice requires some clinical justification.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Royal College of Physicians of Edinburgh	Short Version	17	10/11	Having an advance care plan (or anticipatory care plan in Scotland) would be helpful. The main challenge in the community setting is found in care homes, regarding staffing levels of both qualified and support staff and the frequent changes in staffing. Thus programmes of continued education are required, such as carried out by Hockley et al when advance care planning, involving a three-fold intervention in care homes: care planning, implementation of the last days of life framework and	Thank you for your comment. The Committee agree. The focus of this guideline is clinical care in the last days of life. We have not addressed the issue of advance care planning but recommend that reference is made to any existing advance care plan as part of effective communication and care planning. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently

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				also general palliative care training. (Ref: Hockley J, Watson J, Oxenham D, Murray SA. The integrated implementation of two end-of-life care tools in nursing care homes in the UK: an in-depth evaluation. Palliat Med. 2010;24(8):828-38).	developing guidance in palliative care service delivery and this topic is covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Royal College of Physicians of Edinburgh	Short Version	3	general	The guideline is unclear about who should make the diagnosis that the person is dying, lead discussions and complete documentation. In hospital it should be a doctor who is at least a registrar; in the community, a GP or senior district nurse; in all settings it could also be a palliative care clinical nurse specialist.	Thank you for your comment. These recommendations apply to all healthcare professionals delivering care and may be different in each setting. NICE is currently developing guidance in palliative care service delivery and the issue of staff grade/role/seniority may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
Royal College of Physicians of Edinburgh	Short Version	4	1, 4, 9, 13, 15	We note that these symptoms are common in reversible causes of deterioration, such as delirium, and are therefore useful only in this regard once the patient is known to be progressing towards death.	Thank you for your comment. Reversible causes are discussed in the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8)

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Royal College of Physicians of Edinburgh	Short	6 and 7		Sections 1.2 and 1.3 are about communication and shared decision making. There is no explicit mention in the text regarding assessment of capacity. Assessment of capacity regarding what the patient is able to understand and wishes to participate in is a crucial part of end of life care.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Royal College of Physicians of Edinburgh	Short Version	19	27	This should read "advance" rather than "advanced" care planning.	Thank you for your comment. This has been amended throughout the guideline. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare.
Royal College of Physicians of	Short Version	5	12	We suggest remove the word "prognosis" and insert "likely course of events". The rationale is that it is helpful for patients to actually understand the likely course of events, discussed in a sensitive manner.	Thank you for your comment. We have carefully considered the order of the recommendation and feel that no change is required.

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Edinburgh					
Royal College of Physicians of Edinburgh	Short	9	1	The guidance says "review, preferably daily, with people at the end of life, the possible need for clinically assisted hydration…". It is unclear how a daily review of this would benefit patients and it would be logistically difficult at home. Staff who are less experienced in working with dying patients may mis-interpret this as they *must* give artificial hydration if the patient / family requests it. It would be helpful if the definition of clinically assisted hydration (ie IV/SC/NG fluids) be put in the first bullet, so as to distinguish 'clinically assisted [artificial hydration]' from 'clinically assisted drinking' (ie patient helped by nurse to drink).	Thank you for your comment. The wording of this recommendation has been amended to state "Assess hydration status, and review preferably daily,…" The Committee intend this recommendation to apply to all settings and are aware that clinically assisted hydration may take place in the community, but note that there may be challenges to its implementation. Definitions are provided in the glossary of the full guideline.
Royal College of Physicians of Edinburgh	Short Version	11	17	Add "If the dying person is unable to tolerate oral medication, consider using a syringe pump……".	Thank you for your comment. The Committee feel this is covered in the current recommendation and is detailed further in the full version 'Linking evidence to recommendations' section. In addition, recommendations 1.5.4 and 1.5.5 focus on considering whether the oral route is possible or tolerable.

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Royal College of Physicians of Edinburgh	Short Version	12	1	We suggest this should read "seek specialist advice" as a specialist geriatrician or anaesthetist may be appropriate.	Thank you for your comment. This recommendation advises people to secure this level of advice if symptoms do not improve with treatment. An experienced geriatrician or anaesthetist will be in a position to adjust medications without access to specialist advice and this recommendation remains valid for those prescribers who may have limited experience in prescribing in the last days of life. We believe this is a valuable recommendation to avoid uninformed prescribing that may not effectively manage symptoms, create side effects or cause unwanted sedation.
Royal College of Physicians of Edinburgh	Short Version	16	8	In care homes the nursing team particularly has to be vigilant to see when anticipatory medication should be prescribed for the patient and this may mean them contacting a doctor. We therefore suggest inserting "Ensure that anticipatory medication is prescribed and available as early as possible for people……".	Thank you. After careful consideration the Committee feel no change is required. The Committee consider this recommendation to apply to all settings.
Royal College of Physicians of Edinburgh	Short Version	general	general	Throughout the document it refers to "syringe pumps" as a way to deliver medication. Different recent documents published by NICE refer to "syringe pumps", "continuous subcutaneous injections" and "syringe drivers" all to mean the same mode of medication delivery. This could lead to confusion for the reader of NICE guidelines and we would recommend NICE consistently adopt one term.	Thank you for your comment.the chosen term here reflects the specific use of this mode of administration for this circumstance. We are unable to comment on other guidance terms.

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Royal College of Physicians of Edinburgh	Short Version	general	general	Throughout, the document refers to use of medication that do not have UK marketing authorisation in the UK and are being used off licence. It is correct to make this clear but should perhaps be balanced by saying that the medications outlines in this document being used this way is in accordance with a large body of expert opinion, is considered normal practice in palliative care and refer to the Palliative Care Formulary which contains much of the data to support the use of these medications in this way (Twycross R, Wilcock A, Howard P. 2014 *Palliative Care Formulary* (PCF5)).	Thank you. NICE processes state that if a drug is recommended for an indication in which the medication is off licence then a footnote is required. The linking evidence to recommendation sections within the full guideline gives further detail including current practice and the Committee's expert opinion. Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Royal College of Physicians of Edinbur	Short Version	27		We suggest a footnote is added to the advice on ibuprofen and diclofenac making reference to taking account of frailty, age, risk of GI bleeding, renal function etc.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently,

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gh					they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	FULL	11	1	Some of the guidance is appropriate in this section; however, slightly rewording some parts would help alleviate this	Thank you for your comment. This text has had some amendment following stakeholder consultation. We have removed the exclusion of major trauma and attempted suicide. We have also made edits to the recommendations linked to recognizing dying.
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	FULL	26	3.3.2	Although the RCSLT agree with what the guideline does not cover, we believe it needs to consider the management and support of staff involved in this, especially for one who is not familiar or trained	Thank you for your comment. We are unable to comment further on this issue as the areas you allude to have not been covered by this guideline.
ROYAL COLLEGE OF	NICE	19	8	The RCSLT suggest adding 'investigating what assists family members/carers in their involvement in the management of a dying person'	Thank you for your comment. The process for formulating research recommendations is outlined in section 9.5 of the NICE guidelines manual which can be found at the following link:

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SPEECH AND LANGUAGE THERAPISTS					http://www.nice.org.uk/article/pmg20/chapter/1%20Introduction%20and%20overview. Further detail is also provided in section 4.4.1 of the full guideline. The role of assistance for family members is beyond the remit and scope of this guideline and as such the Committee is unable to make any research recommendations in this area. The Committee have prioritized three recommendations for further research further to their review of the evidence. These are linked to recognizing dying, agitation and delirium and noisy respiratory secretions. Full discussion is provided in Appendix O.
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	NICE	3	3	The RCSLT thinks it is appropriate that the guideline talks about healthcare professionals and not social care or care professionals. Although, we are slightly concerned that throughout there is little or no mention of the Allied Health Professional's contribution; such as speech and language therapists or physiotherapists, within the document. (Although, the document does state 'multi-professional' but perhaps this isn't specific enough as the default is usually doctors and nurses)	Thank you for your comment. We believe multiprofessional refers to all roles who provide clinical care to the dying adult in the last days of life. This may include social care providers and allied health professionals. We have not specified any particular role as a priority provider.
ROYAL COLLEGE OF	NICE	5	11	The RCSLT believe that support from a speech and language therapist should be added	Thank you for your comment. Whilst we are aware of the key role of speech and language therapist at the end of life, we have chosen not to specify any particular role as a priority provider.

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SPEECH AND LANGUAGE THERAPISTS					
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	NICE	5	21	The RCSLT believe that speech, language and communication needs (SLCN) should be added to the list.	Thank you for your comment. Whilst we are aware of the key role of speech and language therapist at the end of life, we have chosen not to specify any particular role as a priority provider.
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS		3	3	This guidance would be helpful to anybody involved in the care of a person who is nearing death - many will be in nursing and residential homes and thus broadening the groups would be appropriate	Thank you for your comment and for participating in the consultation process.
ROYAL COLLEGE OF SPEECH		4	4	The RCSLT suggests there should be an additional point referring to changes in willingness to communicate, clarity and appropriateness of speech and language	Thank you for your comment. We feel that "changes to communication" captures this and is the wording reflected in the evidence identified.

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AND LANGUAGE THERAPISTS					
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	FULL	section 1.1		The RCSLT suggest establishing the direction of change in signs and symptoms	Thank you for your comment. Your concern is addressed by recommendation 3 (1.1.3 in the short guideline). The Committee discussed the bullet points in the recommendation and decided to amend these to state: nearing death, deteriorating, stable or improving.
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	FULL	86		The RCSLT suggest that this guideline includes; that establishing the communication needs of family /carers of patient and also the importance of establishing a communication approach for the person to indicate whether e.g. they have changed their wishes are in pain etc. Simple approaches such as 'yes'/'no' charts or hand signals etc.	Thank you for your comment. The committee feel this is covered by the recommendations made in the communication chapter and further detail is provided in the 'Linking evidence to recommendations' section of the full guideline (6.6), including the importance of tailoring communication for individuals.
ROYAL COLLEGE OF SPEECH AND LANGUA	FULL	section 1.1		The RCSLT suggest adding: 'to establish whether a person has an advantage directive', this is mentioned in 1.3.2 but we believe it should come earlier in the guidance	Thank you for your comment. The Committee believes the order of the recommendations are clear and user friendly and do not require further amendment although we have now made amendments to the terms used in our recommendations to clarify the distinction between

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GE THERAPISTS					advance statements and advance decisions to refuse treatments. Earlier reference to the availability of an advance statement is provided in recommendation 1.2.5.
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	General		General	The document should include mention of the Mental Capacity Act and the need for a capacity assessment, followed by either taking note of the individuals' decisions (if they do have capacity) or the need for a formal 'Best Interests' meeting if they are deemed not to have capacity. Advanced Care Planning is frequently not applied to people with learning disabilities and decisions are often made inappropriately without the participation of the individual, or without their professionals and/or carers who know their circumstances best. Speech therapists have noted several incidences of do not attempt resuscitation (DNAR) decisions being put in place without full discussions, by professionals who think they are qualified to make these decisions without following the proper procedures. We believe this could be addressed in these guidelines with a statement, such as: "Check that the advice given in the Mental Capacity Act has been followed. This includes asking the following: - Does the person have capacity to consent to proposed treatment plans?	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.

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				- If so, are their wishes being followed? - If not, has a Best Interests meeting been held to take account of the views of all carers and professionals involved in the individuals' life?"	
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS		8	27	Add: "especially if they have swallowing difficulties".	Thank you for your comment. This is covered in recommendation 2.4.1 and we do not wish to repeat detail here.
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	FULL	137		The RCSLT believe that the importance of determining appropriate positioning to reduce discomfort should be added	Thank you for your comment. Unfortunately we are unable to comment as we have not completed a specific review in this area as non-pharmacological management was outside the scope of this guideline.
ROYAL COLLEGE OF SPE	FULL	section		Add mouth cleaning (in addition to teeth and dentures).	Thank you for your comment. We have amended this recommendation to state: Offer frequent care of the mouth and lips to the dying person and ensure that their care plan includes the management of dry mouth if needed. 64.

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ECHAND LANGUAGE THERAPISTS		1.4.2			
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	NICE	8	(Section)	The RCSLT believe that the need to moisten the mouth with artificial saliva should be added to this section.	Thank you for your comment. The Committee did discuss the use of artificial saliva, but noted that certain products are pork based and therefore not appropriate in some populations. This is discussed in the full guideline, 'Linking evidence to recommendations' statement in section 8.6.
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	NICE	8	(Section)	Also in this section the RCSLT suggest something needs to added concerning: 'appropriate positioning to reduce discomfort'	Thank you for your comment. As no specific review was conducted for the non-pharmacological management of this symptom this we are unable to comment.

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ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	Short	12	1.5.13	There needs to be mention of the RCSLT's 5 Good Communication Standards as those Reasonable Adjustments should be available to all people with learning disabilities, not just in specialist settings. They could also apply to other groups of people who have SLCN, so that they can better participate in the discussions and decision making. This guidance focuses on the studies that have looked at what has gone badly, rather than being solution focussed.	Thank you for your comment. The review question for this section aimed to identify both barriers and facilitators to good communication. No identified studies commented on the use of the RCSLT communication standards in a population of dying adults and was therefore not included in this review or the recommendations.
ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS	Short	12	1.5.13	The RCSLT also do not believe that these examples are useful and it would be better to leave it as those who have got communication difficulties	Thank you for your comment. The Committee feel the examples listed are valid and no changes to the recommendation have been made.
Royal Devon and Exeter NHS Foundation Trust]	Full	General	General	The Guideline provides a welcome review of the evidence and experienced that has shaped care of the dying over recent years .It is recognised that much of this evidence comes from an oncological perspective where historically there have been strong links between oncologists and specialist palliative care physicians. By improving access to Specialist palliative care to those with non-malignant conditions is to be encouraged and will provide excellent opportunities for clinical research.	Thank you for your comment and for participating in this consultation process.

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Royal Devon and Exeter NHS Foundation Trust]	Full	85	1 5.9	The research recommendation is very valuable as uncertainty regarding recognition of dying is an area which has the potential to lead to "vitalist" clinical decisions. It may be that the impact of league tables and mortality reviews should be examined within the research scope.	Thank you for your comment. The specific details of research scope are beyond the remit of this guideline although further detail can be found about this research recommendation can be found in Appendix O.
Royal Devon and Exeter NHS Foundation Trust]	Full	General		Although the use of artificial nutrition was excluded from the scope the guideline should include support of oral nutrition, assessment of the reasons for decline in oral intake, when this occurs, and assessment of the need for some form of clinically assisted nutrition, when oral intake is reduced or is judged unsafe. This is particularly important in those people with progressive neurological conditions. NICE should have examined this evidence as part of the recognition that decreased oral intake is one of the signs of being in the last few days of life	Thank you for your comment. A full review of the evidence surrounding oral nutrition is beyond the remit and scope of this guideline. The scope identified that the role of clinically assisted hydration would be subject to review. The Committee made a number of consensus recommendations around oral hydration.
Royal Devon and Exeter NHS Foundation Trust]	Full	General	81	Although the guideline states gather information on "changes in the physiological, social, spiritual and psychological needs of the person there is no guidance regarding how this may be achieved. Evidence from The NCDAH audits show this is an area where even simple assessment of need is often omitted completely and yet there is an evolving evidence base for how recognising spiritual and cultural needs can be taught.	Thank you for your comment. The Committee discussed changes in the physiological, social, spiritual and psychological needs of the person and consider the approach needs to be individualised. In addition to this recommendation we also recommend seeking advice from colleagues with more experience and note the important of using clinical judgement.

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Royal Devon and Exeter NHS Foundation Trust]	Full	150	1: 8.6	Overall the whole section on hydration seems to read well and gives a clear explanation except for "Respecting their wishes and preferences" – Clinicians who are less experienced will potentially interpret this statement as they **must** give artificial hydration if patient or family request it. It would be helpful to explain this more clearly i.e. does **not** mean that artificial hydration **must** be given if they want it but their views should be taken into consideration alongside weighing up the risks and benefits followed by the discussion and explanation of the care plan Recommend: Change *respecting* to *take into consideration*	Thank you for your comment. The Committee chose to state 'respecting their wishes and preferences' to capture discussions around culture and religion and also any decisions recorded as part of an advance care plan. The Committee chose 'respected' to acknowledge that while in some cases, it may not be possible to follow them, they would always be considered and be taken into account. This has been added to the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
Royal Devon and Exeter NHS Foundation Trust]	Full	215	14 9.35.1	The guidance regarding off label use of licensed medication is of most concern. Whist it is clear that there is a need to be clear, open & honest that these are not licensed for the use in specific situations there is a significant body of evidence (albeit not RCTs) and expert clinician & patient experience to support their use. The medications mentioned are standard practice and have been for many tears. It is a shame there is not greater acknowledgement of this. Whilst some people will read the whole document and the thorough research review , most people will only read the executive summary/tables. It is therefore	Thank you for your comment. NICE processes state that if a drug is recommended for an indication in which the medication is off licence then a footnote is required. The linking evidence to recommendation sections within the full guideline gives further detail including current practice and the Committee's expert opinion. We have amended the guideline's introductory text and our recommendations to acknowledge the needs of patients who present with reduced capacity and lower levels of consciousness.

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				possible that clinicians, particularly non-medical prescribers and generalists will be very reluctant to prescribe or administer off license drugs which will then put patients at high risk of uncontrolled symptoms during both the palliative and final phase/days of life. It is unrealistic and often burdensome to be trying to have a conversation with a dying patient or their family about the use of unlicensed drugs in the management of their symptoms and to get their consent. This may be interpreted in some areas as needing to gain **signed** consent (according to GMC guidance). This is almost certainly going to raise problems with prescribing, recommending medication and administration and ultimately the opposite of what is intended through this guideline: excellent end of life care. Likewise there is a risk that generalist HCPs will endeavour protect themselves and will not be *prepared to take responsibility for the decision* and may potentially refer many more End of Life patients to Specialist palliative care teams who do not need this degree of specialist input, diverting a scarce resource from areas of true clinical need.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Royal	Full	217	1	Opioids section in table 1: Very small starting doses 2.5 – 5mg orally of morphine and 1.25mg – 2.5mg	Thank you for your comment on the prescribing tables. Because of the recognised importance of

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Devon and Exeter NHS Foundation Trust]				s/c or I/V are being recommended. The limit it to 2 – 4 hourly prescribing is worrying especially if a patient does not respond to the opioid and inexperienced staff then tell the patient they can't have any more until the 2 hours is up. Common complaints in hospital settings and nursing homes are that dying patients have been left in pain. Whilst it is recognised that there has been criticism of over treatment/sedation, unmet clinical need is of equal importance. The guidance either needs to allow a wider range or mandate review within a very short time period of response to the medication Caution is recommended against advising I/V even in hospital unless there is a risk of a specific catastrophic symptom e.g. bleed. It would be helpful to include the alternative of Diamorphine and guidance for patients with renal impairment.	supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Royal Devon and Exeter NHS Foundation Trust]	Full	219	3	Anti-emetics – table 3 p.219: prochloperazine and cyclizine are rarely used first line in clinical practice.. We often encounter problems with side effects in patients on cyclizine. It would be helpful to see some explanation of as far as possible matching cause (where known) of nausea & vomiting to the most appropriate anti-emetic or combination. It is unclear why Levomepromazine is only considered as a second line agent.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Royal Devon and Exeter NHS Foundation Trust]	Full	General	general	Whilst the small print states the tables are for generalists and not covering specialist palliative care prescribing it potentially leaves Specialist Palliative Care clinicians in a difficult position when advising either GP or hospital Drs who may be anxious about deviating from NICE guidance whilst being the named responsible clinician	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Royal Marsden				Section 1.1.3: perhaps could be clearer to ensure that the emphasis is on identifying a patient who may be dying as early as possible and not necessarily waiting for lots of signs of deterioration Section 1.2.6: perhaps this could also be clearer, for example, 'ensure that that the multiprofessional team caring for the patient are aware of prognosis and that this is clearly documented' Section 1.2.7: I think this could go further and specify that if a patient directly asks questions about prognosis or whether they are dying that these should be answered sensitively but honestly Section 1.5.14: include examples of non-	Only respond to highlighted section please. Thank you for your comment. The committee agree and have discussed this in the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8).

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				pharmacological management for breathlessness Section 1.5.20: include examples of non-pharm management for nausea Section 1.5.29: include examples of non-pharm measures for respiratory secretions Implementation: The communication will be most challenging and therefore examples of good practice might be useful Appendix A – Table 2: Breathlessness: parenteral clonazepam no longer available Table 3: Nausea: PRN SC Levo dose is odd at 2.5-5mg Table 4: Anxiety: ditto around parenteral clonazepam Table 5: Delirium: as a HST SPC team we do not routinely use Olanzepine, as directed by our psychiatric services. Would we expect a non-specialist to use Olanzapine?	
Royal Marsden				Section 1.1.3: perhaps could be clearer to ensure that the emphasis is on identifying a patient who may be dying as early as possible and not necessarily waiting for lots of signs of deterioration Section 1.2.6: perhaps this could also be clearer, for example, 'ensure that that the multiprofessional	Cross cutting comment – only answer highlighted section please – other sections have been cut and paste into other comments documents. . Thank you for your comment. 1.2.6: The Committee agrees, recommendation

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				team caring for the patient are aware of prognosis and that this is clearly documented' Section 1.2.7: I think this could go further and specify that if a patient directly asks questions about prognosis or whether they are dying that these should be answered sensitively but honestly Section 1.5.14: include examples of non-pharmacological management for breathlessness Section 1.5.20: include examples of non-pharm management for nausea Section 1.5.29: include examples of non-pharm measures for respiratory secretions Implementation: The communication will be most challenging and therefore examples of good practice might be useful Appendix A – Table 2: Breathlessness: parenteral clonazepam no longer available Table 3: Nausea: PRN SC Levo dose is odd at 2.5-5mg Table 4: Anxiety: ditto around parenteral clonazepam Table 5: Delirium: as a HST SPC team we do not routinely use Olanzepine, as directed by our psychiatric services. Would we expect a non-	2.3.6 encourages healthcare professionals to record individualised care plan discussions and decisions in the dying person's medical records and share the care plan with the dying person, those important to them and all members of the multiprofessional care team. 1.2.7: Thank you for your comment. This recommendation has now been removed although discussion on this issue remains in the Linking evidence to recommendations section of chapter 6.

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				specialist to use Olanzapine?	
Royal Marsden				**Section 1.1.3**: perhaps could be clearer to ensure that the emphasis is on identifying a patient who may be dying as early as possible and not necessarily waiting for lots of signs of deterioration **Section 1.2.6**: perhaps this could also be clearer, for example, 'ensure that that the multiprofessional team caring for the patient are aware of prognosis and that this is clearly documented' **Section 1.2.7**: I think this could go further and specify that if a patient directly asks questions about prognosis or whether they are dying that these should be answered sensitively but honestly **Section 1.5.14**: include examples of non-pharmacological management for breathlessness **Section 1.5.20**: include examples of non-pharm management for nausea **Section 1.5.29**: include examples of non-pharm measures for respiratory secretions **Implementation**: The communication will be most challenging and therefore examples of good practice might be useful **Appendix A** –	Only respond to highlighted section of the comment please. Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.

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				Table 2: Breathlessness: parenteral clonazepam no longer available Table 3: Nausea: PRN SC Levo dose is odd at 2.5-5mg Table 4: Anxiety: ditto around parenteral clonazepam Table 5: Delirium: as a HST SPC team we do not routinely use Olanzepine, as directed by our psychiatric services. Would we expect a non-specialist to use Olanzapine?	
Royal Marsden				**Section 1.1.3**: perhaps could be clearer to ensure that the emphasis is on identifying a patient who may be dying as early as possible and not necessarily waiting for lots of signs of deterioration **Section 1.2.6**: perhaps this could also be clearer, for example, 'ensure that that the multiprofessional team caring for the patient are aware of prognosis and that this is clearly documented' **Section 1.2.7**: I think this could go further and specify that if a patient directly asks questions about prognosis or whether they are dying that these should be answered sensitively but honestly **Section 1.5.14**: include examples of non-pharmacological management for breathlessness	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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				Section 1.5.20: include examples of non-pharm management for nausea **Section 1.5.29**: include examples of non-pharm measures for respiratory secretions **Implementation**: The communication will be most challenging and therefore examples of good practice might be useful **Appendix A** – Table 2: Breathlessness: parenteral clonazepam no longer available Table 3: Nausea: PRN SC Levo dose is odd at 2.5-5mg Table 4: Anxiety: ditto around parenteral clonazepam Table 5: Delirium: as a HST SPC team we do not routinely use Olanzepine, as directed by our psychiatric services. Would we expect a non-specialist to use Olanzapine?	
Royal Marsden				Section 1.1.3: perhaps could be clearer to ensure that the emphasis is on identifying a patient who may be dying as early as possible and not necessarily waiting for lots of signs of deterioration Section 1.2.6: perhaps this could also be	This response is for the highlighted section of the comment only – as multiple sections were referred to by this stakeholder this comment is replicated across different groups of stakeholder responses. Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will

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				clearer, for example, 'ensure that that the multiprofessional team caring for the patient are aware of prognosis and that this is clearly documented' Section 1.2.7: I think this could go further and specify that if a patient directly asks questions about prognosis or whether they are dying that these should be answered sensitively but honestly Section 1.5.14: include examples of non-pharmacological management for breathlessness Section 1.5.20: include examples of non-pharm management for nausea Section 1.5.29: include examples of non-	have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.

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				pharm measures for respiratory secretions Implementation: The communication will be most challenging and therefore examples of good practice might be useful Appendix A – Table 2: Breathlessness: parenteral clonazepam no longer available Table 3: Nausea: PRN SC Levo dose is odd at 2.5-5mg Table 4: Anxiety: ditto around parenteral clonazepam Table 5: Delirium: as a HST SPC team we do not routinely use Olanzepine, as directed by our psychiatric services. Would we expect a non-specialist to use Olanzapine?	
Royal Marsden				Section 1.1.3: perhaps could be clearer to ensure that the emphasis is on identifying a patient who may be dying as early as possible and not necessarily waiting for lots of signs of	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This

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				deterioration	has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
				Section 1.2.6: perhaps this could also be clearer, for example, 'ensure that that the multiprofessional team caring for the patient are aware of prognosis and that this is clearly documented'	
				Section 1.2.7: I think this could go further and specify that if a patient directly asks questions about prognosis or whether they are dying that these should be answered sensitively but honestly	
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				pharm management for nausea Section 1.5.29: include examples of non-pharm measures for respiratory secretions Implementation: The communication will be most challenging and therefore examples of good practice might be useful Appendix A – Table 2: Breathlessness: parenteral clonazepam no longer available Table 3: Nausea: PRN SC Levo dose is odd at 2.5-5mg Table 4: Anxiety: ditto around parenteral clonazepam Table 5: Delirium: as a HST SPC team we do not routinely use Olanzepine, as directed by our psychiatric services. Would we expect a non-specialist to use Olanzapine?	

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Saint Francis Hospice	Short	21	28	As above	Thank you for your comment.
Saint Francis Hospice	Short	21	10-11	Do not believe oropharangeal suction is standard intervention	Thank you for your comment. We have edited this text.
Saint Francis Hospice	Short	7	10-12	What is agreed changes to the care plan are not agreed	Thank you for your comment. The shared decision making process is underpinned by the clinical judgement of the healthcare professionals providing end of life care. The committee appreciates the challenges of shared decision making in end of life care and have presented in this guideline a framework for supporting that decision making that takes into consideration the goals, needs and wishes of the dying person and those important to them, with the support of the multiprofessional team.
Saint Francis Hospice	Short	9	1-3	Need to have clear guidance on guidance before offering clinically assisted hydration	Thank you for your comment. We feel the guidance is clear and have made several clarifications to this section and in the full guideline.
Saint Francis Hospice	Short	9	4-7	As above more information needed to guide discussions on risks and benefits of clinically assisted hydration	Thank you for your comment. Further detail is provided in the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline, which discusses existing comorbidities

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					and delirium.
Saint Francis Hospice	Short	13	1-3	Do not find this helpful very vague even when referring to appendix may not help the generalist	Thank you for your comment. This reflects the limited evidence identified in the last days of life. The Committee were unable to be more specific as evidence was not found to warrant any further detail other than drug class for management of pain.
Saint Francis Hospice	Short	13	16-17	Actual suggestions might be helpful	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Saint Francis Hospice	Short	14	3-6	For the generalist they might not be familiar with octreotide and might be more appropriate to increase dose of hyoscine butylbromide first or clearer guidance on the titration and use of octreotide	Thank you for your comment. We believe that this recommendation is appropriate given the evidence considered. Recommendation 1.5.9 provides guidance to seek specialist advice if symptoms do not improve.
Saint Francis Hospice	Short Appendices	25	16-18	This had not been made clear earlier or on the actual tables that drugs are not listed in order of preference	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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					being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Saint Francis Hospice	Short Appendices	29	Table 1	Ibruprofen is down as a subcutaneous preparation which it is not. Table not clear for titrating someone who is not opioid naïve or when to move to alternate route	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Saint Francis Hospice	Short Appendices	29	Table 3	No mention that sometimes more than 1 antiemetic required together. Also concerned that with the doses of Levomepromazine they are very low and would be difficult to draw up potential of confusion 2.5/5/12.5/25	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain

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					targeted at the non-specialist prescriber and will be made available on the NICE website.
Saint Francis Hospice	Appendices	30	Table 2	Do not say lower dose for breathlessness than pain, also Clonazepam not used widely might be confusing for generalist as well as some specialists	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Saint Francis Hospice	Appendices	30	Table 4	Again just some concerns re unfamiliarity with Clonazepam	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Saint Francis Hospice	Short Appendices	31	Table 5	Haloperidol would not be standard to recommend oral dose	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Saint Francis Hospice	Short	17	10	Question 2 What might help users overcome any challenges Would be a strong evidence base for practice if possible. Clear national guidance on the use of parental hydration outside hospital/ hospice. There needs to be further education on end of life care and in particular the last days of life and communication skills to enable appropriate discussions take place with the patient, family and professionals. There needs to be clear policies/procedures set up to enable generalists to be able to provide artificial hydration appropriately.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Saint Francis Hospice	Short	17	8	Question1 The biggest impact for practice and be challenging to implement could be around maintaining hydration the advice about artificial hydration is difficult to implement for various reasons. In the community, acquiring and	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will

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				administering artificial hydration can be difficult as some GP's may be reluctant to prescribe, there may be a problem with supply and some district nurse services may not have policy/procedure to facilitate this, this couls also be a problem for care/residential homes. It could also be an added burden for the family and the patient is professionals not secure in the why and how of administration. However it is good to challenge what might not be the norm to ensure practice is in line with best practice	have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
Sheffield Teaching Hospitals	Short	General comment		This guideline makes no reference to food or nutrition. This is a significant omission given food is included in the priorities of care and that there are not insignificant numbers of people who will die with established clinically assisted nutrition regimes.	Thank you for your comment. This issue is beyond the remit and scope of this guideline. Nutrition was not prioritised as part of the scope.
Sheffield Teaching Hospitals	Short	General comment		There is very little in this document about specialist palliative care. Whilst we recognise the scope of the document, we think it should be stated that every dying patient should have access to 24/7 palliative care advice if they need it	Thank you for your comment. The guideline is specifically targeted towards non-specialists who may not have specialist level training in end of life care. Where relevant, health and social care professionals are encouraged, within the recommendations to seek the support of specialist palliative care physicians in instances where additional advice is required.
Sheffield Teaching Hospitals	Short	3	1-15	The way these signs of dying are presented, as an alphabetical list, does not feel easy to use. Presenting this information in a way that reflects a clinical approach to a patient may be more helpful,	Thank you for your comment. After careful consideration the Committee have now rewritten this recommendation and separated out the list into signs, symptoms and functional observations to

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				or in the order of grade of evidence.	provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline.
effield aching spitals	Short	4	20	There is something in-between dying and recovering that we frequently see clinically. I.e the patient who has plateaued at a low level and it's not yet clear they are definitely dying, or that they're going to recover.	Thank you for your comment. The Committee discussed the bullet points in the recommendation and decided to amend these to state: nearing death, deteriorating, stable or improving.
Sheffield Teaching Hospitals	Short	5	12	It is also important to establish what people want to know regarding what to expect from symptoms, from the dying process, and how they want to be, managed.	Thank you for your comment. we agree and feel that this recommendation does address this issue. The Committee has encouraged healthcare workers, through its recommendations to ensure that an individualised plan of care is created to addresses current and anticipated care needs and the dying person's preferences for symptom management. The recommendations further encourage the multiprofessional team to ensure that the dying person and those important to them (if appropriate), are also included in discussions around further changes to that care plan.
Sheffield Teaching Hospitals	Short	6	3	Is it important here to explore with the person, in addition to their advance care plan, their particular spiritual, cultural, emotional and psychological needs? Although this is in the shared decision making section it might sit more naturally in the communication section.	Thank you for your comment. We have amended one recommendation in the communication section to encourage healthcare professionals to establish the communication needs and expectations of people who may be entering their last days of life, taking into account (among other things), any cultural, religious, social, or spiritual needs or preferences that should be considered.

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Sheffield Teaching Hospitals	Short	5	17	We think it should be clearer here that the most appropriate available person should be a senior member of the team i.e consultant in charge of the patient or senior nurse. Not just the most convenient person e.g palliative care or the nurse on the ward	Thank you for your comment. The Committee agrees that this is an important issue and have sought to address this in its communication recommendations. As the multidisciplinary team would vary according to patient need, care setting and across Trusts, the Committee thought it best to recommend that 'the most appropriate available' multiprofessional team member be identified to explain the dying person's prognosis. The committee feel it important to recognize that the most appropriate person may be the person with the most experience of having these conversations. This does not always equate to seniority. It has also been recommended that the multiprofessional team should be supported by experienced staff at all times and have the ability to seek further specialist advice if additional support is required.
Sheffield Teaching Hospitals	Short	5	23	There needs to be a stronger statement that what needs to be communicated to the person and/or their relative is that the MDT think they are **dying,** being very specific about that, and as a separate item of information what the prognosis is, and the uncertainty about the dying and prognosis. As it is, it is not clear that this would be clearly communicated. It may be we're left with people using vague statements e.g. "you may not survive this, you're not getting better" etc.	Thank you for your comment. The Committee think this recommendation is clear as currently edited.

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Sheffield Teaching Hospitals	Short	7	4	It may be more helpful to separate out the different possible settings as things are different in hospital to the community. So perhaps be more specific about what is expected in those different settings. It would be unusual for an inpatient to have the contact details for the consultant looking after them, as they are on the ward.	The guideline applies to all setting and the Committee recognises that there may be challenges to its implementation, but that is an aspirational recommendation. . Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section in the full guideline.
Sheffield Teaching Hospitals	Short	10	5	One might also consider stopping the fluids if they are not improving the symptoms, or if they are causing other significant symptoms such as respiratory secretions.	Thank you for your comment. The Committee consider the most important reasons for reducing or stopping clinically assisted hydration to be signs of possible harm or if the person no longer wants it. They do not wish to be so prescriptive to add further detail, but consider that clinical judgment guides further decisions as outlined in recommendation 2.4.10. Further detail has been added to the 'Linking evidence to recommendations' statement in section 8.6 in the full guideline.
Sheffield Teaching Hospitals	Short	8	26	We're aware that sponges are no longer best practice for mouth care,	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.
Sheffield Teaching Hospitals	Short	9	10	May or may not relieve distressing symptoms	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids.

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Sheffield Teaching Hospitals	Short	Hydration section	Page 8	Overall this section is quite good and well balanced, with some caveats (see below)	Thank you for your comment and for participating in the consultation process.
Sheffield Teaching Hospitals	Short	15	10	The inclusion of atropine on this list is un-necessary and probably will lead to confusion. Hyoscine hydrobromide is more sedating and causes more delirium. Would it not be clearer to re-order the list with glycopyronnium first (best evidence) or hyoscine butylbromide (more familiar and less sedation)?	Thank you for your comment. The drugs listed here are in alphabetical order rather than order of preference. Further detail is given in the full guideline 'Linking evidence to recommendations' section.
Sheffield Teaching Hospitals	Short	16	General comment	For anticipatory prescribing we think it needs to be clearer (indeed the message from palliative care often is) that you should ensure there are medications prescribed for pain, breathlessness, respiratory secretions, Nausea and vomiting and agitation. The way it is currently worded it sounds as though if someone thinks a symptom might not happen, then they don't have to prescribe. It is this that leads to dying patients having unacceptable delays in waiting for symptom control	Thank you for your comment. The recommendations made are to adopt an individualised approach to anticipatory prescribing, which is detailed further in the 'Linking evidence to recommendations' section of the full guideline (chapter 10). The Committee consider that the benefits and harms of prescribing or not prescribing medications be considered. In addition place of care and time it would take to obtain medications are also deciding factors when considering anticipatory prescriptions. The Committee recognised the complexities surrounding anticipatory prescribing, but do recommend that anticipatory prescribing be individualised for patients. Administration of medications prescribed in anticipation by a clinician involved in the dying person's care should be reviewed before administration in light of the current symptoms and treatment efficacy fed back to the lead health care

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					professional as recommended in 1.6.5 and 1.6.6. The Committee discussion is captured in the 'Linking evidence to recommendations' section for this review area. We recognize that this is a balance between timely administration to avoid distress and the need for a tailored and individualised approach to anticipatory prescribing that avoids a blanket and repeated approach to prescribing. We hope that our recommendations build in a process for review before administration in the case of prescribing in advance of an event and make explicit the need to monitor the efficacy of this treatment before continuing to administer.
Sheffield Teaching Hospitals	Short	General comment on prescribing tables pages 27-33		The advice given here on starting doses of medication for the syringe drivers is far too variable with inappropriately high starting doses, particularly if someone was opioid naïve. There is little reference to converting from background or from PRN requirements. The principle of giving guidance is right, however the guidance given here does not seem helpful.	Thank you for your comments on the prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Sheffield Teaching Hospitals	Short	30	2	The table of advice for nausea and vomiting (table 3) doesn't make sense, in that if one of the first line medications doesn't work then it may not be appropriate to jump straight to levomepromazine. Also cyclizine should only very rarely be used. There are also typos in this table.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Shooting Star Chase				Young Adult moving from Children to Adult services – the justification is that this group of transition young people are so often forgotten. Their presenting needs are worthy of separate consideration and at a time when consideration for support for young people with life limiting illness reaching adult hood is proven to be an increasing number of people it would be folly not to include them – the change in law from Children's law to adult law is also significant I would request an addition to the final paper to consider any Transition Persons/ Child moving from Child to Adult palliative Care. The reason I request this is clear, that while there is a plethora of information on transition and child and adult hospice care little is done to join up the	Non-registered stakeholder. No response required

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				services. I find in my new role families are not as prepared as they should be and the world of adult care/law is so very difference – while it would not need a substantive section to be added I believe it would be most useful to demonstrate the joined up approach for the small but growing number of young people presenting with often complex situations included being ventilated which adult palliative care my not have fully grasped.	
South West Yorkshire Partnership NHS Foundation Trust	Full	65	66.	67. We are concerned that the use of oral hygiene sponges are being suggested in light of the **CHOKING HAZARD** that they pose, with no reference to MHRA alerts – (MHRA April 2012, Dec 2014: MDA/2012/020). There should be a clear and documented risk assessment prior to use and guidelines followed in accordance with the MHRA alert. The actual risk of using these sponges, we suggest, is not actually known as incident reporting systems are not always completed for near misses or incidents of the sponges coming adrift of the stick during use. Whilst the evidence is sparse around oral hygiene in the last days of life what there is clearly demonstrates that oral hygiene sponges do not effectively clean but small headed, soft bristled	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.

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				toothbrushes (e.g. paediatric toothbrush) are effective and do not cause soft tissue damage which is often cited as a concern by health care professionals. All other NICE guidance pertaining to oral care indicates the use of a toothbrush (PH 55). We are concerned that those requiring assistance with oral care, because they are unable to do this for themselves due to weakness or because they are dying, receive different care compared to those that are independent. It is suggested that care is currently based on custom and practice rather than evidence based, certainly following our own audit, practice is confused and wide ranging with oral care at times being neglected. The use of oral sponges is not concordant with the Royal Marsden Manual of Clinical Nursing Procedures (ninth edition, 2015) for mouth care and do not feature in the equipment list. This manual is the basis for many organisation's care plans. It is also disappointing that the opportunity has not been taken to comment, and therefore eradicate, the use of lemon and glycerine and blackcurrant and glycerine mouth swabs as they exacerbate the symptoms of dry mouth by exhausting the salivary glands as they cause hyper salivation and alter the pH of the oral mucosa.	

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				The Trust has developed last days of life oral hygiene management guidance which is based on evidence and best practice which we are happy to share.	
South Worcestershire Clinical Commissioning Group	Short	4	15	We would suggest adding a reference to rapidly falling Barthel score, as this is a commonly used indicator within the Gold Standards Framework	Thank you for your comment. After careful consideration the example of ECOG has been removed from the recommendation and replaced with: Functional observations, for example deteriorating performance status, social withdrawal, changes in communication. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (5.8), which now includes reference to the Barthel score.
South Worcestershire Clinical Commissioning Group	Short	5	13	We would suggest using the term 'life expectancy' rather than 'prognosis'.	Thank you for your comment. The Committee believes the recommendation, as edited is clear and does not require further amendment.
South Worcestershire Clinical Commissioning Group	Short	6	10	We would suggest using the term 'life expectancy' rather than 'prognosis'.	Thank you for your comment. The Committee thinks this recommendation is clear as currently edited.
South	Short	6	22	We would suggest that this should also include	Thank you for your comment. The committee agrees

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Worcestershire Clinical Commissioning Group				reference to assessment of mental capacity, and to advise the need to establish if LPA appointed for health.	that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
South Worcestershire Clinical Commissioning Group	Short	6	24	We would suggest a change to 'advance care plan or advanced decision to refuse treatment'.	Thank you for your comment. This has been amended.

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South Worcestershire Clinical Commissioning Group	Short	8	15	We would suggest that the wording should be changed to 'discuss the risk and benefits of drinking to the dying person and those close to him/her as appropriate'.	Thank you for your comment. The Committee have considered your comment, but think their current wording is clear.
South Worcestershire Clinical Commissioning Group	Short	8	26	Please refer to Medical Safety Alert MDA/2012/020, which states that the foam heads of oral swabs may detach from the sticks during use and present a choking hazard for patients.	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.
South Worcestershire Clinical Commissioning Group	Short	11	16	Consider using injectable ports (e.g. Insuflon) if repeated doses required (Refer to EU Safer Sharps regulations).	Thank you for your comment. After careful consideration the Committee feel that no change is required.
South Worcestershire Clinical Commissioning Group	Short	11	21	Consider changing to 'start with the dose most likely to provide symptomatic relief / alleviate symptoms'.	Thank you for your comment. After careful consideration the Committee feel that no change is required.
South	Short	12	10	We would suggest changing 'the dying persons	Thank you for your comment. We agree and have

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Worcestershire Clinical Commissioning Group				preferred route of administration' to 'the most appropriate route of administration'.	added in "if appropriate"
South Worcestershire Clinical Commissioning Group	Short	12	23	This should read 'Only offer oxygen therapy to people known or clinically suspected to have hypoxia and are symptomatic'. Refer to Cochrane evidence.	Thank you for your comment. The evidence review was unable to show whether oxygen was beneficial or not for the management of breathlessness in the last few days of life, however the consensus of the Committee was that oxygen may be beneficial to people who are symptomatic with known or suspected hypoxia based on their clinical experience. The recommendation has been amended to state "Only offer oxygen therapy to people known or clinically suspected to have symptomatic hypoxaemia" and additional text has been added to the 'Linking evidence to recommendations' section of the full guideline (please see section 9.5).
South Worcestershire Clinical Commissioning Group	Short	12	9	We would suggest that reference is made to using a pain assessment tool.	Thank you for your comment. Further detail has been added to the 'Linking evidence to recommendations' in the full guideline to provide examples (please see section 9.5).
South	Short	13	16	We would suggest clarifying this section, and	Thank you. The Committee acknowledge the

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Worcestershire Clinical Commissioning Group				providing examples.	importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
South Worcestershire Clinical Commissioning Group	Short	13	2	We would suggest that a benzodiazepine should only be used if anxiety is a contributing factor.	Thank you for your comment, The recommendations drafted reflects the evidence considered. For more detail please see chapter 9 (section 9.9) of the full guideline.
South Worcestershire Clinical Commissioning Group	Short	14	2	We would suggest changing this to 'obstructive bowel disorders who have nausea and **frequent large volume** vomiting'.	Thank you for your comment. After careful consideration, the Committee did not feel any amendment to their recommendation was necessary
South Worcestershire Clinical Commiss	Short	15	10	We would suggest adding a note in relation to the use of hyoscine hydrobromide - may cause increased sedation.	Thank you for your comment. We expect prescribers to be aware of contraindications and side effects of any drug they use.

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oining Group					
South Worcestershire Clinical Commissoining Group	Short	15	3	We would suggest providing examples of non-pharmacological measures, e.g. suctioning or positioning	Thank you. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
South Worcestershire Clinical Commissoining Group	Short	28	Table 2	Referencing numbers could be misinterpreted as dosages.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
South Worcestershire	Short	31	Table 4	Referencing numbers could be misinterpreted as dosages.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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Clinical Commissoining Group					being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
South Worcestershire Clinical Commissoining Group	Short	32	Table 5	Referencing numbers could be misinterpreted as dosages.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Southport & Ormskirk NHS Trust		21	21	Don't understand (reported in 23 92% of dying patients) doesn't make sense	Thank you for your comment. This section has been edited and the text changed to read 23 – 92%.

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68. Southport & Ormskirk NHS Trust		69	70.	Typo – should be Advance not Advanced	Thank you for your comment. This has been amended. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare
Southport & Ormskirk NHS Trust		21	39-44	This comment could be also applied to clinically assisted hydration when it is undertaken for the benefit of those important to the patient and health professionals who cannot accept dying as it is!!!! At least be consistent.	Thank you for your comment. The Committee has sought to address this by making a recommendation about advising the dying person and those important to them that there is uncertainty whether: a) giving clinically assisted hydration will prolong life or the dying process and b) not giving clinically assisted

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					will hasten death. The Committee felt strongly that a dying person and those important to them should be made aware of the uncertainty surrounding the effects of clinically assisted hydration on survival due to the evidence showing equivocal results.
Southport & Ormskirk NHS Trust		16	25	Add 'or rectum' at end of sentence	Thank you for your suggestion. This has been amended.
Southport & Ormskirk NHS Trust	Full	17	4-7	'..consider treating noisy secretions if causing distress…' If antisecretory agents not given as soon as RTS recognised to prevent further secretions, unlikely to be effective. If wait until they are distressing, too late as they will not be reabsorbed by medication.	Thank you for your comment. As there was limited evidence to support use of antisecretory agents this Committee consensus was also taken into consideration. The group discussed the risks and benefits at length and these are detailed in the 'Linking evidence to recommendation section'. In addition we have also made a research recommendation as there is uncertainty in this area.
Southport & Ormskirk NHS Trust		18	1-3	AGREE – very important point to include re cyclizine and heart failure – often forgotten	Thank you for your comment.
Southport & Ormskirk NHS Trust		18	29-32	AGREE - important	Thank you for your comment.
Southport	full	15	20,21	'following the person's preferred route of	Thank you for your comment. We agree and have

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& Ormskirk NHS Trust				administration' may not be possible or practical. Should be reworded as ' taking into account the person's preferences when choosing an alternative route'	amended the recommendation, adding "and where possible".
Southport & Ormskirk NHS Trust		220	1	AGREE with using the term anxiolytic and NOT tranquilliser or sedative. THANKYOU	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Southport & Ormskirk NHS Trust		217	1	Diclofenac 100mg sup once daily is much more appropriate in the dying Since some areas still use diamorphine rather than morphine for solubility etc please give as an alternative Where is the rationale for waiting for 2 hrs if an opioid has not relieved pain when it reaches its peak at one hour. If pain has not been relieved by then, then to repeat the dose is entirely acceptable? Should not however be repeated within the hour. {dose]mg not more often than hourly as needed	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Southport & Ormskirk NHS Trust		219	3	At the end of life where there may only be one chance to get it right, little to guide the cause of nausea and vomiting and often multiple causes, why not use a broad spectrum antiemetic such as levomepromize first line, rather than recommending cyclizine which cannot be used in heart failure, will crystallise with hyoscine butylbromide used in obstruction and works for only some of the causes of N&V; or haloperidol which again has a specific range of effect or metoclopramide which has been recently subject to warnings about adverse effects and limitation of dosage and time limits for use. Buccal prochlorperazine, apart from having only weak effects at all its receptor sites, is a foul taste for most patients and where the mouth is dry will not be dissolved absorbed. Not a good choice at this time of life, for practical reasons.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Southport & Ormskirk NHS Trust		222	2	Glycopyrronium prn SC dose is 200 micrograms q4h and not 400 micrograms (see palliativedrugs.com or PCF5)	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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St Joseph's Hospice	Short	19	27	Should read 'advance' care planning	Thank you for your comment. This has been amended throughout the document.
St Joseph's Hospice	Short	4	21	The word 'recovery' is confusing. Maybe clearer to say 'has a potentially reversible condition that warrants treating' or 'slightly improving'	Thank you for your comment. The Committee discussed the bullet points in the recommendation and decided to amend these to state: nearing death, deteriorating, stable or improving.
St Joseph's Hospice	Short	4	1 - 15	The signs and symptoms of dying would be better listed with the most common first rather than in alphabetical order	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (5.8).
St Joseph's Hospice	Short	9	4	Reverse the order of this sentence – ie concerns raised are addressed first.	Thank you for your comment. The order and content of this sentence was discussed with the Committee and they believe this to be clear.
St Joseph's Hospice	Short	9	4	Add 'Patients are often comfortable without clinically assisted hydration at end of life'	Thank you for your comment. The Committee considered this issue during discussions on the evidence and this is noted in the 'Linking evidence to recommendations' section of this chapter.
St Joseph's Hospice	Short	9	14	Add 'can cause distressing problems such as increased accumulation of secretions and fluid overload.	Thank you for your comment. This recommendation has been amended. This is also covered in recommendation 2.4.8 and further detailed in the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.

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St Joseph's Hospice	Short	9	24	Add 'and excess chest secretions'	Thank you for your comment. No evidence was identified for this issue, but further detail is provided in the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
Short	27	Table 1		No 'maximum dose' for opioids given. Non-specialists shouldn't be switching opioids without specialist advice	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Short	27	Table 1		Add 'risk of accumulation of morphine in renal failure'	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Short	27	Table 1		Concerns regarding suggesting Diclofenac/NSAID's at end of life by non-specialists due to increased	Thank you for your comment on the prescribing tables. Because of the recognised importance of

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				gastric problems	supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Short	28	Table 2		Advice to increase opioids to the maximum dose is misleading as there is no maximum dose stated	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Short	28	Table 2		Why is Clonazepam mentioned before Midazolam? Non-specialists should not be prescribing Clonazepam routinely without specialist advice.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently,

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					they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
St Joseph's Hospice	Short	30	Table 3	Table lists all anti emetics (without reference to considering underlying cause of N&V) which is an haphazard approach.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
St Joseph's Hospice	Short	30	Table 3	Contra indications are written at foot – it is most important that these come in text so that Cyclizine is not routinely given to everyone.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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St Joseph's Hospice	Short	31	Table 4	Non-specialists should not be prescribing Clonazepam routinely without specialist advice.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
St Joseph's Hospice	Short	32	Table 5	Non-specialists should not be prescribing Olanzapine routinely without specialist advice.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
St Joseph's Hospice	Short	33	Table 6	Suggest Atropine should not be included – not used commonly in *chest* secretions.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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					implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
St Joseph's Hospice	Short	33	Table 6	Suggest adding that Glycopyrronium is cheaper than Hyoscine hydrobromide and does not cause side effects of agitation therefore the better choice of drug.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
St Luke's Hospice, Sheffield		General		In terms of collating comments on the guideline, which is very important to the care of our patients, we are disappointed this has occurred directly during major holiday period. The timing of the consultation has meant that some staff have been unable to respond e.g. term time contracts and those on extended leave. It has also not been possible to take this through our hospice medicines management group. The length of the full guideline has meant dividing up the consultation to allow staff to comment	Thank you for your comment and for your participation in the consultation process. The standard consultation period of 6 weeks was used for this guideline, and as per NICE policy stakeholders were advised of the start of the consultation process. To assist with wider dissemination of this guideline however, a press release was also distributed highlighting to the public the availability of the draft guideline for consultation. It is not NICE's policy to avoid summer and other

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				in the timeframe but means no one has had oversight of the full document. We are concerned that there are typo's and sentences that need reformatting throughout the document which we have not commented on above.	high, holiday periods, but we will convey this comment to our guideline commissioner. We also look forward to conducting final guideline edits to address the concerns in your comment regarding typographical errors.
St Luke's Hospice, Sheffield		General		*The guideline recommendations seem sensible and are welcome to support care for the dying adult.*	Thank you for your comment and for participating in the consultation process.
St Luke's Hospice, Sheffield	Full	81	1	Impact in terms of change of practice is limited but should be easy to implement within a palliative care plan	Thank you for your comment
St Luke's Hospice, Sheffield	Full	82	1-6	Impact in terms of change of practice is limited but should be easy to implement within a palliative care plan	Thank you for your comment
St Luke's Hospice, Sheffield	Full	General across guideline		Lack of acknowledgement and awareness of patients' spiritual issues. There is acknowledgment of the Spiritual needs of patient but no detailed descriptions of what they should look like	Thank you for your comments. As we have not reviewed the evidence we are unable to make specific recommendations, but have made reference to the NHS Chaplaincy guidance in the shared decision making chapter (please see 7.6)
St Luke's Hospice, Sheffield	Full	108		Provides relatively clear basis for communication of which end of life care training can be based for end of life patient. Challenge will be disseminating appropriate training to clinicians in a timely way to be of benefit in clinical practice.	NICE is currently developing guidance in palliative care service delivery and the issue of education and training may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link:

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					http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
St Luke's Hospice, Sheffield	Full	149	1	In palliative care we use 500ml bags of normal saline to allow flow through sc cannula	Thank you for your comment. Resource use and costs were agreed with the Committee and were deemed appropriate for the majority of care. It was recognised that there may be some variation in practice; however it was felt that this would not have a substantial impact on cost.
St Luke's Hospice, Sheffield	Full	137	16	Requires training for administration in community and unfamiliar to GPs	Thank you for your comment. Service Delivery, including training and education, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
St Luke's Hospice, Sheffield	Full	137	18	We are concerned that variation in access to equipment e.g. drip stands, fluids could be difficult in the community setting. Sheffield is currently commissioning a service from an extended hours pharmacy to provide NaCl 0.9% in the community and is looking to roll this out within palliative care services.	The Committee intend this recommendation to apply to all settings, including the community. Your response suggests that providing this type of service is possible. NICE is currently developing guidance in palliative care service delivery and the issue of resources may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link:

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					http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
St Luke's Hospice, Sheffield	Short	8	26	We are concerned that sponges may detach from stick as per MHRA alert. Our hospice uses moi sticks instead. There are also favoured glycerine sticks that can be supplied.	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.
St Luke's Hospice, Sheffield	Short	9	1	This should state review daily (the document states preferably daily)	Thank you for your comment. This is based on Committee consensus as no evidence review was conducted. Therefore we are unable to provide a stronger recommendation in this regard.
St Luke's Hospice, Sheffield	Full	164	15	There is a Cochrane review Jan 2010 on the use of benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant disease in adults which has not been included? No studies of oral benzodiazepines or bronchodilators included	Thank you for your comment. The Cochrane review on benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases was reviewed for inclusion in this review. However owing to the population used for the Cochrane systematic review being wider and including patients outside of the last days of life, this was not included in the systematic review for this guideline. No studies including bronchodilators, or oral benzodiazepines for the treatment of breathlessness in the last days of life were identified in the search used.
St Luke's Hospice, Sheffield	Full	155		Can this be reworded as this has the connotation that providing symptomatic relief could cause a more rapid deterioration in the dying person.	Thank you for your comment. This has been amended.

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St Luke's Hospice, Sheffield	Full	173	5	Broncodilators if evidence of reversible airways obstruction	Thank you for your comment. The Committee have recommended to identify and treat reversible causes of breathlessness. No evidence was found for the use of bronchodilators
St Luke's Hospice, Sheffield	Full	176-182		Some general guidance on how to treat nausea and vomiting would be useful	Thank you for your comment. The Committee have made general recommendations on nausea and vomiting, but do not recommend specific drugs as there was no evidence to recommend one anti-emetic over another.
St Luke's Hospice, Sheffield	Full	207	4	Specify the non-pharmacological methods that should be used e.g. repositioning and suction.	Thank you for your comment. The Committee acknowledges the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
St Luke's Hospice, Sheffield	Short	13	1	We are concerned over errors between morphine preparations. Specify whether IR morphine e.g. oramorph liquid or morphine injection (this is missing in table 2 on page 28)	Thank you for your comment. We do not have evidence from our review to support this changes on the prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these prescribing tables are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed

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					from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
St Luke's Hospice, Sheffield	Full	65,67		Consistency when referring to opioids (not opiates)	**Thank you for your comment. This has been amended.**
St Luke's Hospice, Sheffield	Short Appendix C5	67		No mention of vomiting and treatments for this only nausea	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
St Luke's Hospice, Sheffield	Full	217	1	It needs to be made clearer that you need to titrate in increments up to the 'maximum dose' as could be interpreted that you just jump up to the top dose.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain

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					targeted at the non-specialist prescriber and will be made available on the NICE website.
St Luke's Hospice, Sheffield	Full	217	1	Ibuprofen and diclofenac not available as a sc preparation. Should mention ketorolac or refer to specialist pall care team.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
St Luke's Hospice, Sheffield	Full	222	2	Concerned that hyoscine hydrobromide is listed first in the table for noisy secretions when this is also unlicensed in palliative care and more likely to cause delerium in the dying patient. In Sheffield and similar in many areas hyoscine butyl bromide is used first line sc for noisy secretions.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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St Luke's Hospice, Sheffield	Short	28	2	Clonazepam is now only available as an unlicensed medicine since the drug company no longer manufacture in the UK it is now imported. It is important to consider other routes or use of clonazepam as a sc bolus to minimise risk. There is also a risk that clonazepam will bind to PVC tubing in syringe driver (see Dickman The syringe driver book 3rd edition) which means we may have to titrate to an effective dose when initiated in a syringe driver. A sc bolus is often effective for up to 18 hours due to the long half-life and metabolism of clonazepam.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
St Lukes' Hospice	Full	11	4	Why is this restricted to "NHS services"?	Thank you for your comment. The guideline is aimed at all healthcare professionals who might be involved in the care of a person who is nearing death in any setting where NHS services are provided and we're pleased to confirm that this includes: • Care homes (with or without nursing) • Hospices • Hospitals • Hostels • Places of detention • Private residences.
St Lukes' Hospice	Full	13	23	We are concerned that the words "Ensure any changes.. are understood by the dying patient…" seems rather ambitious since a large proportion of patients may be unable to understand as they may	Thank you your comment. We believe that it is important to include the dying person in this recommendation even though we recognize the clinical circumstances you describe in which case

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				be delirious or unconscious	the importance would be transferred to ensuring that those important to the dying person agree and understand the changes to the care plan.
St Lukes' Hospice	short	6	4-7	ACP – no explanation. Or description of difference between ADRT. Include link to MCA for clarification	Thank you for your comment. We have made amendments to a number of recommendations to clarify that the important information of relevance includes; advance statement, advance decision to refuse treatment and lasting power of attorney for health and welfare Advance Care Planning and Advance Decision to Refuse Treatment have been discussed in the 'Linking evidence to recommendations' section of the full version of the guideline. Definitions of both items have also been included in the glossary and the introductory text of the guideline. The committee agree that level of consciousness and mental capacity at end of life are important issues when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with

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					limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
St Lukes' Hospice	short	6	10	Document clearly in a patients record the decisions regarding prognosis and any priorities of care in the patient's health records	Thank you for your comment. The Committee thinks this recommendation is clear as currently edited.
St Lukes' Hospice	short	5	13	How will these skills and the many other referenced in the document be trained on an on-going basis to all who need it.	Thank you for your comment. Service delivery, including training is outside the scope of this guideline. There is a service delivery guideline in production that may address this issue. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
St Lukes' Hospice	short	7	4	The requirement to identify a "lead" healthcare professional is one we agree with but this will have a big impact on current practice. The responsibility to ensure shared decision making is not currently one widely practiced by senior clinicians who tend to operate within unidsiciplinary teams (hospital) or solely in GP.	Thank you for your comment. NICE is currently developing guidance in palliative care service delivery and the issue of team structures may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
St Lukes' Hospice	short	6	13	How will these skills and the many other referenced in the document be trained on an ongoing basis to all who need it.	Thank you for your comment. This recommendation has now been removed although discussion on this issue remains in the Linking evidence to

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					recommendations section of chapter 6.
St Lukes' Hospice	Full	16	30	Change "diagnosis" to "cause"	Thank you for your comment. We have carefully considered the order of the recommendation and feel that no change is required.
St Lukes' Hospice	short	9	1	Remove "with people at the end of life"	Thank you for your comment. We have amended the recommendation, which now reads: Assess, preferably daily, the dying person's hydration status, and review the possible need for starting clinically assisted hydration, respecting the person's wishes and preferences.
St Lukes' Hospice	short	1	1	Would "care of the dying adult in the last days of life" would more accurately describe the document?. Then move the line 6 p27 to the end of the opening paragraph. This would improve the document by drawing alongside this guidance other guidance for end of life care in the last year. This would provide important recommendations for how to manage end of life earlier than a few days and can be used to respond to patients wishes or guide lthem accordingly to a more useful patient experience	Thank you. We have defined dying adult in the glossary, and the introduction text. The context of the guideline is described in the introduction, and defined what we mean by dying person in glossary. we have amended the title
short	P29	Table 3		Too many choices of anti-emetics and this may prove difficult for junior clinicians. Is the intention for people to use this as a textbook or one from which local guiideleines will be developed? Doses are quite high (especially haloperidol and opioids in table 1 p27) considering that the majority	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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				of patients are likely to be more elderly. Would the document be better using doses for this cohort and suggest higher does if no response or in younger patients?	members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
short	P30	Table 4		Is clonazepam available parenterally?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
short	27	Table 1		Ibuprofen as a choice of parenteral NSAID. What about other NSAIDS and Ketorolac?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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St Wilfred's Hospice	Short	1	Box	The box says Who is it for? But doesn't says What is it for? What actually is this guideline for? The NHS already has masses of end of life care guidance. Indeed each (old) Cancer Network produced comprehensive guidelines which still exist and are being updated. What is more guidance for? EOLC does not need more guidance but the implementation of existing guidance. Recommendation number 42 from Neuberger was that CCGs should commission EOLC "especially in hospitals. I know CQC reports on acute trusts are suggesting large increases in palliative medicine provision. Stuff like that is what is needed – not more guidance. On its own, this guidance is no better than the LCP.	Thank you for your comment. This guideline responds to a need for an evidence-based guideline for the clinical care of the dying adult throughout the NHS. This is different from other important NHS initiatives also labelled 'end of life care' which are aimed at improving care for people in the last year or so of a chronic condition, a good example of this is the work you mention developed to support cancer patients. This guideline is aimed at all healthcare professionals who might be involved in the care of a person who is nearing death in any NHS setting. NICE is currently developing guidance in palliative care service delivery and the issue of commissioning may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799 NICE guidance informs a number of key documents and processes that measure implementation in practice of its recommendations. It is used to develop quality standards that local care commissioning groups should use to inform commissioning of end of life services and also to support Care Quality Commission inspections visits. Thank you for participating in the consultation

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					process.
St Wilfred's Hospice	Short	17	8	I remain unclear on the purpose of the guideline. What is it for? None of it is new … Cancer networks already have guidelines based on evidence and good practice. Why do we need more?	Thank you for your comment. This guideline responds to a need for an evidence-based guideline for the clinical care of the dying adult throughout the NHS. This is different from other important NHS initiatives also labelled 'end of life care' which are aimed at improving care for people in the last year or so of a chronic condition, a good example of this is the work you mention developed to support cancer patients. This guideline is aimed at all healthcare professionals who might be involved in the care of a person who is nearing death in any NHS setting. Importantly this guideline covers the clinical care of all people at the end of life, not just those dying from cancer thus its intended audience is much broader than the cancer networks you reference .
St Wilfred's Hospice	Short	18	6	This is not real need – we have masses of guidelines already Another one won't change anything	Thank you for your comment and for participating in the consultation process.
St Wilfred's Hospice	Short	General	General	The recent health Ombudsman's report included several examples of poor end of life care. A press release from Ombudsman highlights three such examples of failings by NHS Trusts, stating the occurrence of these incidents "could have been minimised if doctors and nursing staff had taken care	Thank you for your comment. This guideline responds to a need for an evidence-based guideline for the clinical care of the dying adult throughout the NHS. This is different from other important NHS initiatives also labelled 'end of life care' which are aimed at improving care for people in the last year or so of a chronic condition, a good example of this is

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				to follow guidelines and best practice." My premise is that producing yet more guidelines won't change this situation a jot … The thing that will change the situation is to implement Neuberger recommendation number 42 that EOLC should be actively commissioned by CCGs. This should be done	the work you mention developed to support cancer patients. This guideline is aimed at all healthcare professionals who might be involved in the care of a person who is nearing death in any NHS setting. Thank you for participating in the consultation process. A service delivery guideline on improving palliative care services has been commissioned by NICE. We would recommend you participate in the scoping process for the development of that guideline to raise the issue about commissioning. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799
St Wilfred's Hospice	Short	19	27	Typo: it should be "advance" (no "d" needed)	Thank you for your comment. This has been amended throughout the document.
Short	1	Box		Under Who is it for? Commissioners and providers should be separated They have very different roles	Thank you for your comment. This is standard NICE text that highlights that the guideline is relevant and as such we are not able to amend.
St Wilfred's Hospice	Short	4	21	Use "improving" not recovering. Oddly "improving" is then used in line 25 …	Thank you for your comment. The Committee discussed the bullet points in recommendation 1.1.3 and decided to amend these to state: nearing death, deteriorating, stable or improving.

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St Wilfred's Hospice	Short	3	Line 5	"Recovering" implies cure; would "improving" be better? The word "often" is unhelpful. What does that mean? More or less than 50% of the time? Suggest replacing "is often" with "can"	Thank you for your comment. The Committee discussed the use of this word and agreed that it was clear. We have, however, added the word 'recovery' to the glossary, explaining our intended meaning, a return of a normal state of health, mind and strength. Regarding the second part of your comment, we agree with your suggestion and have replaced 'often with 'can'.
St Wilfred's Hospice	Short	3 & 4		1.1.1 and 1.1.2 are the wrong way round. The info in 1.1.2 should come first	Thank you for your comment. The intention of recommendation 1.1.1 is to first gather information and then (1.1.2) assess signs and symptoms. The Committee agree that no change is required.
St Wilfred's Hospice	Short	4	20 & 21	"Stable" is missing – when it is included elsewhere	Thank you for your comment. The Committee discussed the bullet points in the recommendation and decided to amend these to state: nearing death, deteriorating, stable or improving.
St Wilfred's Hospice		4	7 & 8	The Outcome & Assessment Complexity Collaborative (OACC) suggests use of the Australian Karnofsky Performance Scale, not ECOG. Should this guideline be up-to-date and include AKPS as well?	Thank you for your comment. After careful consideration the example of ECOG has been removed from the recommendation and replaced with: Functional observations, for example deteriorating performance status, social withdrawal, changes in communication. Further detail has been added to the 'Linking evidence to recommendations'

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					section of the full guideline to state that other functional observational may be appropriate, including the Karnofsky performance scale.
St Wilfred's Hospice	Short	4	15 +	Add "Bed bound" which is very discriminating for previously mobile people	Thank you for your comment. The examples given are based on the associated evidence review, detailed in the full guideline. (Please see section 5.8). The list is not definitive.
St Wilfred's Hospice	Short	3	10	Who should gather information? I wouldn't expect to identify last days of like until I'd gathered such info …	Thank you for your comment. The constituency of the multiprofessional team would vary according to patient need, setting of care and Trust. It is therefore difficult to identify one role that would be ultimately responsible for collecting information. The recommendations reinforce the need for all healthcare professionals to support the creation of an individualised care plan and also to ensure that this is shared with all members of the team as well as with the dying person and those important to them.
St Wilfred's Hospice	Short	7	14-17	1.3.4 Add a section on fast track referral for continuing care	Thank you for your comment. Further detail has been added to the 'Linking evidence to recommendations' section for this chapter in this regard (see section 7.6).
St Wilfred's Hospice	Short	7	18-26	1.3.5 Add activities of daily living	Thank you for your comment. All items listed cover activities of daily living.
St Wilfred's	Short	5	12	Should this read "… about their prognosis or impending death"?	Thank you for your comment. As the prognosis could be that the person is recovering, we believe

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Hospice				Prognosis is an abstract, sometimes distant concept but impending death is much more immediate and useful language	that prognosis is the correct term.
St Wilfred's Hospice	Short	9	1-3	1.4.4 "Respecting" their wishes is the wrong word. "Listening to their wishes and acting where possible" would be better. Not all wishes can be respected and met …	Thank you for your comment. We have carefully considered the order of the recommendation and feel that no change is required.
St Wilfred's Hospice	Short	8	18-23	1.4.2 Add checking for oral thrush (Candida)	Thank you for your comment. Unfortunately this was not prioritised as part of the scope.
St Wilfred's Hospice	Short	8	24-27	1.4.3 Mouth sponges are oddly recommended for oral hydration … mouth sponges are "banned" in Wales and have been the subject of more than one MHRA alert https://assets.digital.cabinet-office.gov.uk/media/5485ac0440f0b60241000271/con149702.pdf . Seems wrong to recommend them. Certainly no longer used in Chichester	Thank you for your comment. This example has been removed from the recommendation. Additional text about the MHRA alert has been added to the full guideline.
St Wilfred's Hospice	Short	12	21-22	1.5.15 This section should come before 1.5.14	Thank you for your comment. This has been amended.
St Wilfred's Hospice	Short	11	17-19	1.5.6 Add "if unable to take oral meds". Not every dying person has to have a syringe driver	Thank you for your comment. The Committee agree that not every dying person will require a syringe pump, however after careful consideration felt that

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					no change to the recommendation was required. This reflects the need for those who are receiving multiples doses of any as required medicines to potentially have them administered via the most comfortable route. Further detail has been added to the 'Linking evidence to recommendations' section of Chapter 9.
St Wilfred's Hospice	Short	12	19-20	1.5.14 Add examples eg positioning, relaxation	Thank you for your comment. The Committee acknowledge the importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
St Wilfred's Hospice	Short	14	20	Add a section on falls prevention	Thank you for your comment. Falls prevention was not prioritised as part of the scope.
St Wilfred's Hospice	Short	14	9	1.5.23 Add use of delirium screening tools	Thank you for your comment. This area was not prioritised as part of the scope.
St Wilfred's Hospice	Short	15	10-13	One of these should be recommended as a first line – not four options … suggest glyco or butylbromide	Thank you for your comment. The drugs listed here are in alphabetical order rather than order of preference. Further detail is given in the full guideline 'Linking evidence to recommendations' section.

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St Wilfred's Hospice	Short	16	16-26	1.6.4 Add: (a) Safety and storage of drugs (b) Costs of prescribing v costs of unrelieved symptoms v costs of avoidable admission	Thank you for your comment. We are unable to comment on storage as a review was not prioritised in this area. B) The cost considerations for these recommendations were reported in the Full Guideline under the 'Linking evidence to recommendations' section in chapter 10.
Sue Ryder	Short	18	27	Sue Ryder welcomes the fact that NICE are recognising the role of specialists helping generalist colleagues.	Thank you for your comment and for participating in the consultation process.
Sue Ryder	Short	1	1	Sue Ryder believes that these guidelines should mirror the 5 priorities of care. There needs to be consistency between NICE guidelines and the 5 priorities of care.	Thank you for your comment. The Committee considered the policy documents that outline the five priorities of care at all times but drafted their recommendations after due consideration of the evidence. Reference is made throughout the guideline to the current policy documents relevant to this area.
Sue Ryder	Short	3	2	Predicting timing of death is not an exact science, providing detailed prognosis regarding this is not possible and there has to be acknowledgement of a degree of uncertainty so the focus needs to be on supportive care.	Thank you for your comment. We agree and acknowledge the difficulty in recognising dying and discuss this in the introduction and in the 'Linking evidence to recommendations' section of the full guideline (please see section 5.8). The NICE version states this in the introduction to the recognising dying section and states the importance of clinical judgement.
Sue	72. Sh	73	74.	75. Sue Ryder feels that clarification of the "last	Thank you for your comment. We define last days

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Ryder	ort			few days of life" would be helpful, as this could include both those who are starting to die and may be weeks away from death, as well as the true last few days and hours	of life as the last 2 to 3 days of life, as defined in the method section of the full guideline (please see section 4.2.4.1).
Sue Ryder	Short	5	2	It is incredibly important to communicate when someone is believed to be dying to the person and their loved ones. The focus should be on the best personalised care for the individual.	Thank you for your comment. The committee agrees with you and have written recommendations that support this ideal. Healthcare professionals are encouraged to prioritise the needs, goals and wishes of the dying person and to maintain an individualised approach throughout the delivery of care at the end of life.
Sue Ryder	Short	6	16	Shared decision making needs to be addressed earlier in dying process rather than last few days	Thank you for your comment. The guideline covers the clinical care of adults who are in the last few days of life (defined as last 2 to 3 days). The Committee believes it's important to recommend these standards for communication and shared decision making in an effort to ensure that healthcare teams in all settings, maintain an individualised approach to care of the dying person and prioritise the person's goals, wishes and needs. We acknowledge that it would be important, where possible, for this process to take place as soon as possible and not to wait for the last days of life.
Sue Ryder	Short	8	12	Sue Ryder welcomes the guidance on Clinical Assisted Hydration. It should only be administered if appropriate and be assessed on an individual basis. It should also take into account whether the person has a preference, and the impact on the individual and their overall care plan	Thank you for your comment we agree and have given further details in the full guideline chapter 8.6.

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Sue Ryder	Short	9	4	Sue Ryder's experience is that hydration in the last few days is important to the relatives of those dying. A paragraph discussing communication with relatives would be helpful here.	Thank you for your comment. Further detail is provided in the 'Linking evidence to recommendations' section of the full guideline and also please see recommendations on communication and shared decision making.
Sue Ryder	Short	10	15	Sue Ryder welcomes medicine management that helps treat symptoms associated with dying, this is very important for those not in the receipt of medicines in the past.	Thank you for your comment.
Sue Ryder	Short	10	15	Education and training on this should be aimed at anyone that delivers end of life care, not just acute staff. This should have a particular emphasis on supporting staff delivering care to those individuals with long-term conditions.	Thank you for your comment. Service Delivery, including is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Sue Ryder	Short	11	13	Use of rectal medicines is not common practice and not really embedded within the culture of care within the UK. The guidelines supporting this may help initiate a cultural change for people that cannot receive medication orally at the end of life.	Thank you for your comment
Sue Ryder	Short	14	22	Sue Ryder feels that in the last few days noisy secretions are usually more of an issue for the relatives than the patients. A paragraph discussing communication with relatives would be helpful here	Thank you for your comment. This is discussed in detail in the full guideline, 'Linking evidence to recommendations' section 9.30.
Sue	Short	16	1	Anticipatory prescribing provides continuity of care	Thank you for your comment.

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Ryder				and Sue Ryder welcomes it use. It has an important role to play in managing symptoms out of hours, and could potentially reduce the need for acute admissions by proactively advocating use in community settings, where instant access to medications is very different to acute wards	
Sue Ryder	Short	16	27	Ensuring the right level of clinical support is vital; care needs to be flexible and responsive, particularly in community settings so it can be delivered 24/7. The role of the district nurse team is critical in community settings. We welcome having specialist colleagues in acute hospitals available over 24/7 periods which support and advise generalist staff on symptoms enabling personalised care.	Thank you for your comment. Service Delivery, including 24/7 availability of specialist palliative care, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Teenage Cancer Trust	Full	General	General	Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and outcomes for the seven young people aged between 13 and 24 diagnosed with cancer every day. We fund and build specialist units in NHS hospitals and provide dedicated staff, bringing young people together so they can be treated by teenage cancer experts in the best place for them. Through education of young people about the signs of cancer and working with health professionals to improve their knowledge, we work to significantly improve their diagnosis experience. And through our	Thank you for your comment. A guideline is currently being produced by the National Collaborating Centre for Women and Children's health. This work is entitled: End of life care for infants, children and young people and covers the populations you mention in your comment. Further details can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0730.

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				own research and working with our partners in the NHS, across the UK governments, and organisations both nationally and internationally, we strive to improve outcomes for young people. There are around 2,500 teenagers and young adults diagnosed with cancer each year across the UK36, while 295 young people aged 15-24 die from the disease annually37,38,39. Cancer is the most common cause of non-accidental death in young people, and five-year survival rates remain lower in teenagers than in children40. While survival rates for cancer in this age group have been increasing in recent years, they vary widely by cancer type from 96% in germ cell tumours to 56% in bone tumours41. As a result, it is very important that the needs of young people approaching the end of their lives are considered and met. We welcome the	

[36] North West Cancer Intelligence Service (2013)
[37] Office for National Statistics (2011), Cancer mortality by age England and Wales
[38] Information Services Division Scotland, http://www.isdscotland.org/Health-Topics/Cancer/Publications/index.asp?ID=903 (Accessed September 2013)
[39] Northern Ireland Statistics and Research Agency, http://www.nisra.gov.uk/archive/demography/publications/annual_reports/2011/Table6.4_2011.xls (Accessed September 2013)
[40] Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer
[41] Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer

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				publication of this draft guideline for adult services, but urge NICE to replicate the process for children and young people as soon as possible.	
Teenage Cancer Trust	Full	General	General	Teenagers and young adults have very specific psychosocial needs which need to be carefully assessed in the development of a guideline for end of life care. We support the majority of themes in this draft document, but highlight the importance of dovetailing this guideline with the upcoming guideline for children and young people. Whilst we welcome the creation of a separate guideline for children and young people, it is critical that there is no break in service provision or quality for young people moving into adult services. Transition to adult services can be extremely difficult for teenagers and young adults; the process is far from smooth and, as a result, their specific needs are often overlooked or set aside during and after transferral, seriously diminishing the continuity of care. In addition, there is a significant lack of hospice care for teenagers and young people42, meaning that many of them are forced to make use of services which cannot prioritise their end of life requirements in an age-appropriate manner. Given the particular demands of teenagers and young adults, it is very important to	Thank you for your comment. NICE is in the process of developing the following guidelines, which should address the important issues that you have raised: Transition from children's to adult services, with an anticipated publication date of February 2016. End of life care for infants, children and young people, with an anticipated publication date of December 2016. These guidelines are highlighted in the 'related guidance' section of the Care of the Dying Adult guidance. Further details can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0730.

[42] Grinyer and Barbarachild (2011), Teenage and young adult palliative and end of life care service evaluation

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				make sure that services and models of care do not falter during transition from one set of services to another.	
Teenage Cancer Trust	Full	General	General	There are fundamental differences in end of life care for teenagers and young adults with cancer which require specific consideration. More young people with cancer die in hospital compared to other age groups (52% of young people compared to 48% of other age groups) and more die at home (32% of young people compared to 24% of other age groups43). There are also variations in place of death depending on the type of cancer a young person has, with 67% of young people with lymphoma who die in hospital compared to 26% who die at home44. This guideline needs to take these differences into account to ensure end of life care is improved for all patients in adult services, including the practical considerations of the dying in different locations and the necessary skills and equipment.	Thank you for your comment. The guideline covers all locations and settings with the aim to improve consistency of care. There is also a service delivery guideline in production that may address this issue.
Teenage Cancer Trust	Full	110	1	We are concerned with the lack of importance placed on training healthcare professionals to communicate with patients and family members about end of life issues. Teenagers and young	NICE is currently developing guidance in palliative care service delivery and the issue of education and training may be covered by that work. Please note that more detail about the development of this

[43] National Cancer Intelligence Network, (2011) Place of death for Children, Teenagers and Young Adults with Cancer in England
[44] National Cancer Intelligence Network, (2011) Place of death for Children, Teenagers and Young Adults with Cancer in England

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				adults need to have specialist staff who are trained to understand their specific needs; the National Cancer Patient Experience Survey has repeatedly found that 16-25 year olds report worse experiences with GPs, have less confidence in doctors, and report lower understanding of their condition and treatment[45]. If still occurring at the end of life, these shortcomings could make the process significantly harder for all involved, whereas trained specialists can both understand and meet the particular needs of this population. As well as funding specialist staff across the UK, we have been working with Coventry University since 2006 to design and maintain a series of specialist accredited courses for health care professionals which develop the skills necessary to work with young cancer patients. Whilst we understand that training recommendations lie outside the remit of this draft guideline, we ask that the importance of training staff in end of life communication is recognised, and that the success of training collaborations such as ours are considered in the development of the guideline for children and young people.	guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799

[45] Department of Health (2010, 2012, 2013, 2014), National Cancer Patient Experience Survey

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Thames Hospice and Wexham Park Hospital	Full	17	8 - 11	Is this intended to be an order of preference for these drugs? – My concerns would be that hyoscine Hydrobromide and atropine both have more significant adverse side effect profiles and neither would be first choice – preferable 1st choices would be hyoscine butylbromide or Glycopyrrolate – listing them is this order seems to favour the use of Hydrobromide and atropine.	Thank you for your comment. These medications are listed providing licensed medications first and then other non-licensed medications are listed alphabetically, and not in order or preference as per NICE standards.
Thames Hospice and Wexham Park Hospital	Full	237		Really useful data to support anticipatory orescribing.	Thank you for your comment.
Thames Hospice and Wexham Park Hospital	Full	217		Subcutaneous NSAIDs are a specialist intervention – not sure if this is suitable for non specialist initiation. I don't think Ibuprofen is available in UK as an injectable preparation. In our practice we will occasionally use Ketoprofen subcutaneously if a n anti-inflammatory is strongly indicated and risk/benefit is considered.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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Thames Hospice and Wexham Park Hospital	Full	217 and 218		Does the evidence support 2 hourly dosing of opioids? Pharmacology would expect a minimum one hour interval.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Thames Hospice and Wexham Park Hospital	Full	218		Clonazepam not routinely available in UK – only non UK licensed product available – may not be useful for non-specialist due to difficulty in accessing.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Thames Hospice and Wexham	Full	219		As above clonazepam injection not readily available	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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Park Hospital					implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Thames Hospice and Wexham Park Hospital	Full	222		Hyoscine Hydrobromide is licensed option for s/c use however it has a significantly poorer side effect profile – concerns that the order of choice would lead to preference for HHB or atropine over Hyoscine Butylbromide or Glycopyrronium.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Brain Tumour Charity	Full	12	13-20	**Recommendation 6:** We agree with this recommendation, with its recognition that identifying communication expectations of those caring for a dying person are vital to the quality of care they receive at the end of life.	Thank you for your comment. The Committee considered communication and shared decision making to be important areas for inclusion on this guideline and have made recommendations highlighting the importance of including both the

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				Communication is one of the seven strands of the Gold Standards Framework in palliative care[46], and with the right level of training for healthcare professionals involved in the care of the dying person, this recommendation has the potential to improve patient experience at the end of life. The one measure that should be added to this recommendation is to identify the next of kin/carer of the dying person. Many brain tumour patients experience rapid cognitive degeneration following diagnosis and treatment, meaning that in the last few days of life, they may lack the competence to understand the nature of their prognosis. In this situation where the patient has lost capacity to make decisions over their treatment and care, it is vital that healthcare professionals are able to identify a person who can help them to assess the dying person's speech, language or other communication needs.	dying person and if appropriate those important to them, which may include next of kin, or carer. The committee consider identifying next of kin as standard medical practice and this level of detail was not felt to be needed.
The Brain Tumour	Full	12-13	38-42; 1-3	**Recommendation 10:** We agree with this recommendation.	Thank you for your comment. After careful consideration and in light of the evidence review

[46] The Gold Standards Framework in Primary Care, *"Information Leaflet for Patients, Families and Friends,"* 2013. Accessed online at: http://www.westsuffolkccg.nhs.uk/wp-content/uploads/2013/08/GSF-Information-for-Patients-Families-Friends.pdf

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Charity				However, where an advanced care plan has been put together, it is critical that recommendation 15 is also implemented, so that named lead healthcare professional is assigned to take responsibility for implementing those preferences of the dying person in the last days of life. We have made further comments about advanced care planning in response to recommendation 17.	conducted that supported the development of this recommendation, the committee did not wish to add any further detail to this recommendation. Minor amendments have been made to recommendation 15 but given that this recommendation has been made in light of a review of the evidence behind shared decision-making, the committee did not wish to adjust this as you have suggested.
The Brain Tumour Charity	Full	13	29-37	**Recommendation 17:** Whilst we welcome the sentiments of this recommendation, for people with a brain tumour diagnosis, care planning needs to be instigated at the earliest possible stage once a person receives a terminal prognosis in order to ensure their preferences can be implemented, particularly the nomination of a Lasting Power of Attorney (LPA) who can take health care decisions on behalf of a patient if they become incapacitated. Our Losing Myself: The Reality of Life with a Brain Tumour report[47] showed that out of 1017 people either living with, or caring for a person with a brain tumour, 55% had not been provided with end of life	We agree that advance care planning should be done prior to the last days of life but this is out of the time frame for our scope. Although we acknowledge the importance of the issues you raise for people with brain tumours, we are unable to make comment on the issue of the nomination of a Lasting Power of Attorney.

[47] The Brain Tumour Charity, *"Losing Myself: The Reality of Life with a Brain Tumour,"* June 2015. Accessed online at: http://www.thebraintumourcharity.org/Resources/SDBTT/the-research/documents/the-brain-tumour-charity-final-digital.pdf

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				care options, and 49% had not been given appropriate information about end of life care. These figures demonstrate the large variation in patients being given the option of advanced care planning and advanced decisions to refuse treatment. We are concerned that if advance care planning does not take place at an early stage of the patient pathway, creating an individualised plan of care in the last few days of life would be too late to adequately meet the dying person's preferences around treatment and care. This is primarily because of the cognitive degeneration that many brain tumour patients face during their treatment, and the resulting impact on their capacity to provide informed consent towards the end of their life. We are pleased that one of the recommended elements listed as part of an individualised plan of care is "preferred care setting," which could help more people to exercise control and choice over the place of their death. However, given that a lack of advanced care planning prevents the majority of patients who wish	

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				to die at home from being able to do so[48], this would require a substantial shift of resources from hospital to the community setting, particularly at the end of life when there is greater time pressure.	
The Brain Tumour Charity	Full	17-18	28-38; 1-3	**Recommendations 55-56:** We agree with the recommendation. However, in order to ensure that a person receives an adequate level of symptom control in the home or hospice facilities, this will require greater collaboration between healthcare professionals and out-of-hours services in the community, and for recommendation 16 to be implemented so that the resources required for the care of the dying person can be met. This is particularly important when exercising a dying person's wishes to die in their own home. A failure to provide adequate symptom control in home care settings could lead to higher hospital admissions, a lower quality of life for the dying person and higher costs to the NHS. In reference to recommendation 56, we call on NICE	Thank you for your comment. Service delivery, including 'the coordination of healthcare services' is not included in the scope of this guideline. NICE is currently developing guidance on palliative care service delivery and this topic may be included in that guideline. More details can be found at the following link: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799 NICE only refer to other NICE guidance in its suite of guidelines, so we are unable to refer to the Gold Standard Framework in this work, however, the recommendations have been amended to encourage healthcare professionals responsible for delivering end of life care to establish the communication needs and expectation of the dying person, taking into account any cultural, religious, social or spiritual needs or preferences. We feel that this is appropriately captured in this recommendation and no further edits are required.

[48] Macmillan Cancer Support, "*Can we live with how we're dying?*" June 2014. Accessed at: http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Endoflife/EndofLifereport-June2014.pdf

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				to consider how it can be broadened to include some elements of the Gold Standard Framework's model of symptom control, which stresses the need to address social, psychological and spiritual concerns of the patient.[49]	
The Brain Tumour Charity	Full	13	18-25	**Recommendation 15:** We agree with this recommendation. Our Losing Myself: The Reality of Life with a Brain Tumour report[50] showed that out of 1,017 people either living with, or caring for a person with a brain tumour, 49% had not been given appropriate information about end of life care. Therefore, we are pleased that this recommendation recognises the need for an information lead to provide a point of contact and support for family members and carers of a dying person during an extremely difficult time. For carers who are looking after a dying person in their own home, having a point of contact who can	Thank you for your comment and for participating in the consultation process.

[49] The Gold Standards Framework in Primary Care, *"Information Leaflet for Patients, Families and Friends,"* 2013. Accessed online at: http://www.westsuffolkccg.nhs.uk/wp-content/uploads/2013/08/GSF-Information-for-Patients-Families-Friends.pdf
[50] The Brain Tumour Charity, *"Losing Myself: The Reality of Life with a Brain Tumour,"* June 2015. Accessed online at: http://www.thebraintumourcharity.org/Resources/SDBTT/the-research/documents/the-brain-tumour-charity-final-digital.pdf

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				signpost to out-of-hours services is crucial for ensuring good quality care at the end of life, and help reduce the barriers for people who wish to die at home to do so.	
The Brain Tumour Charity	Full	13	26-28	**Recommendation 16:** We agree with the sentiments of this recommendation, but it would require closer collaboration between local commissioners and out-of-hours services provided by the voluntary sector organisations in the last few days/weeks of life. At present, only 8% of CCGs in England[51] commission the level of support services such as emotional support and advice which are available to patients and carers twenty four hours a day, seven days a week. These services often play a pivotal role in identifying and meet the needs of dying people, their carers and their loved ones in the last days of life. To improve this situation, we believe that CCGs in England should specifically commission these support services, particularly for those receiving palliative care or dying at home.	Thank you for your comment. Service delivery, including 'the coordination of support services' is outside the scope of this guideline. There is a service delivery guideline in development that may address this issue. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.

[51] Sue Ryder, *"Dying Doesn't Work 9-5,"* The Facts. Accessed online at: http://www.sueryder.org/how-we-help/Policy-and-campaigns/Our-campaigns/not-9-to-5/facts

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The Brain Tumour Charity	Full	15	13-21	**Recommendations 31-33:** We support these recommendations, which have the potential to address failures in end of life care that were recently identified by the Parliamentary and Health Service Ombudsman[52]. However, for these measures to be implemented there is a need for healthcare professionals to be adequately trained in pain management, so that patient needs can be identified and treated successfully. NICE's guideline for Palliative Care for Adults with Cancer suggested that greater provision of education and training in this area could *"lead to improvements in knowledge, attitudes and clinical behaviours of doctors and nurses,"* with a subsequent improvement in patient outcomes.	Thank you for your comment. Service Delivery, including training, is beyond the remit and scope of this guideline. NICE is currently developing guidance in palliative care service delivery and this topic may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
The Brain Tumour Charity	Full	15	22-25	**Recommendation 34:** We support this recommendation in principle. Many brain tumour patients lack the capacity to verbally communicate they are in pain due to speech loss or an induced conscious level. Therefore, the	Thanks for your comment. We have added additional detail to the 'Linking evidence to recommendation' section stating that those important to the dying person may also be able to help assess pain (please see section 9.5).

[52] Parliamentary and Health Service Ombudsman, *"Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care,"* June 2015. Accessed online at: http://www.ombudsman.org.uk/__data/assets/pdf_file/0019/32167/Dying_without_dignity_report.pdf

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				use of a scoring tool such as behavioural pain assessment would help to assess their treatment needs more effectively in the last days of life. The one area of concern we have with this recommendation is if a dying person is also affected with physical symptoms that could prevent healthcare professionals from being able to measure the level of pain, as expressed in movements of the legs, arms and face. In this scenario, it is important to identify the next of kin/carer of the dying person who may be better able to assess their level of pain when they have lost the capacity to communicate. Our *Losing Myself: The Reality of Life with a Brain Tumour* report[53] showed that 4 out of 5 people living with a brain tumour are severely affected by mobility problems, which could have an impact on their ability to express/feel physical pain.	
The Brain Tumour Charity	Full	18	29-35	**Recommendations 64-65:** We agree with this recommendation, but it requires that care planning takes place at an early stage at the time of terminal prognosis (recommendations 16 and 17) to ensure that healthcare professionals work alongside out-of-	Thank you for your comment. The recommendation state "as early as possible", but the Committee were unable to comment on any earlier timeframe as the remit of this guidance is last days of life. The Committee intend this recommendation to apply to

[53] The Brain Tumour Charity, *"Losing Myself: The Reality of Life with a Brain Tumour,"* June 2015. Accessed online at: http://www.thebraintumourcharity.org/Resources/SDBTT/the-research/documents/the-brain-tumour-charity-final-digital.pdf

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				hours care providers to make arrangements to ensure that the resources are in place so patients can have access to symptom control medication when needed. This is especially important when a dying person is being cared for in their own home. Given the level of cognitive degeneration that many people with brain tumours face, medications may need to be administered by family members on their behalf and this needs to be addressed within the recommendation.	all settings, including the community.
The Hillingdon Hospital palliative care team	short	general	general	Thank you. Clearly a lot of work and thoughtful consideration for which we are grateful. Overall the guide was considered to be comprehensive and practical. Some guidance, e.g. concerning the management of hydration, was particularly helpful and clear. (This was prepared as a joint response from The Hillingdon and Michael Sobell at Mount Vernon Hospital palliative care teams – at the time of writing the permissions from Mount Vernon Cancer Centre and trust were outstanding so the names of their health professionals have not been included).	Thank you for your comment and for participating in the consultation process.
The Hillingdon Hospital palliative	short			Empty Field	Empty Field.

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care team					
The Hillingdon Hospital palliative care team	Short	4	1-15	Group bullet points together in a time frame e.g. weight loss, social withdrawal earlier; mottled skin, noisy secretions late signs.	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. Further detail has been added to the 'Linking evidence to recommendations' section of the full guideline (Please see section 5.8).
The Hillingdon Hospital palliative care team	short	6	13-15	May require further explanation	Thank you for your comment. This recommendation has now been removed although discussion on this issue remains in the Linking evidence to recommendations section of chapter 6.
The Hillingdon Hospital palliative care team	short	8	13-17	In our hospital we write up i.e. prescribe 'offer food' & 'offer water' & 'mouth care' on the drug chart	Thank you for your comment the content of which is noted.
The Hillingdon Hospital palliative care team	Short	8	14	We are concerned that this may lead to increased unnecessary referrals to SALT for assessment in hospital settings, when a simple bedside assessment by generic staff would be sufficient	Thank you for your comment. We agree. The Committee consider this recommendation applies to generalists.
The	short	12	19-20	May need more detail e.g. 'offer fan' etc.	Thank you. The Committee acknowledge the

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Hillingdon Hospital palliative care team					importance of non-pharmacological symptom management and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. We are unable to provide specific examples as we have not conducted a specific evidence review. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
The Hillingdon Hospital palliative care team	short	12	22	Add 'as/ if appropriate'	Thank you for your comment. The Committee consider identifying and treating reversible causes of breathlessness as very important. They considered that clinical judgement be used as to whether this was possible or not and that no further detail was needed.
The Hillingdon Hospital palliative care team	short	14	14	Add 'existential issues'	Thank you. We have listed examples here and are aware that others also exist and expect healthcare professionals to use clinical judgment to explore these.
The Hillingdon Hospital palliative care team	short	14	15	Add 'if appropriate'	Thank you. We are aware that reversible causes may not be possible to treat, but expect healthcare professionals to use clinical judgment to explore these.
The	short	14	1-6	This is too complex to deal with in 2 bullet points.	Thank you. We are aware that this is a complex

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Hillingdon Hospital palliative care team				We would prefer 'please contact your specialist palliative care team for advice'	area, but expect healthcare professionals to use clinical judgment to explore these.
The Hillingdon Hospital palliative care team	short	15	11, 17	Leave out atropine, (for specialist palliative care use)	Thank you for your comment. The drugs listed here are in alphabetical order rather than order of preference. Further detail is given in the full guideline 'Linking evidence to recommendations' section (9.30). The evidence review identified atropine to be effective and the Committee considered in a valid treatment option for some people.
The Hillingdon Hospital palliative care team	short	15	24-26	onsider glycopyrronium – less likely to cause side effects, particularly in some groups of patients e.g. parkinsons	Thank you for your comment. These medications are listed providing licensed medications first and then other non-licensed medications are listed alphabetically, and not in order or preference as per NICE standards.
The Hillingdon Hospital palliative care team	short	27	2	Layout suggests diclofenac PR is 1st line for opioid naive who can't swallow – we do not agree with this approach *(undignified, lots of contraindications, better alternatives)*	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be

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					made available on the NICE website.
The Hillingdon Hospital palliative care team	short	27	2	Leave out sc NSAIDS (ask for SPCT advice)	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon Hospital palliative care team	short	27	2	Starting dose for elderly frail we use 5mg morphine sulphate sc/ 24 hr	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon	short	27	2	Add to notes (d) conversion oral to sc morphine	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing

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Hospital palliative care team					symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon Hospital palliative care team	short	27	2	Add to notes (e) seek SPCT advice for patients with renal failure	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon Hospital palliative care team	short	28	2	For non-malignant respiratory patients (COPD etc) start lower oral morphine 1-2mg *(they are much more sensitive to morphine)*	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This

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					important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon Hospital palliative care team	short	28	2	Start lower for frail elderly and COPD etc 5mg/sc/24hr	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon Hospital palliative care team	short	28	2	Clinically difficult to roll over a dying breathless patient to administer rectal diazepam (add it as a choice in notes at bottom of table?)	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The	short	28	2	Clonazepam really not used as a 1st line in generic	Thank you for your comment on the prescribing

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Hillingdon Hospital palliative care team				practice here or in surrounding boroughs – staff not used to it – not readily available - prefer midazolam as 1st choice and only choice – then seek SPCT advice	tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon Hospital palliative care team	short	30	2	Consider adding seek SPCT advice for levomepromazine in renal failure	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon Hospital palliative care	short	31	2	Leave out clonazepam as it is not familiar drug for generic teams – prefer to use drugs they are used to like midazolam then ask for SPCT advice if they are not controlling symptoms	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from

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team					members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon Hospital palliative care team	short	31	2	The footnotes are good and helpful. Suggest for (b) we would 'substitute' not 'add' antipsychotic in that situation.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon Hospital palliative care team	short	32	general	Is this table (5) needed Consider adding footnote to table 4 to suggest adding antipsychotic drugs earlier if patient has psychotic symptoms	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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The Hillingdon Hospital palliative care team	short	33	2	Glycopyrronium 1st please: less side effects and in our experience it works better	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon Hospital palliative care team	short	33	2	Remove atropine – too many side effects and there are better alternatives	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Hillingdon Hospital	short	general	tables	Overall comment: tables too complex with too many options – particularly for generic staff e.g. in DGH and community settings. Prefer to use a small range of drugs with which they are familiar and seek SPCT	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now

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palliative care team				advice if symptoms not controlled.	being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Interlink Foundation	Full	11	5	We are concerned with the grouping of dementia along with end stage patients such as those with advanced cancer, lung disease. We feel it increases the risk of discrimination to the patient with advance dementia based on their incapacity, leading to clinical interventions being withheld inappropriately as they may be assumed to be futile due to quality of life of the patient with dementia.	Thank you for your comment the sentence to which you refer introduces the breadth of populations for which this guideline is relevant.
The Interlink Foundation	Short	6	4	Question 2: Our organisation developed a Jewish Advance Directive – which captures important elements of advance care planning such as a designated consultee, identifying a value system, patients wishes to receive ANH and information sharing. We have implemented this locally and it has made a significant difference to easing decision making. This document has had senior legal scrutiny by a QC, is easily transferable to other faith groups and we would be happy to share it.	Thank you for your comment. Implementation of new policies and procedures are outside the remit of this guideline, however, NICE has a dedicated Implementation team that may support best practice in this area.
The Interlink	Full	110		(1) We have some concern with the implementation of information sharing	(1) Thank you for your comment. The committee agrees that mental capacity at

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Foundation				recommendations for Jewish patients and particularly with the statement that "clinicians should always act in the in the dying person's best interest". According to the Mental Capacity Act, Best interest should always take account of the persons value systems. (2) Within Jewish Torah ethics, informing a patient of the timing of their expected death and prognosticating about their condition may lead to a risk that the patient will 'give up hope'. Even the risk of this happening is such that Jewish law does not support informing a patient of expected death. We would prefer a system where there is sufficient workforce training that this important faith ethic is anticipated by staff and is therefore a premise at the outset when dealing with Jewish patients. (3) Question 2 Our organisation has produced some printed guidelines and cultural awareness training for health care staff, which may be helpful for workforce training particularly in the few concentrated Jewish areas in the UK.	end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009. (2) Thank you for highlighting the traditions of the Jewish community. The recommendations encourage healthcare professionals to: • establish the needs of the dying person as early as possible, • use an individualised approach to end of life care, • take into account any cultural, religious social or spiritual needs or preferences that should be considered. • prioritise the goals and wishes of the dying

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					person. (3) Your suggested training material is noted, however we are unable t use this in the context of this guideline. The NICE implementation team who have a responsibility for sharing best practice may be interested and we will direct them to your comment.
The Interlink Foundation	Full	12	21-32	We are concerned that this recommendation will lead to patients becoming discouraged and losing the will to live leading to a shortening of life and reduced life quality. Jewish ethics would always encourage retaining some uncertainty when discussing prognosis or expected death.	Thank you for your comment. The Committee consider this to be a very important issue and have therefore highlighted in their recommendations that discussions with the dying person on their prognosis should not take place if they do not wish to be informed. Another recommendation that supports this ideal, asks healthcare professionals to establish the communication needs and expectations of people who may be entering their last days of life and to take into account any cultural, religious social or spiritual needs or preferences. We do not feel any edits are required having considered these issues in the context of the important faith issues you outline, some of which may be different for other faiths.
The Interlink Foundation	General			No mention is made of process for deciding DNAR - and supporting the patient and family in this decision. This has been a contentious issue as DNAR decisions often do not include family members or the patient. They are sometimes made	Thank you for your comment. We recognise that CPR and DNAR decisions are an important area in care of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas are more likely

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				too early which leads to a concern that it is inappropriate. Also, DNAR sends a 'message' to care staff that the patient is in the dying phase and interventions that could be appropriate are not offered. We would like to see this guidance emphasise the need for following best interest protocol. Also that clinical decisions apart from resuscitation must not be influenced by a DNAR.	to have a wider impact on clinical practice. DNAR discussions will not be included in this guideline.
The Interlink Foundation	general			References are only made to artificial hydration. The Liverpool Care Pathway and other documents referred to Artificial nutrition and hydration. We would like to see evidence and reference to nutrition and at the very least to glucose added to the hydration. The research did not highlight the role of glucose or other nutrients but we would assume this sustains the energy of the patient and gives them an increased chance for prolonged life . Furthermore, Jewish ethics would support this as basic care.	Thank you for your comment. Nutrition is beyond the remit and scope of this guideline.
The Interlink Foundation	short	10	7	We are concerned that this statement may imply that whenever a patient cannot tolerate a nasal gastric tube or a cannula placement is uncomfortable, Artificial hydration will be withdrawn. Particularly in the mentally incapacitated patient who cannot express his wishes, the cues of pulling out the tube may be misconstrued. We would like to see the guidance changed to encourage clinicians to first try alternate infusion routes rather than stop hydration.	Thank you for your comment. This has been removed from the recommendation and further detail added to the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
The	S	9	26	We are uncomfortable with this guidance of	Thank you for your comment. The decision to

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Interlink Foundation	hort			recommending a therapeutic trial of Artificial Hydration and feel it will lead to poor acceptance in implementation. It places too much onus on proving benefit from hydration where the patient is showing signs of delirium or thirst. The comatose patient may also benefit from hydration but not show these signs. We would prefer the guidance to encourage a trial of hydration for all patients and only to be withdrawn where contra indicated.	consider a trial of clinically assisted hydration should be based on an individualised approach taking into account benefits and harms and our recommendation corresponds to the strength of the evidence considered. We have made further amendments to our recommendations in this section and additional detail has been added to the 'Linking evidence to recommendations' statement in section 8.6 of the full guideline.
The Interlink Foundation	Short	9	26	Question 1: In general, we feel that prevailing practice has to change with respect to Artificial hydration to facilitate its administration more easily in private and community settings so as to avoid costly and distressing hospital admissions to remediate dehydration in the dying patient and In particular when hydration can only be administered through parenteral delivery.	Thank you for your comment. We agree and intend this recommendation to apply to all settings and would expect clinically assisted hydration to take place without a move to hospital, but note that there may be challenges to its implementation.
The Interlink Foundation	Short	9	8-14 15-20	We feel this guidance is biased in favour of withholding hydration as the clinician is instructed to advise patient and near ones that hydration is unlikely to prolong life. There is never absolute certainty about anticipating death within 3 days. But if fluid is withheld , then death will be the outcome. Therefore, we would prefer to see this guidance withdrawn completely. This guidance about hydration may face significant resentment in implementation from many patients who will remain sceptical about the evidence particularly as the	The Committee considered the evidence presented (despite being of limited quality) to them to show equivalence in efficacy and adverse events between clinically assisted hydration and usual care or placebo and therefore considered clinically assisted hydration as a valid option, with the caveat that risks and benefits should be discussed and other factors such as level of consciousness and swallowing difficulties are taken into account. Further detail is available in the 'Linking evidence to

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				evidence does concede that hydration increases the comfort of the patient and counters delirium and thirst . Jewish law views hydration as basic care and therefore would be mandated (unless clinically contra indicated). It may inadvertently intimidate the vulnerable patient and/ or near ones who wish to adhere to this faith mandate when confronted with this statement to advise the patient that hydration does not prolong life…. As mentioned in point 5 , the Jewish advance practice would be an example of good practice to clarify the Jewish position at the outset that the patient wishes to have AH.	recommendations' statement in section 8.6 in the full guideline. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether clinically assisted hydration will prolong life or the dying process or hasten death if it is not given. The Committee were aware of religious views on clinically assisted hydration and note in the full version of the guideline to take these into account when considering the role of clinically assisted hydration (see also recommendation 2.4.4)
The Interlink Foundation	full	212	10	We would prefer to see the term 'symptomatic benefit' changed to 'clinical benefit'. No mention is made of providing the dying person with ongoing treatments that are not directly related to the underlying condition leading to dying . For example - thyroid treatment, diabetic medications, simple antibiotics for infections. We feel that these should be sustained as per our ethical viewpoint that these treatments are considered basic care – independent of quality of life evaluations. They should be given unless contra indicated.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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The Interlink Foundation	Full	160	17	Question 1: We share concern about implementation with respect to anticipatory dosing to manage symptoms. We support dose by dose review to avoid too much unnecessary medication along with side effects. We have seen community nurses give 'cocktails' of drugs in anticipation of symptoms, rather than evaluating need. Overall aim would be to strive for minimum effective dosage and range of medications rather than standard multi pharmaceutical package. In general, this is an area that would benefit from additional workforce training which is not indicated in the guidelines.	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.
The Interlink Foundation	Full	211	1-4	Question 1: We feel this will be difficult to implement and it may help if the an information leaflet is produced to reassure families that noisy respiration is not clinically advisable to treat including that anti muscarinics may be detrimental to patient. We are concerned that otherwise relatives may unwittingly pressure staff to prescribe anti muscarinics that may give unacceptable side effects. In addition, Full guidelines seem to conflict with the summary document that do not recommend trying anti muscarinics. We suggest the	Thank you for participating in the consultation process. The information you have provided in your comment will assist the NICE implementation and resourcing team with finalising the guideline. This has helped the team to consider the areas which will have the biggest impact on practice and be challenging to implement, in addition to what would specifically help users to overcome any challenges.

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				recommendation in the summary guidelines are removed.	
The Royal College of Anaesthetists	Full	21	40	Clinical comment – there seem to be a typo or confusion in the wording: 'bladder retention' should be 'urinary retention'.	Thank you for your comment. This has been amended.
The Royal College of Anaesthetists	Short	General	General	Clinical comment - The guideline is repetitive in stressing the need for full and frank consultation with all concerned, regular review, and the identification of a responsible party to coordinate the care. Of course all this is important and we are in full agreement with these principles, especially in light of the recent criticism of the Liverpool Care Pathway, however stating these needs clearly once would be sufficient.	Thank you for participating in the consultation process.
The Royal College of Anaesthetists	Short	General	General	Clinical comment - Whilst we understand that the focus of this guideline is on the last days of life, the reality is that for many patients the dying process can take many weeks or months. The authors of the guidelines should consider using this guideline to address the broader dying process.	Thank you for your comment. This is outside the remit and scope of the guideline which was to develop an evidence-based guideline on clinical care in the last few days of life. Other NICE guidelines address palliative care in a broader sense and also in specific disease related guidance.

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The Royal College of Anaesthetists	Short	General	General	Clinical comment - Our clinical members would like to see mention of the resource implications for palliative care in and out of hospitals which appears to be fairly stretched in the NHS currently.	Thank you for your comment. Service delivery, including resource implications for palliative care was outside the remit and scope of the guideline. NICE is currently developing palliative care service delivery guidance that may address this issue. Please note that more detail about this work can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
The Royal College of Anaesthetists	Full	23	42	Clinical comment - Will this guideline be excluding dying adults in surgical specialities as the wording in this sentence suggests?	Thank you for your comment. The guidance is targeted at all health and care professions providing end of life care. The text does not exclude surgical specialties. Indeed we feel the guidance may be of direct relevance to such settings where care providers do not necessarily have specialist skills in providing end of life care.
The Royal College of Anaesthetists	Short	3	11	Lay comment - Who is going to gather information on the 'spiritual' needs of the person? Discussion between priest/spiritual leader and patient should be entirely confidential.	Thank you for your comment. The Committee consider these recommendations to be applicable to whoever is responsible to delivering care but that this may also involve conversations with other professionals who may be able to share information without breaking confidentiality
The Royal College of	Short	3	17	Lay comment - "those important to the person" is very vague. Relatives could argue whether they are 'important' or not to the dying patient. Defining those who are important may save problems.	Thank you for your comment. The Committee discussed this and deemed it to be the most appropriate term. This is defined in the full guideline as: The people important to the dying person

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Anaesthetists					including family members and anyone else significant as decided by them, such as a partner or close friends.
The Royal College of Anaesthetists	Full	General	General	Clinical comment - Although this guideline covers situations when it may not be possible to communicate with the patient at times, it would be helpful to have a flow chart or some such to show the pathway that clinicians should follow when it's not possible to communicate effectively (unconscious, suffering stroke, dementia etc) and when relatives/carers are unwilling, unable or unavailable to be consulted. What would be the basic care if decisions on end of life care are left totally up to the clinicians?	Thank you for your comment. NICE guidelines do not replace clinical judgement; established standards of care in the NHS would prevail in the event of the circumstances described in your comment. The Committee's intention is that the recommendations in this guidance present a framework for delivering individualised care, while considering the wishes, goals and needs of the dying person. Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
The	Full	134	Rec.	Clinical comment - Question 1: this recommendation	Thank you for your comment. The Committee

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Royal College of Anaesthetists			15	will require further clarification or examples as to who the named lead healthcare professional should be. Would it be a member of the palliative care team or a member of nursing/medical staff on the ward caring for the patient? With shift work continuity of care can be difficult and contact details given may only be utilised during office hours or when the particular lead healthcare professional is on duty. Do the guideline authors mean for this lead healthcare professional to be a member of the palliative care team within a hospital? Emphasis needs to be on establishing clear pathways in each hospital to access specialist services to help care for these patients both in and out of hours (palliative care teams, pain consultants, nurse specialists).	consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section.
The Royal College of Anaesthetists	Short	5	12	Lay comment - 'How much information they would like about their prognosis'. Our lay respondents strongly support this approach. Many dying people do not want to know all the information/details.	Thank you for your comment.
The Royal College of Anaesthetists	Short	6	13-14	Lay comment – Our lay respondents support this proposal; many close relatives wish to spare their dying loved ones all the details about their prognosis, even though this may cause problems with next of kin.	Thank you for your comment. This recommendation has now been removed although discussion on this issue remains in the Linking evidence to recommendations section of chapter 6.
The	Short	7	1-2	Lay comment - "any cultural, religious, social or	Thank you for your comment.

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Royal College of Anaesthetists				spiritual preferences that should be considered." Our lay respondents believe that this is absolutely crucial and vital; often the preferences between dying patient and relative will be different.	
The Royal College of Anaesthetists	Full	138	Blue box	Clinical comment - In the sentence 'adverse events both procedural and from positive fluid balance' should the bracketed comment read pulmonary oedema rather than 'pleural effusions'?	Thank you for your comment. This has been amended.
The Royal College of Anaesthetists	Short	8	24-25	Lay comment - 'Encourage people important to the dying person to help with mouth care or giving drinks." Our lay respondents agree with this proposal.	Thank you for your comment
The Royal College of Anaesthetists	Short	9	13-14 10-11	Lay comment - "Death is unlikely to be hastened by not having clinically assisted hydration." Our lay members believe that the general public probably do not realise the importance of this and may need to be put in writing. Clinical comment - Our clinical members also support the provision of hydration as palliation of an unpleasant and distressing symptom.	Thank you for your comment. The Committee have amended the wording of the recommendation to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given. The order of the recommendations reflects the Committee's decision that the dying person should

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					be supported to drink by oral means first if they wish and are able to before clinically assisted hydration is considered. The decision to consider a trial of clinically assisted hydration should be based on an individualised approach taking into account benefits and harms.
The Royal College of Anaesthetists	Full	General	Delirium	Clinical comment - Other points of contact for assistance in the management of delirium in addition to palliative care teams would be intensive care doctors and nursing staff. Considerable progress has occurred in this area for the management of delirious patients in an ITU setting which would be transferable to the care of dying patients.	Thank you for your comment. The Committee are aware that many specialties may have additional valuable input, but we are unable to be so prescriptive in this non-specialist guidance.
The Royal College of Anaesthetists	Short	10	21-23	Lay comment - "Stop any previously prescribed medicines that are not providing symptomatic benefit or may cause harm." Our lay members strongly support this proposal.	Thank you for your comment.
The Royal College of Anaesthetists	Short	11	17-18	Lay comment - 'Consider using a syringe pump.' Our lay members think that this is an excellent proposal.	Thank you for your comment.
The Royal College	Short	11	6	Lay comment - "Any other medicine being taken to manage symptoms." A written record should be kept of all medicines a patient is on. Doing it orally during	Thank you for your comment. We believe that written documentation would always be common clinical practice in this area.

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of Anaesthetists				the last few days of life could be a problem.	
The Royal College of Anaesthetists	Short	12	1-2	Lay comment - 'Seek specialist palliative care advice'. Our lay members have commented that, although this may seem an appropriate and humane course of action, it may in the end lead to prolonged suffering.	Thank you for your comment. After careful consideration the Committee feel that no change is required. The group felt that in some cases specialist help is required and may provide important symptom management if appropriate.
The Royal College of Anaesthetists	Short	14	18-19	Lay comment - 'Seek specialist advice if the diagnosis of agitation or delirium is uncertain." Is this practical? Can this be realistically done in the last few days of life?	Thank you for your comment. We believe that this should be implemented wherever possible even in the last days of life, particularly to support appropriate pharmacological management
The Royal College of Anaesthetists	Short	16	12-13	Lay comment - 'Use an individualised approach.' Our lay members agree with the principles behind this proposal, but are sceptical about whether it can be implemented in the current climate of NHS cuts.	Thank you for your comment the content of which is noted. We would hope that end of life care providers take these recommendations into account as soon as our guideline publishes.
The Royal College of Anaesthetists	Short	General	General	Clinical comment - Our clinical members feel that there is too much focus on possible adverse effects of palliation – for example pulmonary oedema. Such conditions should be recognised as an inevitable consequence of dying and not avoidable problems to be identified and treated.	Thank you for your comment. Pulmonary oedema is described as an example only. Further clinical situations are discussed in the 'Linking evidence to recommendations' sections of all relevant chapters of the full guideline

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The Royal College of Anaesthetists	Full	General	General	Clinical comment – the document is well written. The tables for prescription of medications in the dying adult will be particularly useful to non-palliative care specialist doctors on wards and in intensive care unit settings.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
The Royal College of Psychiatrists	Full	31		When discussing adverse effects of antipsychotics, 'extrapyramidal side effects' are mentioned, but not explained. This should be expanded in more detail, especially since (for example) Dystonia can be an extremely unpleasant side effect and common in those neuroleptically naive.	Thank you for your comment. This refers to the overarching outcome the Committee were keen to identify. We found no evidence of adverse effects of treatment linked to extrapyramidal side effects. This is further discussed in the relevant 'Linking evidence to recommendations' section 9.17 and reference has been made to dystonia.
The Royal College of Psychiatrists	Full	16		Point 45 specifies to 'Treat any reversible causes of agitation, anxiety or delirium, for example, fear and psychological causes, or certain metabolic disorders' – although we are in agreement regarding the treatment of psychological and organic causes, the word 'fear' included at this point strikes us as inappropriate. Fear of death for many is a natural reaction with the person requiring degrees of social, spiritual and family support. However to include it in this sentence with a requirement for 'treatment' feels	Thank you for your comment. After careful consideration this recommendation has been amended and "fear" has been removed as an example. Further detail on dystonia has been added to the 'Linking evidence to recommendations' section of the full guideline.

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				incorrect and overtly biological. An alternative phrasing might be: 'Assess for and manage any reversible causes of agitation, anxiety or delirium, for example, fear and psychological causes, or certain metabolic disorders.' P31, when discussing adverse effects of antipsychotics the phrase extrapyramidal side effects is mentioned, but I don't believe is explained. I feel this could be expanded in more detail especially since (for example) Dystonia can be an extremely unpleasant side effect and common in those neuroleptically naive.	
The Royal College of Psychiatrists	Full	general	general	The draft NICE guideline on Care of the Dying adult should be congratulated for its considered, person centred and accessible recommendations. Comments have only been made on specific areas relevant to the expertise of liaison psychiatry but the theme throughout of attending to psychological needs as part of a comprehensive approach is very pleasing to see. A focus on delirium, anxiety and agitation is in line with clinical experience of the most common and distressing psychiatric presentations in the final few days of life. It is disappointing that evidence base for	Thank you for your comment. Thank you for your comments on the prescribing tables. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website

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				interventions in these domains remains so poor but this is a difficult area in which to conduct research and the proposed study to generate evidence on management of delirium is to be welcomed. In the main, the faculty would support the recommendations of the guideline however would like to offer a few points for consideration. The recommended doses of haloperidol and olanzapine for delirium and agitation are quite high. In practice with older people with delirium, clinical experience would suggest that haloperidol 0.5mg BD or olanzapine 2.5mg bd would usually be sufficient as a starting regular dose with availability of PRN doses that can then used to titrate to effect. The starting doses quoted may result in sedation or extrapyramidal side effects in elderly, frail patients especially if they are neuroleptic naive. The risperidone doses are more in line with usual clinical practice for management of delirium. If the doses quoted are to be taken forward we would suggest that there is a recommendation to start at the minimum doses in the range and even further caution be applied in elderly patients. Abrupt discontinuation of serotonergic antidepressants can precipitate anxiety and agitation (sometimes to a severe degree) and this can	

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				sometimes occur when patients are no longer able to take oral medications and tablets are stopped. We would suggest that this issue is mentioned specifically as it is not uncommon for patients to be prescribed SSRIs toward the end of life and when and how to stop them is not an infrequent area of clinical uncertainty. Management in this scenario would be to consider substituting with an SSRI in liquid form e.g. fluoxetine and treat anxiety/agitation with a benzodiazepine as per the guidelines.	
The Royal College of Radiologists	Full/Short	General	General	The Royal College of Radiologists (RCR) welcomes the publication of this guideline. The Full guideline is extremely detailed and the RCR feels that, for most practitioners, this will probably be used as a reference document, with the Short version used on a day-to-day basis.	Thank you for your comment and for participating in the consultation process. In addition to the versions you mention, a further version for patients is available. It is the developer's hope that by presenting several versions of this guideline, users are able to access its recommendations in a format that's useful and informative.
The Royal College of Radiologists	Short	Pages 19-23		Recommendations for Research - the RCR fully supports the proposed areas for research. In particular item 1, "Recognising Dying", is an area where further research is needed. Increasingly frequently, interventions aimed at avoiding death, some of which are futile, can obstruct the process of recognising that the patient is entering the last few days of life.	Thank you for your comment and for participating in the consultation process.

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The Royal College of Radiologists	Short	General	General	The draft guideline does not address the issue of recognising the dying process in the context of futile attempts at antibiotic therapy for overwhelming infections and other final therapeutic interventions. The RCR feels it is important to recognise when these interventions will almost certainly prove futile.	Thank you for your comment. We are unable to provide a specific response as this issue is outside the scope of the guideline and therefore was not subject to any focussed evidence review.
The Royal College of Radiologists	Short	Page 3-4	Section1	This section describes the factors which should be taken into account when establishing that a patient is entering the last few days of life. Although this section lists these factors, the guideline does not really state how these factors impact on decision making and the decision will probably rely on clinical experience.	Thank you for your comment. The list describes examples that may suggest the person is entering the last days of life, which should be used in conjunction with the other recommendations on information gathering. The start of the section states that 'The recommendations supplement the individual clinical judgment that is required when making decisions about the certainty of prognosis and how to manage uncertainty'
The Royal College of Radiologists	Short	Page 4		The RCR feels that Cheyne-Stokes Breathing is not adequately defined.	Thank you for your comment. Cheyne-Stokes Breathing is defined in the glossary of the full version of the guideline.
The Royal College of Radiologists	Short	General	General	The RCR notes that the draft guideline does not deal with the very difficult issue of communicating with patients and families the issue of "DO NOT ATTEMPT CARDIO-PULMONARY RESUSCITATION (CPR)". These decisions have been made more difficult by recent legal decisions,	Thank you for your comment. We recognise that CPR and DNAR decisions are an important area in care of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas are more likely to have a wider impact on clinical practice. DNAR

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				compounded by widespread misunderstanding of the principles of CPR portrayed in the media.	discussions will not be included in this guideline.
The Royal College of Radiologists	Short	Page 5	1.2.2	In relation to discussing prognosis, the RCR suggest it would probably be best to sensitively establish what level of detail is required. This is related to item 1.3.1.	Thank you for your comment. How much information they would like about their prognosis is covered in rec 1.2.1 in the communication section.
The Royal College of Radiologists	Short	Pages 8-10	Section 1.4	The RCR feels this is a very important area and was one of the perceived weaknesses of the Liverpool Care Pathway. We suggest that these issues are related to the palliative needs of the patient. It is difficult to understand why good mouth care would not be a routine component of nursing care for any patient.	Thank you for your comment. We agree that good mouth care is an important part of care for any patient as required.
The University of Essex	Full	General	General	We propose changing the wording of the draft and summary whenever possible in order to facilitate provision for joined-up care at the end of life, as recommended by: • the Leadership Alliance for the Care of Dying People ('One Chance to Get it Right', p.42, p.75) • The Department of Health ('NHS Mandate' 2014-15, p.3) • The Parliamentary and Health Service Ombudsman ('Dying Without Dignity' p.24). We have identified below the most appropriate	Thank you for your comment. We will deal with each of your comments in turn. We believe we have encompassed a joined up approach to care in the last days of life within the context of our remit to provide evidence based guidance on the clinical care of the dying adult.

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				places to make the changes, proposed a number of actions and added a brief rationale after each proposed action.	
The University of Essex	Full	11	10-11	Action: Replace sentence with: 'If it is thought that a person may be entering the last days of life, where information is not contained within the Advance Care Plan, gather information on: (etc)'. Rationale: In its current form, the draft suggests that healthcare professionals need only gather information on 'the person's medical history and the clinical context, including underlying diagnoses; the person's goals and wishes; and the views of those important to the person with respect to future care', when it has been identified that the person may be entering the last days of life. Yet this information may already have been gathered as part of the Advance Care Plan. The proposed action is meant to ensure that healthcare practitioners refer to the Advance Care Plan, where such a plan exists.	Thank you for your comment. The Advance Care Plan is covered under recommendation 14. This first recommendation is about gathering all current information to assess whether the person is dying.
The University of Essex	Full	11	39 - 40	Action: Include a third option: 'remaining stable or stabilising'. Rationale: Healthcare professionals are asked to determine whether the person is 'nearing death' or 'recovering'. This leaves out the possibility that the person's condition has remained stable. This further	Thank you for your comment. The Committee discussed the bullet points in the recommendation and decided to amend these to state: nearing death, deteriorating, stable or improving.

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				possibility is included in 1.1.4 line 4. Consistency would be improved by including the third option, as proposed.	
The University of Essex	Full	12	13-14	Action: Replace sentence with: 'With reference to the Advance Care plan, if one exists, establish the communication needs and expectations of people who may be entering the last days of life, taking into account:'. Rationale: same as for comment 2.	Thank you for your comment. We are content with the wording as we have drafted it.
The University of Essex	Full	12	21-28	Action: Having implemented the action proposed in comment 5, switch the ordering between 1.1.7 and 1.1.8. Rationale: This will encourage healthcare professionals to identify the lead coordinator prior to discussion of the prognosis with the patient. This will help ensure that patients and those important to them know who to turn to from the very beginning of end of life care, such that service users experience joined-up communication	Thank you for your comment. The recommendations in the full guideline reflect the order in which the evidence has been reviewed. Recommendation 5 has been developed as part of the recognising dying review and recommendations 7 and 8 are from the review on communication. In this version of the guideline it is not possible to separate them but the NICE version of the guideline provides an appropriate distinction which facilitates their reading in practice.
The University of Essex	Full	12	25-26	Action: Add the further requirement that healthcare professionals should identify a **lead communicator**. This person will be in charge of coordinating the relevant information and communicating it (when appropriate) to patients and/or those important to them. Proposed rewording: 'Identify the most appropriate available multiprofessional team	Thank you for your comment. After careful consideration, the committee did not wish to make changes to their recommendation in the area you suggest. The committee did not feel that any evidence to support the identification of a lead clinician had emerged from their review.

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				member to coordinate information relevant to the dying person's prognosis and to explain that prognosis based on the professional's: …' Rationale: This will promote joined-up care by ensuring that both patients and those important to them have a clearly identified 'go-to' person. It will alleviate the anxiety of service users, who often find it difficult to gather the information they need when time is short and stress is high (cf. 'Dying Without Dignity' p.14).	
The University of Essex	Full	12	35-36	Action: add a clause to end of bullet point at line 36: 'and information regarding how to contact the lead coordinator and other members of the multiprofessional team'. Rationale: Same as comment 5	Thank you for your comment. After careful consideration, the committee have not made the change you have suggested.
The University of Essex	Full	13	18-20	Action: Add a further clause: 'Unless the lead communicator is not in a position to do so,' to the beginning of line 18. Rationale: Joined-up care would be best served if the lead healthcare professional was also the lead communicator, as per Action 5. above. We recognise that this may not always be possible, or even advisable (for example if the lead communicator does not have the relevant medical expertise). Still, the addition of the clause is meant to draw attention to the ideal configuration so that it is	Thank you for your comment. After careful consideration, the committee have chosen not to make the amendment that you have suggested. The committee did not feel that any evidence to support the identification of a lead clinician had emerged from their review.

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				put into practice whenever possible.	
The University of Essex	Full	13	30	Action: Add 'with reference to the Advance Care Plan, if one exists.' to the end of the sentence that concludes on line 30 (full draft)/ line 19 (summary). Rationale: same as for comments 2 and 5.	Thank you for your comment. After careful consideration, the committee did not wish to amend the recommendation along the lines you have suggested. We believe given recommendation 10, any available Advance Care Plan would be considered automatically.
Together for Short Lives	Short	General	General	The needs of young adults at the end of their lives are different from older adults - and also from children. There is a wide range of conditions, from which young adults die and their condition often fluctuates. As they reach adulthood, young people will also have varying developmental needs. While some young adults may wish and be able to have more autonomy and express choice over their care, others may have profound cognitive impairment so decisions will need to be made in the context of their family unit. The clinical guideline should emphasise the need for age-appropriate end of life care to be provided to this unique group, in age-appropriate settings. Both of these groups will include young adults who will have lived with life-limiting conditions as children and young people - and in some instances from birth. They will have undergone transition from children's to adult's palliative care services. This group of young adults in growing in number due to	Thank you for your comment. We acknowledge the importance of the issues you raise. We have added some text to the introduction of the full guideline and contextual information in the NICE guideline to reflect the need for age-appropriate end of life care to be provided to young adults in age-appropriate settings. We would draw your attention also to the NICE guideline currently in development on End of life care for infants, children and young people which can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0730

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				improved medical treatments, information and support (Fraser LFK et al 2013, Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010). Adulthood is often the time when young people with life-limiting conditions (for example, Duchenne Muscular Dystrophy) experience a deterioration in their condition. This means that they are more likely to need end of life care once they have started to use adult services.	
Together for Short Lives	Full	28	6	This section should include the upcoming NICE guidance 'Transition from children's to adult services'. This is expected to be published in February 2016.	Thank you for your comment. The guideline has been amended accordingly.
Together for Short Lives	Short	3	5	We are concerned that although the recommendation acknowledges that 'it is often difficult to be certain about whether a person is dying', there is no reference to the additional challenges faced when anticipating when young adults are entering their end of life phase - particularly when they are living with a life-threatening or life-limiting condition and/or are cognitively impaired. Young people have a range of conditions with unpredictable trajectories, which may mean they have repeated 'end of life' episodes, any of which could be the final one. Palliative care	Thank you for your comment. We acknowledge the importance of this issue. Additionally guidance is currently being produced by the National Collaborating Centre for Women and Children's health. This work is entitled: End of life care for infants, children and young people and covers the populations you mention in your comment. Further details can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0730. The scope of this guideline acknowledges transition of care to adults children as part of Children's palliative care.

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				services also have relatively little experience of caring for such individuals. The guideline should recognise these factors.	
Together for Short Lives	Short	5	17	We call for the guideline to emphasise the need for clear communication between children's and adults' services if a young person enters the end of life stage while in transition from children's to adults' services.	Thank you for your comment. We acknowledge the importance of this issue. Service Delivery, including transition from children to adult services, is outside the remit of the guideline. NICE is in the process of developing guidance entitled: Transition from children's to adult services, with an anticipated publication date of February 2016. NICE is also currently developing guidance on palliative care service delivery and this topic may be included in that guidance. More details can be found at the following link: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
Together for Short Lives	Short	9	15	This recommendation should acknowledge that some young adults will want their parents or guardians to be involved in decisions about withholding or withdrawing hydration. We ask that the Royal College of Paediatric and Child Health's document 'Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice' is used to inform the guideline.	Thank you for your comment. Please also see the section on shared decision making and communication and the NICE guideline for further recommendations about involving loved ones in making decisions. There is also NICE guidance in development on end of life care for infants, children and young people, anticipated publication date: December 2016: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0730. We believe the document to which you refer may be best referenced in this guideline.

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Together for Short Lives	Short	10	24	This recommendation should address the fact that some adults will lack mental capacity to make decisions about their end of life care. In such cases, their family may be involved in making such decisions. This should be addressed in any subsequent recommendations which are not covered in this clinical guideline. The extent to which young adults are regarded as having capacity to make decisions about their care should take into account the importance of the issue in question. The capacity needed by an individual to decide whether to refuse food and drink, for example, is different to that required to decide which clothes to wear.	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area which apply to all adults 18 years and older and covers the clinical care in the last days of life. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
Torbay & Southern Devon Health & Care	Short	7	4	Concerns about what/who determines the "lead healthcare professional" i.e. would it be a Consultant, GP, Specialist Nurse, Nurse, AHP? There is a danger that nobody takes the lead and no-one is identified.	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. The Committee recognises that there may be challenges

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Trust				Examples of who this could be would good. Please note if this is determined to be a Consultant this would not be manageable in the community setting.	to its implementation, but that is an aspirational recommendation.
Torbay & Southern Devon Health & Care Trust	Short	9 10	1-29 1-13	There is quite an emphasis on clinically assisted hydration this could prove difficult if persons are being cared for at home. From experience it would depend on the quality of the conversation about the risks and benefits especially line 26 this may not be achievable in the community setting.	Thank you for your comment. The Committee intends this recommendation to apply to all settings and are aware that clinically assisted hydration may take place in the community, but note that there may be challenges to its implementation. We feel our recommendations are sufficiently balanced to indicate that there is no direct suggestion to initiate clinically assisted hydration but rather consideration of individualized needs.
Torbay & Southern Devon Health & Care Trust	Short	10 11 27-33	18 23 Tables	Appendix A refers to prescribing advice for non-specialist prescribers. This is quite prescriptive. There are differences in areas re first line drugs to use for various symptoms. A lot of the prescribing advice does not correspond with our local guidance (Torbay & Southern Devon). An example of this is table 1 suggests Morphine Sulphate and we would use Diamorphine as our first line drug choice. Could the advice state to refer to your local guidance or formulary.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Trevor Rimmer	Full	23	8-21	This paragraph gives the impression in parts – like the media campaign – that the majority of patients may have experienced such problems. It runs the risk of being quoted back selectively by a hostile press.	Non-registered stakeholder. No response needed.

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Trevor Rimmer	Full	general	general	It is vitally important that good and meticulous care of the dying patient is seen as part of clinical practice. It should in most cases be within experienced clinician's range of competencies. The importance of readily available specialist help must be stressed, but not to the degree that non-palliative specialists (an inelegant but understandable term) feel that only palliative clinicians can do this. I am in awe of the task undertaken here, and greatly impressed. Few of my comments are of great critical import. Some seem petty and pedantic – but it is important that this is actually read and understood., Long and complex prose glides over the eyes, especially in a long document. I am a simple soul, and ambiguities and complexity confuse me. I like to think I am not alone. I think the tone is on the whole well balanced. I have been painfully aware that there is, from some quarters of the press and certain interest groups, zealous criticism of some aspects of palliative care. The balance in this document is important, but I feel one should be wary of fuelling excessive anxieties from this group. I shall not comment on chapter 4, especially 4.2. I know that it is required, but the statistical section is not for the non-illuminated.	Non-registered stakeholder. No response needed.
Trevor Rimmer	Full	24	11	The abbreviation GDG has not been defined at this point. Needs "Guideline Development Group" added here.	Non-registered stakeholder. No response required.

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Trevor Rimmer	Full	20	42-48	The sentences here are long and hard to read. The concepts are important. I suggest removing the conjunctions – here "and" – and replacing 2 sentences of 30 and 34 words respectively with 4 sentences. For example: "Many of the drugs used to ease delirium are classed as sedatives. It can be difficult for inexperienced clinicians to reduce the manifestations of delirium without causing undue sedation. An excessively large dose of sedative medication may compromise respiration. A perceived risk of over-sedation is that the dying person's life may be shortened because of the sedation itself."	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	20	44-6	The lines "It is self-evident that an inappropriate large dose of sedative medication can compromise respiration…" seems excessive (should have been "inappropriately" btw) and self-repetitive. The same sense, if less dramatic, can be made with "An excessively large dose of sedative medication may compromise respiration…"	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	21	15-34	This is an important question. I think distinctions are needed. The term "respiratory secretions" is inexact and partly inaccurate, as many (most?) cases are due to saliva, a digestive secretion, not being swallowed; others due to bronchial secretions inadequately coughed up from large airways. The problem is, of course, insufficient clearing of secretions from the	Non-registered stakeholder. No response needed.

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				pharynx, causing moist noisy breathing as air passes through them. Distinguishing (if possible) the two may mean that there may be different and better approaches. The ethical issue is quite precise. It is important that moist noisy breathing in the patient who has awareness is assessed differently form that in the unaware comatose patient. In the latter case, a treatment that may not help the individual patient, but may ease distress in those close to them whilst causing no discomfort to the patient may be regards as being to the greater good. I have seen many instances, I fear – but fewer in my DGH since repeated individual education of senior nurses and junior doctors – where antimuscarinics have been used in conscious patients with noisy breathing, to their subsequent discomfort. Thus I certainly support this area of research.	
Trevor Rimmer	Full	23	13	Should not really read "…increasingly loud opposition from the media, professions and the public." ? I am uncertain whether "loud" is an appropriate adjective here. "Increasing opposition" suffices.	Non-registered stakeholder. No response needed.
Trevor Rimmer	Full	23	30-35	This is a positive paragraph. I wonder if (with appropriate changes) it would be better as the second paragraph, as it "sets out the stall" on a positive change this evidence based guideline is making, before discussing the history behind it.	Non-registered stakeholder. No response required.

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Trevor Rimmer	Full	249	Glossary - Pain	This definition is vague – looks more Oxford English Dictionary than medical. Pain may not be highly unpleasant; this definition would also cover other symptoms, such as severe vertigo, nausea or delirium. May I suggest the International Association for the Study of Pain definition: "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage."	Non-registered stakeholder. No response required
Trevor Rimmer	Full	25	35	What is "NHSE". Undefined in document.	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	35	15	I wondered what "ormarkers" were. Then the penny dropped. (It had been a long week)	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	38	11	What dose "worse than chance" mean? Does it mean that results in this category would actually be less accurate than chance, or no better? The phrase as used implies the former – but does not leave a "no better than chance" category.	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	11	19 - 35	Q1: There does not appear to be a logical sequence to this otherwise useful list. Reduction in mobility and social withdrawal would precede deterioration in loss of consciousness and Cheyne-Stokes respiration. Not of course an inevitable step by step progression, but an attempt to place in some sort of progressive order would help learning and recognition.	Non-registered stakeholder. No response required
Trevor Rimmer	Full	11	22	Imprecise. Progressive or advanced derangements of renal function tests and/or liver tests are more	Non-registered stakeholder. No response required.

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				typical guides. Radiology rarely so for last few days of life.	
Trevor Rimmer	Full	11	27-28	Use of ECOG is restrictive, not used by all, especially outside oncology world. More would use WHO (almost the same!) or Karnofsky, I feel. Other measures of performance status are available. Verbal descriptor better. E.g. "Decreasing ability to perform activities of daily living, especially if unable to care for self, confined to bed or chair (ECOG/WHO Performance Status 4; Karnofsky 20 or 10)"	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	11	38	Suggest adding "… may be" to end of line. It allows for uncertainty at this time and emphasizes monitoring	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	54	6-7	No reference here made to prognostic tools. Sentence implies that they are around and disregarded. I am not aware of a useful tool indicating that a patient is near the end of life other than the descriptive list elsewhere in this document – e.g. table 12.	Non-registered stakeholder. **No response required**
Trevor Rimmer	Full	55	Table 12	First appearance of "PICO2 since p 29v8. It may help the reader to define it once more in the first table.	Non-registered stakeholder. No response required
Trevor Rimmer	Full	58	Table 14 etc.)	The descriptor for the figures is written "(median/ range/ 95% CI)". Pedantic point – this is not quite right. There are two sets here, but 3 descriptors. (I double checked back in the text to check that this	Non-registered stakeholder. No response required

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				was the 95% confidence interval, and not for example the interquartile range). I suggest the heading should be something like "Median (range – 95% CI)" to clarify and match the pattern of the figures.	
Trevor Rimmer	Full	63-65	Table 6, Population column	The size of the sample is inconsistently placed. Small point.	Non-registered stakeholder. No response required
Trevor Rimmer	Full	64	Table, top row, 3rd column	Headed "Population" – I assume that this should read "n=18, nursing staff … etc"	Non-Registered Stakeholder. No response required
Trevor Rimmer	Full	79	7-28	A common criticism of palliative medicine has been the intense focus on cancer. There are historical reasons for this, not relevant here of course. However, using the ECOG as the first clinical item without some preamble runs the risk of this criticism being repeated. The focus of this guideline is Dying, rather than dying from cancer. If there is a paucity of evidence in other settings/diagnostic groups then this may need pointing out at the start of this section. If ECOG is to be recommended elsewhere, as it is, then an explanation of why it can be extrapolated is needed at some earlier point, or reference made to	Non-registered stakeholder. No response required

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				WHO scale etc. This is of course done later on pp83-84.	
Trevor Rimmer	Full	86	Section 6	It may be out with the scope of this guideline, but the quality of communication before the last days of life would be expected to have an effect on the quality of communication in the dying period. This may be better posed in the research question section and/or under advance care planning.	Non-registered stakeholder. No response needed.
Trevor Rimmer	Full	14	41	Recovery from dying is not possible, by definition. I suspect that the words "from dying" do not belong. Does this mean whether a degree of recovery or improvement is possible?	Non registered stakeholder. No response required.
Trevor Rimmer	Full	146-147	Table 40 last 4 rows	The comments in the last column refer to ascites rather than the biochemical items being discussed.	Non registered stakeholder. No response required.
Trevor Rimmer	Full	154	8.6 Other considerations	IN many areas, artificial hydration, including subcutaneous hydration, is not available in the community. This may be a barrier to a desired discharge.	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	15	18-21	Ambiguous meaning, needs change in punctuation. I suggest a colon after "times" - "…used at other times: for example, matching the…"	Non-registered Stakeholder. No response required.
Trevor Rimmer	Full	15	22-25	Ambiguous punctuation again, makes it harder to read. Again I suggest a colon before "for example". There is an unnecessary comma after disabilities.	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	15	30-31	Consider switching the two sentences around. I would be tempted to state rather that oxygen is	Thank you for your comment. We have carefully considered the recommendation and feel that no

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				unlikely to help other causes of breathlessness (than hypoxaemia). Some agitated patents close to death have difficulty tolerating oxygen masks/cannulae. Adding a codicil thus "Only offer oxygen therapy to people known or clinically suspected to have hypoxaemia, *continuing if they feel benefit and can tolerate the mask/nasal cannulae".* A thought.	change is required.
Trevor Rimmer	Full	16	17-21	There is a didactic slant to use of hyoscine first and octreotide second. This is hard to back up with strong evidence – more opinion than evidence based I guess, and to some degree cost based. Many would argue with this, including myself, especially in patients with short prognosis. Octreotide probably provides a more rapid response in reducing volumes of vomit.	**Non-registered stakeholder. No response required.**
Trevor Rimmer	Full	16	22-25	A bit difficult to read. Punctuation thus may help, e.g: "Be aware that agitation in isolation is sometimes associated with other unrelieved symptoms or bodily needs: for example, unrelieved pain or a full bladder"	Thank you for your comment. After careful consideration the Committee felt that no change was needed.
Trevor Rimmer	Full	16	33-37	76. Respiratory secretions are not noisy. Breathing through retained secretions is. Saliva is NOT a respiratory secretion, but reduction in salivary flow is probably more successful than reducing the volume and increasing viscosity of bronchial secretions. I support the emphasis on explanation and	**Non-Registered Stakeholder.** **No Response required.**

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				non-pharmacological measures before reaching for the anti-muscarinics.	
Trevor Rimmer	Full	17	8-11	I personally would list the drugs that are less likely to cause delirium listed first – that is glycopyrronium and hyoscine butylbromide. I believe these to be the most widely used.	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	174	Other considerations	1st paragraph, last but one sentence. I suggest the use of the term "muzzle area" rather than "snout area", - the latter sounds potentially offensive in comparison. I guess "nose, cheeks and mouth" is longer but even less potentially offensive.	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	184	1st paragraph	I was surprised to see the suggestion of the use of NG tube without the balancing comment that many find this intolerably uncomfortable at the end of life. Discomfort of procedures is not well studied. The only one I know of is *Pain and discomfort associated with common hospital procedures and experiences. Morrison RS, Ahronheim JC, Morrison GR, Darling E, Baskin SA, Morris J, Choi C, Meier D. Journal of Pain and Symptom Management 1998; 15 (2): 91-101* In this study patients rated pain and discomfort of 10 commonest procedures. NG tube was the second most painful and most uncomfortable, including mechanical ventilation. Study not subject to your level of scrutiny	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	238	Table 80	Cost of inpatient specialist palliative care – is this per episode or per day?	Non-registered stakeholder. No response required.
Trevor Rimmer	Full	220	Table 4	SC recommendations re clonazepam. The injectable form is no longer in the BNF, and is difficult to	Thank you for your comment on the prescribing tables. Because of the recognised importance of

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				acquire. This will affect its use by non-specialists.	supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
Trust Development Opportunity	Full	general	general	There is no mention within the guideline of repositioning for comfort or the management of SCALE.	Thank you for your comment. Non-pharmacological management of symptoms was not addressed within the guideline. The Committee acknowledge the importance of such approaches and have made a number of consensus recommendations in the absence of an evidence review to reflect their importance. Further detail can be found in the 'Linking evidence to recommendations' sections in Chapter 9 of the full guideline.
Trust Development Opportunity	Full	11	7	We are concerned as to why patients likely to die following major trauma or attempted suicide would not have their wishes respected or receive the same standard of EOLC as other patients.	Thank you for your comment. This has been amended, as the guideline does apply to people in the populations you mention.
Trust Development Opportunity	Full	general	general	There is a missed opportunity to recommend a standard care plan to document EOLC plans and to evaluate care.	Thank you for your comment. The guideline has not been able to address all issues relevant to the care of the dying adult. This issue is beyond the remit and scope of this guideline.

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Trust Development Opportunity	Full	11	19-35	We are concerned that this list does not specifically include assessment of deteriorating vital signs against a planned ceiling of treatment as a clear indicator of a patient entering the final phase of life	Thank you for your comment. After careful consideration the Committee have rewritten this recommendation and separated out the list into signs, symptoms and functional observations to provide clarity. This recommendation provides examples only and it is noted that clinical judgement is required when making decisions about the certainty of prognosis. Further detail around ceilings of treatment has been added to the 'Linking evidence to recommendations' section of the full guideline.
Trust Development Opportunity	Full (or short)	108	1	"Taking into account: Their cognitive status and if they have any specific speech, language or other communication needs" is about all that's said on communication. While these are predominantly clinical guidelines, it doesn't feel that this is sufficiently detailed with regard to such an important area. Perhaps stating the obvious, but there is no reference to the use of translators for those for whom English is not a first language, or recognising the sometimes unique communication needs of those, for example, with dementia or learning disabilities.	Thank you for your comment. We have provided a cross reference to the NICE guideline on patient experience in adult NHS services where recommendations already exist to support the issues you raise.
Trust Development Opportuni	Full (or short)	26	37	a) Again, this is predominantly guidance on clinical best practice. But perhaps cultural needs should be listed amongst areas not covered by the study. Culture and faith gets	a) Thank you for your comment. We are unable to provide specific detail within the context of this guideline but make reference to the importance of considering cultural and faith perspectives in

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ty				a cursory acknowledgement at best (e.g. with regard to hydration) and the guidance doesn't tell staff of the cultural nuances to be respected when caring for the dying. b) Perhaps it could reference a resource such as http://lmrpcc.org.au/admin/wp-content/uploads/2011/07/Customs-Beliefs-Death-Dying.pdf?	various recommendations in the guideline beyond the hydration recommendation. b) Thank you for your suggestion, this resource may be if use to the implementation team at NICE and we will make them aware of this resource.
Trust Development Opportunity	Short	Overall	Overall	The word "capacity" does not appear once in the document. Although communication and shared decision making is covered in the full guidance, it feels somewhat of an oversight to exclude such an important topic from the short version. Similarly, there is no mention of the role of an Independent Mental Capacity Advocate (IMCA).	Thank you for your comment. The committee agrees that mental capacity at end of life is an important issue when considering the ability to communicate and participate in decision-making. Further discussion is already provided in the 'Linking evidence to recommendations' section of the relevant chapters in the full guideline on these issues and we have made further additions to the guideline to provide clarity and to direct professionals to additional guidance in this area. Additionally, the social care team at NICE is currently developing a guideline entitled: Supporting decision making for people with limited mental capacity, details on this guideline are available at: www.nice.org.uk/guidance/indevelopment/gid-ng10009.
University Hospital Birmingh	Full	14	22	This might seem a small point to health care professionals but relatives will sometimes also ask about eating and nutrition in patients thought to be	Thank you for your comment. Nutrition is beyond the remit and scope of this guideline.

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am				dying. I think the issue of drinking and clinical hydration is covered well in this guidance but nutritional guidance is absent (unless I have missed it) . In addition sometimes patients who are already receiving clinical nutrition and are thought to be dying need this to be addressed if it is causing symptom burden. If the 'diagnosis' of dying means that clinical nutrition would be contrary to their expressed wishes not to have treatment that may not be of benefit to them then this also needs to be addressed and may be a reason to withdraw this treatment The LCP review also commented on this aspect of care of the dying and so I am surprised it is not covered in this new guidance.	
University Hospitals Leicester	Full	11	general	Please define 'last days'. In places this is referred to as last 2-3 days, in others as the last 14 days	Thank you for your comment. The clinical focus is the care provided in the last two to three days of life. Section 4.2.4.1 defines the guideline population in this way. When considering the evidence, the Committee also agreed a number of parameters to guide the protocols developed and therefore the types of studies included and the data retrieved. For example, studies that captured data within 14 days of death would be considered directly applicable. Recognizing that prognosis may be uncertain at the end of life , the Committee felt that it would be appropriate to consider evidence up to 30 days as indirect evidence .

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University Hospitals Leicester	Full	20	42-48	We are concerned that the statement made here will lead to increased anxiety amongst clinicians about using sedative medication and avoidance of this, resulting in undertreatment of agitation.	Thank you for your comment. The text in this section has been amended.
University Hospitals Leicester	Full	20	General	Is this the correct place for this? We felt it should come at the end after Anticipatory prescribing	Thank you for your comment. The order of the research recommendations appear in the order of the relevant chapters.
University Hospitals Leicester	Full	24	16	Young people will still be covered by this guidance as the TYA (teenage and young adult) group is 13-25yrs.	Thank you for your comment. Our scope specifically addresses the care of the dying adult defined as over 18. Many of our recommendations will be of relevance to the care of people younger than this age but we are aware of guidance currently being produced by the National Collaborating Centre for Women and Children's health. This work is entitled: End of life care for infants, children and young people and covers the populations you mention in your comment. Further details can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0730
University Hospitals Leicester	Full	24	9-14	This is contradictory to statements made elsewhere, as here it states that the order is from most to least distressing symptoms or signs. Please remove this statement, or alter the wording	Thank you for your comment. We disagree. This text provides an overall context for the ordering of the chapters as perceived by the Committee. We do not feel change is required.

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University Hospitals Leicester	Full	52	29 - 35	Question: Who did the GDG feel should be leading this research?	Thank you for your comment. This is standard text that reflects the considerations for prioritization for research. Further detail about the research recommendations made by the Committee can be found in Appendix O.
University Hospitals Leicester	Full	General	General	We felt that the inclusion of studies / clinical evidence in the main document was at times distracting, and could be included in an appendix at the end.	Thank you for your comment. We believe it valuable to provide the reader this information as part of the evidence review.
University Hospitals Leicester	Full	General	General	The overarching theme seems to be that the evidence for all areas covered by this guidance was generally of low to very low quality. This is disappointing, particularly when the authors keep advising clinicians to refer to local policies as clinicians are likely to refer to these when reviewing local policy. Was there not a way to develop stronger guidelines despite the poor quality evidence?	Thank you for your comment. NICE clinical guidelines are recommendations, based on the best available evidence, for the care of people by healthcare and other professionals. They are based on the best available research evidence and expert consensus. The Committee have drafted their recommendations in line with guidance provided in the NICE guidelines manual which can be found at the following link: http://www.nice.org.uk/article/pmg20/chapter/1%20Introduction%20and%20overview. The manual states in section 9.3.3 that some recommendations may be made with more certainty than others depending on the evidence. Our recommendations are constructed accordingly.

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University Hospitals Leicester	Full	General	General	We felt the GDG could have linked the guidance better to the Priorities of Care	Thank you for your comment. The Committee considered the policy documents that outline the five priorities of care at all times but drafted their recommendations after due consideration of the evidence. Reference is made throughout the guideline to the current policy documents relevant to this area.
University Hospitals Leicester	Full	80	10	It is not clear what the conceptual framework adds here	Thank you for your comment. We believe that this has the value of graphically demonstrating improvement/recovery and deterioration with an overarching representation of the interacting issues that require attention in both circumstances. Further explanatory text has been added.
University Hospitals Leicester	Full	81	No. 3	Questions: What are the signs that a patient may be recovering?	Thank you for your comment. We have not done a review to look at signs and symptoms for recovery – however introduction to the chapter gives a list of signs of recovery. We have made an additional recommendation to address this issue.
University Hospitals Leicester	Full	83	General	What are the spiritual changes you refer to? Font needs reducing	Thank you for your comment. This is the theme identified by the qualitative review and includes existential changes and the use of symbolic language. We have amended the font
University Hospitals Leicester	Full	General	General	There needs to be better guidance on when to involve specialist palliative care teams, as "early involvement" and "prompt" are too vague. 24/7 access for shared decision making may not be easily accessible for face to face involvement across all	Thank you for your comment. This guideline is for healthcare workers delivering end of life care in the last few days of life, and thus puts into context the 'early involvement' and 'prompt' timeframes referred to in the guideline. The Committee hopes that the

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				settings.	communication and shared decision making recommendations support multidisciplinary teams across all settings, and regardless of capacity to meet face to face or not, to continually share information across the team, consult with experienced team members when needed and seek specialist advice when clinical situations warrants that approach.
University Hospitals Leicester	Full	135	General	Question: (1) How does the GDG substantiate the statement it was "convinced that these recommendations would improve patient care at a reasonable additional cost" if there is no evidence for this? It seems a biased statement. (2) What is the evidence to support interviewing people in the last days of life may provoke unnecessary stress?	Thank you for your comment. (1) The recommendations outlined for this review promote how shared care decision making should be done and advise on how this should be communicated amongst the team. None of the recommendations promote an increase in resource use such as clinician time. The recommendations were made to ensure good practice was being adhered to and therefore it was felt that these recommendations would not lead to a drastic change in current practice therefore having a minimal impact on costs. (2) The recommendations drafted by the Committee encourage healthcare professionals to maintain an individualised approach to the provision of end of life care. Members of the multidisciplinary team are asked to establish the communication needs and expectations of the dying person and the committee believes this will include instances in which the dying person may not wish to be involved in the dying person or informed of their prognosis.

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University Hospitals Leicester	Full	107	16	Question: What are the factors which facilitate or inhibit communication? This is never made clear	Thank you for your comment. A description of the evidence on the factors relating to the dying person that facilitate or inhibit communication is described in section 6.5 of the full guideline.
University Hospitals Leicester	Full	14	12	If patients are unable to sip, they need oral care in addition to lip care – this is not clear here.	Thank you for your comment. We have amended this recommendation to state: Offer frequent care of the mouth and lips to the dying person and ensure that their care plan includes the management of dry mouth if needed.
University Hospitals Leicester	Full	Hydration (137 – 154)	General	This section caused the greatest concern amongst those giving feedback to us. The evidence statements report that there is no clinical difference in clinically assisted hydration (CAH) over placebo on Quality of Life, wellbeing, survival or relief of symptoms. Versus usual care you report there was no clinical benefit over wellbeing or symptom relief and there was no clinical benefit in preventing delirium. Clinicians within our Trust have expressed concern that these recommendations are written in such a way as to suggest CAH should be given, and the statement that CAH may relieve distressing symptoms in the recommendation does not seem to fit with the evidence presented which indicate no clinical benefit. It should be made clearer that death	Thank you for your comment. The Committee have amended the wording of the recommendation to which you refer to state that giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may introduce other problems associated with giving fluids. Also the Committee wanted to highlight the lack of evidence around survival and that it is uncertain whether providing clinically assisted hydration will prolong life or the dying process or hasten death if it is not given. We are aware of the challenges of swallowing problems at this time. The Committee discussed the

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				is unlikely to be hastened by not having CAH, and we suggest it should be rephrased to state that survival is not improved by CAH (as you yourselves say in the evidence on page 151). We felt recommendation 27 could be misleading to the public. In our experience of SALT assessments, unless medical teams make a decision to 'feed at risk', SALT recommend that patients be made 'nil by mouth' (NBM). Therefore education needs to be extended to SALT teams around feeding at the end of life. Throughout the guidance, if there is no evidence supporting an intervention, the GDG seemed unprepared to make a recommendation. However, it states that "the experience of the GDG was that there is benefit in some circumstances" – we did not feel it was appropriate for the GDG to base some recommendations on personal experience, and not others and that this suggested bias. (Pg 151) Pg 152: Where evidence has come from a limited patient group, can it really be extrapolated to all patient populations to make a wide generalisation. Locally it is difficult to provide subcutaneous fluids at home, and this may lead to an increase in patients being admitted at the end of life and having medicalised deaths in a place not of their choice. Was this considered in an economic review? How should daily review occur in the community?	importance of providing oral fluids to maintain hydration. The Committee acknowledged that, even if it was considered at risk, supporting oral hydration because of thirst, at the dying person's request could be considered. In the economic review no studies were found on this topic and some economic considerations were made when making the recommendations; these are reported in the 'Linking evidence to recommendations' section. The order of the recommendations reflects the Committee's decision that the dying person should be supported to drink by oral means first if they wish and are able to before clinically assisted hydration is considered. Further detail is given in the full version of the guideline under 'Linking evidence to recommendations' statement in section 8.6. The Committee intend this recommendation to apply to all settings, including the community. They recognize that there may be challenges currently with local implementation but were aware of many examples where this was already taking place in England. Further detail regarding the health economic perspective on this issue is captured in the Linking evidence to recommendations section of

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					section 8.6 of the full guideline. NICE is currently developing guidance in palliative care service delivery and the issue of resources may be covered by that work. Please note that more detail about the development of this guideline can be found at the following link: http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.
University Hospitals Leicester	Full	176	26	Add "…of this guidance" to the end of the sentence	Thank you for your comment.
University Hospitals Leicester	Full	18	21-23	Please clarify what 'do not improve promptly with treatment' means – there is insufficient guidance throughout the document on what is a reasonable timeframe to monitor symptoms and response to medications before requesting palliative medicine review. The Priorities of Care guidance suggests 24 hours, but there isn't a similar timeframe here	Thank you for your comment. The Committee made this recommendation to highlight the importance of seeking specialist palliative care advice if needed and were unable to be more prescriptive as to triggers of this. The Committee expect healthcare professionals to use their clinical judgement and seek advice when they feel necessary.
University Hospitals Leicester	Full	182	General	Within this section it states that there is increased clinical benefit at using octreotide at day 3 – why then recommend using it after just 24hours if hyoscine butylbromide is not controlling symptoms? As hyoscine butylbromide can require uptitrating over 72hours, is it appropriate to use this 1st line in a patient in the last days of life? The cost benefit of using it 2nd line seems limited if changing at 24hours.	Thank you for your comment. 24 hours was chosen based on the short prognosis in these people and the group did not want symptoms to remain unresolved for a longer time period. The group noted that in their clinical experience octreotide has a lower side effect profile and is faster acting than hyoscine butylbromide and that swopping at 24 hours was appropriate based on clinical judgement.

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University Hospitals Leicester	Full	210	General	Why was 12 hours chosen? It doesn't seem practical for patients being cared for in the community. Particularly when there is an earlier statement saying this symptom doesn't distress patients	Thank you for your comment. The Committee recommend trialling treatment for 12 hours and then switching based on the evidence review that indicated that these drugs may be clinically effective at 12 hours. The group did not want symptoms to remain unresolved for a longer time period as the prognosis in these people is very short. The group note that clinical judgement should be used to support consideration of a longer trial in those in whom death is anticipated outside this time frame.
University Hospitals Leicester	Full	210	General	Patients with difficult secretions and tracheostomies could also be discussed with head and neck CNSs who often have experience in this.	Thank you for your comment. The Committee are aware that many specialties may have additional valuable input, but we are unable to be so prescriptive in this non-specialist guidance.
University Hospitals Leicester	Full	Antic ip pres c	General	Local experience is that generalists need guidance on medications to be prescribed for routine symptoms 'just in case' otherwise this simply doesn't happen. It is helpful to stress the need for communication with patients and relatives about these.	Thank you for your comments. We agree. Because of the recognised importance of supporting non-specialist prescribers in managing symptoms in the last days of life, the prescribing tables for this audience are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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University Hospitals Leicester	Full	Pain	General	It was not felt to be particularly helpful to have no recommendations made about analgesia. We felt that a comment that dose reductions, or an alternative opiate may be required for renal failure.	Thank you for your comment. The Committee were unable to be more specific as evidence was not found to warrant any further detail other than drug class for management of pain. Further detail on opioids for use in renal patients has been given in the 'Linking evidence to recommendations' section.
University Hospitals Leicester	Full	213	Rec 62	There needs to be guidance on WHEN to refer to palliative care – ie. Same day, within 24 hours or longer.	Thank you for your comment. As no review question was conducted in this area we are unable to be more specific, however the Committee expect that clinical judgement will inform when specialist care is needed. The Committee has drafted recommendations that help to ensure that the dying person's care team has access to experienced and specialist support at all times.
University Hospitals Leicester	Full	213	Rec 60	Should syringe pump be referred to as a 'continuous subcutaneous infusion'?	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.

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University Hospitals Leicester	Full	217	General	Locally we use Ketorolac subcutaneously.	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
University Hospitals Leicester	Full	218	General	Clonazepam is not available in parenteral form	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
University Hospitals	Full	218	General	Smaller doses of morphine are usually used for managing breathlessness for opiate naïve patients (eg. 1-2mg orally)	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional

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Leicester					implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.
University of Surrey	Short	3 12 1 3		The guideline itself appears to be an amalgamation of the old LCP, the Actions for End of life Care 2014-2016 report, and the more recent 'One Chance to get it Right' report from the Leadership Alliance for Care of Dying People (2014), with its 5 Priority areas. The NICE guideline is detailed- but in some areas, such as medication advice, a small amount of detail is given (such as suggesting specific drugs) where I feel that a general pointing to a general class of the drug used would be better (such as recommendation 43 and 51, where some detail about the drug of choice is given, but not enough detail, so I do wonder the point of including it- would be better to refer then to specific local prescribing guidelines). Opening paragraph: Distinction clearly specified in relation to Emergency/Acute and Chronic Illness (Care of Dying Adult) - very good. Recognition that patient is dying is acknowledged, decisions made in accordance with patient's needs & wishes, regularly reviewed	Thank you for your comments. The recommendations have been made following a review of the evidence in all of the areas in the scope. Where clinical and cost-effectiveness evidence was found, we have been able to provide detailed guidance regarding specific medications to use. Where evidence, was lacking, the Committee chose to recommend a class of drug only to support the use of local prescribing guidelines. Recommendations 1.1.1 – 1.1.5 are made regardless of setting.

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		3		Significant emphasis on the biomedical & diagnostic focus in the hospital setting in recommendations 1-5. Is this focus the same for the community setting?	
University of Surrey				colleagues at RSH currently running trial re this	Thank you for your comment.
University of Surrey				not my area	Thank you for your comment.
University of Surrey				Whose responsibility is it to record the dying person's record of care? Is the responsibility the same for the hospital and community setting? Can patient's wishes be recorded in medical and nursing notes and by Advanced Nurse Practitioner (ANP) who work autonomously in the community setting? This needs clarification as the specialist nurses who work with long-term conditions patients will usually know the patient and family very well. Clarify GP role here if possible, and state timeframe in relation to progression of patient's illness symptoms.	Thank you for your comment. This recommendation is applicable to all health care professionals. This has been clarified in the 'Linking evidence to recommendations' section of the full guideline.
University of Surrey				It mentions Healthcare professional (HCP), what about the role of 'carers'? How is the 'carer' defined in relation to 'talking about end of life care' with patients and relatives? What language do 'carers' use to explore 'end of life care' with patients or	Thank you for your comment. This guideline is aimed for Health Care professionals who are responsible for delivering care to people in the last days of life. Carers are welcome to use our guidance. Additional detail has been added to the

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				relatives? Is there a training need here? May also be useful to guide carers to helpful literature such as 'Difficult conversations'	'Linking evidence to recommendations' section of this chapter. The available guidance you mention has been added.
University of Surrey	Full	general		these recommendations are 'excellent' and such clarification is very much needed for ICU patients, where agitation and delirium can be quite common.	Thank you for your comment and for participating in the consultation process.
University of Surrey		3		Needs of families identified	Thank you for your comment.
University of Surrey		3		Patient and carers involved in decisions about treatment & care to the extent that they want	Thank you for your comment. We agree and have discussed this in the shared decision making chapter. The focus, as stated in Recommendation 1.3.1 is on the dying person and the level of involvement they want in decision making. There are several recommendations involving those important to the dying person, which may also include carers if appropriate, within the communication and shared decision chapters.
University of Surrey	Full	5.2		Sensitive communication	Thank you for your comment. Communication is covered in a separate chapter (chapter 6).

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University of Surrey		7	6.2	Individual plan of care- diet & fluids, symptom control, psychological, social & spiritual support agreed, coordinated & delivered with compassion. review question - seems important that practitioners feel able to disclose uncertainty where this exists	Thank you for your comment.
University of Surrey	Full	9.1		It may be useful here to start the recommendations with patients/carers views and wishes if they are known from the outset (**recommendations 7 & 10** as first priority?) review question - assumptions and perhaps prejudice regarding patients ability to be involved in decision making e.g bias re age, culture or class?	Thank you for your comment. After careful consideration, the committee do not wish to re-order the recommendations in section 6.6 as you suggest. We consider it more important to establish communication needs and expectations before discussing prognosis or their preferences so that these may then be addressed in the most appropriate way. We make reference to culture in particular in the 'Linking evidence to recommendations' section (6.6)
University of Surrey		7.2		review question - the ability to make time and have private space for care conversations & sensitivity to cultural and values' differences	Thank you for your comment. We are unable to edit the review question at this stage in the development of the guideline. However, we have amended our communications recommendation to encourage healthcare professionals to establish the communication needs and expectations of people who may be entering their last days of life, taking into account any cultural, religious, social or spiritual needs or preferences that should be considered. The committee relied on guidance provided in the NICE guidance entitled, Patient Experience in the adult NHS services and made direct cross reference

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					to this for existing recommendations on the issues you raise. More information on this guideline can be found at: https://www.nice.org.uk/guidance/cg138
University of Surrey		9 9		*clinically assisted hydration'* – is this defined as a medical intervention or a palliative? What is the difference? How well do we anticipate patients/carers and relatives understand this terminology? Term used in MCA is artificial hydration – should this term be used for consistency? similar point- define *'a therapeutic trial of clinically assisted hydration'* – this appears very medical and not sure it can be understood by the public? I now see that this point is clarified in **recommendation 30,** but again, the public/patients may not understand the words *'enteral or parenteral nutrition'*	Thank you for your comment. The Committee have chosen to use the term clinically assisted hydration and this is defined in glossary of the full guideline. NICE also produce an information for the public version of this guideline aimed at lay people. This version of the guideline will, in addition, provide a glossary of complex terms.
Wandsworth End of Life Care Clinical reference Group – Wandsworth Clinical Commissioning	Short	5	23-27	Emphasis on good communication is really important as it is core to good care but it can be challenging for some healthcare professionals to talk to patients and relatives about the potential for dying. This may be related to uncertainties around an expected timescale, which is clearly mentioned in your sections on identifying dying, or because it may involve a change in the direction of treatment and care which some doctors find difficult. In addition, in many cases doctors undertaking these conversations have to take account of wide	Thank you for your comment. The Committee agrees that communication about prognosis is challenging and important part of palliative care. However, service delivery, including education and training initiatives, are outside the remit of the guideline. NICE is currently developing guidance on palliative care service delivery and this topic may be included in that guidance. More details can be found at the following link: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799.

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Group				variations in patients' and families' expectations, information needs and coping strategies and this can be difficult too. I believe this area of work is challenging but getting it right will have a significant impact on delivery of good end of life care. I think that the reason identifying dying sometimes doesn't happen is precisely because it precipitates that sensitive conversation about prognosis, the future direction of care and the potential for dying. It would help to promote an extensive programme of education and specifically training in communication skills across the system to enable healthcare staff to have the confidence to do this well, sensitively and with compassion.	
Wandsworth End of Life Care Clinical reference Group – Wandsworth Clinical Commissioning Group	Short	7	29	It is really important that the plan is shared with close relatives and carers too – we have experience of occasions locally where a patient's wishes regarding care have not been met because a family member or carer hasn't known about the plan. For example a patient had said they wanted to die at home, but a relative called for an ambulance shortly before death as they were very anxious and weren't aware of the patient's wishes. People should be encouraged to discuss their preferences with family and carers so everyone is informed, and it's helpful to write it down and keep a copy of this prominently in the house together with contact details for professional care staff as well as significant family members and carers.	Thank you for your comment. We have amended the recommendation as suggested, to encourage people providing end of life care to share the care plan with the dying person, those important to them and all members of the multiprofessional team. The recommendations in this section go on to prioritise the needs and wishes of the dying person and to establish the communication needs and expectations of people who may be entering their last days of life, taking into account whether they would like a person important to them to be present when making decisions about their care. However, recommendations also articulate the importance of providing those important to the dying person with an opportunity to talk about any fears

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				As an example of practical resources/ good practice, earlier this year we opened an End of Life Care Coordination Centre in Wandsworth to assist with planning and delivering good care to people dying in the community setting. Part of the role of the care coordinators is to support the very tired and emotionally exhausted families and carers; to be able to respond in a compassionate way to distressed relatives or friends phoning for advice.	and anxieties and to ask questions about the care of their loved ones in the last days of life and to create opportunities for further discussion with a member of the care team if needed.
Wandsworth End of Life Care Clinical reference Group – Wandsworth Clinical Commissioning Group	Short	6	16	It is really good that Shared decision making is clearly emphasised early in the document and includes addressing patient choice, personal goals and wishes.	Thank you for your comment.
Wandsworth End of Life Care Clinical reference Group – Wandsworth	Short	7	29	Sharing with members of MDT – it might it be helpful to mention here it's also important to share salient information about patients' care plans, including their wishes and preferences, with colleagues working on different shifts throughout the day/ week.	Thank you for your comment. Your suggested detail has been added to the full guideline 'Linking evidence to recommendations' section.

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Clinical Commissioning Group					
Wandsworth End of Life Care Clinical reference Group – Wandsworth Clinical Commissioning Group	Short	7	4	Identifying a lead healthcare professional is an important issue in all care settings and I think results in better care/ management. It can be helpful to have a second named person (doctor) who knows the patient well enough to be able to step into the role if lead HCP goes of sick or on annual leave. In my experience it can happen that there isn't an effective handover of information or care planning.	Thank you for your comment. The Committee consider that the level of detail is appropriate and that local policy or decision making may inform what are the most suitable contact details to provide. Additional detail can be found within the full version of the guideline in the 'Linking evidence to recommendations' section.
Wandsworth End of Life Care Clinical reference Group – Wandsworth Clinical Commissioning Group	Short	8	13	This line is so important I wonder if it should be a formatted as a separate paragraph, on its own, for emphasis: you might consider adding "even if it is only small sips of water."	Thank you for your comment. We have carefully considered this recommendation and feel that no change is required.

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Wandsworth End of Life Care Clinical reference Group – Wandsworth Clinical Commissioning Group	Short	8	20	Is it worth adding that when a dying person is unable to swallow, even moistening the lips and mouth can give great comfort?	Thank you for your comment. Lip care is included in recommendation 2.4.2 and discussed in the 'Linking evidence to recommendations' section of the full guideline.
Wandsworth End of Life Care Clinical reference Group – Wandsworth Clinical Commissioning Group	Short	11	24	Is there an opportunity here to recommend that physicians should remember to prescribe appropriate break-through doses of prn end of life care medications, in all settings, to ensure good symptom control?	Thank you for your comment. The Committee has made separate recommendations for anticipatory prescribing. We feel that breakthrough doses implies a background medication. We have not made this assumption and have referred to 'as required' medication only in this recommendation.
Wandsworth End of Life Care Clinical reference	Short	12	1	I think para 1.5.9 is an important advice statement. Might it be helpful to add "or if the clinical situation is complex" ?	Thank you for your comment. After careful consideration the Committee feel that no change is required.

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Group – Wandsworth Clinical Commissioning Group					
Wandsworth End of Life Care Clinical reference Group – Wandsworth Clinical Commissioning Group	Short	12	3	I was looking for a statement about Anticipatory Prescribing on page 11 which covers general advice on prescribing matters. I am wondering if the excellent section 1.6 on Anticipatory prescribing should come here, after para 1.5.9 ahead of the pages on specific symptom management advice (paras1.5.10 – 1.5.32). I think that would give the topic better "visibility" in the document.	Thank you for your comment. The Committee feel no change is required.

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Wandsworth End of Life Care Clinical reference Group – Wandsworth Clinical Commissioning Group	Short	12	7	After urinary retention, could consider adding "obstruction or signs of inflammation/ infection".	Thank you for your comment. As no review was conducted in this area we have not given a definitive list. We have referred to urinary retention as an example and are aware of other examples.
Wandsworth End of Life Care Clinical reference Group – Wandsworth Clinical Commissioning Group	Short	12-15	1.5.10-32	I think these 5 sections on symptom management will be very helpful.	Thank you for your comment.
Wandsworth End of Life Care Clinical reference	Short	13	13	Could include here - signs of dehydration or infection, oral problems such as thrush, signs suggestive of obstruction, and assessing degree of anxiety or confusion	Thank you for your comment. This lists states "may include" and the group are aware of other examples.

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Group – Wandsworth Clinical Commissioning Group					
Wandsworth End of Life Care Clinical reference Group – Wandsworth Clinical Commissioning Group	Short	27	Note a)	"Assess need for laxative and anti-emetic". Do you think this should be a stronger recommendation? – Such as "consider co-prescribing a laxative for regular use and an anti-emetic for prn use whenever prescribing opioid analgesia."	Thank you for your comment on the prescribing tables. Because of the recognised importance of supporting generalist prescribers in managing symptoms in the last days of life, these are now being further developed separately as an additional implementation resource by NICE with support from members of the guideline Committee. Consequently, they have been removed from the guidance. This important implementation resource will remain targeted at the non-specialist prescriber and will be made available on the NICE website.