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31	Acupuncture Association of Chartered Physiotherapists	General	General	AACP are requiring justification from NICE regarding the issue of Acupuncture not being reviewed as a treatment strategy for Patients and Carers requiring Supportive and Palliative Care. It was noted that during consultation with stakeholders, 5 out of 8 groups recognised the impact and relevance of complementary therapies however Acupuncture should be considered as an adjunct rather than complementary. There were large concerns noted that "therapies" have a role in the coping mechanisms of patients/carers and if not reviewed, will have a negative impact on these groups. It is appreciated that not all patients/carers will need to access these services but consideration for the use of Acupuncture for all groups that may require access, should be paramount.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. CSG4 will remain as a separate published guideline.
32	Acupuncture Association of Chartered Physiotherapists	General	General	It was also noted that many groups did not complete the discussion during the allotted period. There was a large dominance of answering the earlier questions in the scope rather than the later ones. This suggests that further input from stakeholders in the form of another draft scoping group is required in order to achieve complete clarification of the huge issues within this scope. From this it could be concluded that the scope of the document is not fit for purpose.	Thank you for your comment. NICE conducts a range of exercises to gain the views of stakeholders, including workshops and stakeholder consultations. Following consideration of all stakeholder comments both at the workshop and through consultation it has been agreed that the guideline will focus on service delivery within the last 12 months of life for all conditions.
33	Acupuncture Association of Chartered Physiotherapists	General	General	The holistic needs assessment from the National Cancer Survivorship Initiative identifies that patients/carers may have concerns from physical symptoms, many of which may be amenable to Acupuncture specifically, or input from other complementary therapies generally, particularly when	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated

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				orthodox drug options are not viable. Non-review of Acupuncture and other therapies avoids looking at the whole person which is the basis of the holistic needs assessment. By definition, supportive care does not mean that the patient is dying (as noted by the scoping groups) thus potentially there are well-being benefits to be gained from reviewing the positive effects of Acupuncture specifically. It was highlighted (several times) in the scoping groups that for these groups, the review should be based on patient needs and not clinician needs.	within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
34	Acupuncture Association of Chartered Physiotherapists	General	General	Acupuncture has benefits for a number of symptoms experienced particularly by patients at a time when other drug options or strategies may be contraindicated. In the previous document (2004), Section 11 highlighted the lack of evidence at the time and therefore guidance was difficult. However many systematic reviews for Acupuncture have come into the public domain since 2004 and these should be **considered** on their merits. For example, there is systematic review evidence for treatment of symptoms relating to: Chronic Pain, Chemically and drug induced nausea and vomiting, Xerostomia, Dyspnoea, Insomnia, Well-being, Depression, and Post- chemotherapy fatigue. In addition, there is anecdotal evidence for anxiety,	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				intractable hiccough and hot flushes (Leng 2013). Lian et al (2014) included 33 RCT's in their review of palliative care in Cancer patients and results suggest that acupuncture may assist in reducing chemotherapy or radiotherapy induced side effects and cancer pain. It should be noted that the Cochrane Review have also indicated positive results for Acupuncture. Towler et al (2013) suggested that acupuncture should be considered for symptom management with Cancer patients when there are **limited treatment options** based on a review of 17 systematic reviews. Garcia et al (2013) reviewed 41 RCT's and results indicated that acupuncture is an appropriate **adjunct** treatment for chemotherapy induced nausea and vomiting. This review validated the results from an earlier systematic review (Ernst et al 2010).	
35	Acupuncture Association of Chartered Physiotherapists	General	General	Formal training for Acupuncture was an issue in the 2004 guidelines. Since then AACP have designed a formal training pathway for Acupuncture which minimises risk to the patient. Leng (2013) also assessed the availability of acupuncture in hospices and palliative care services concluding that the lack of a suitable practitioner was the issue rather than a lack of evidence to support its use and value. More advanced training specific to this cohort of patients is also available through AACP as CPD for	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				physiotherapists working in oncology or palliative care. This has been initiated to support recommendations about the underuse and value of acupuncture in hospice and palliative care (Leng 2013, Standish et al 2009)	
36	Acupuncture Association of Chartered Physiotherapists	Page 5	110	AACP is also concerned that purely RCT data is being used to inform decisions. We argue that RCT data is not necessarily the most appropriate form of data for these groups of patients: qualitative data should also be considered. The group is also concerned that NICE will limit future research opportunities for the use of Acupuncture. This is in direct opposition to the many patients and carers who want to promote an enabling approach to healthcare rather than returning to a disabling approach. NICE has the opportunity to be part of a commitment to modern day health care which is not solely reliant on orthodox treatments which it stands to lose if research for Acupuncture becomes limited. Most Acupuncture practitioners work in a responsible relationship with conventional medicine in order to serve for patient benefit. Patient centred care should mean exactly that.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The type of data that will be used in the guideline will be decided later during development when defining the protocols for each question**.**
37	Acupuncture Association of	General	General	It is estimated that 40% of patients needing supportive or palliative care access a range of complementary therapies including Acupuncture during the course of their illness in the UK and up to 70% do so in USA.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the

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	Chartered Physiotherapists			Acupuncture specifically is available in 30%- 60% of hospices and palliative care services in the UK (Leng 2013) suggesting a "productive co-existence" as stated in the NICE 2004 guidelines. It remains valid to state that patients are accessing acupuncture as an addition to rather than in place of orthodox cancer treatments and qualitative feedback suggests this may reduce the pharmacological burden for them whilst offering a cost effective supportive treatment option which is not the sole responsibility of the charitable sector.	new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
38	Acupuncture Association of Chartered Physiotherapists	General	General	It should be noted that medical oncologists are using acupuncture to support their patients and have written specific guidance on the use of acupuncture in cancer care (Filshie 2006).There appears to be a growing demand from Oncologists for access to suitably qualified acupuncture practitioners to meet the needs of patients with uncomfortable **side effects** from treatments (e.g. peripheral neuropathy, hot flushes, fatigue) symptoms which may not readily respond to pharmacological means and is a preferred treatment option for many. Withdrawing acupuncture from the menu of choice for patients and their medical teams would seem to be a step backwards at a time when cost effectiveness and patient choice is indicated. Eminent organisations such as the Kings Fund and Hospice UK support the use of Acupuncture for	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				treatment of pain and distress cause by side effects.	
26	**Alliance for Natural Health**	2	37	The equality impact assessment does not adequately explain why certain groups e.g. complementary therapies, are excluded from the scope. Given recognition that the public is strongly drawn to some of these therapies because of knowledge about their beneficial effects on health or quality of life, their exclusion will result in lower socio-economic groups being more disadvantaged if such therapies can only be accessed privately. Additionally, the equality impact assessment and scope appears to have ignored socio-economically disadvantaged groups, other than homeless people and traveller communities, that should require special consideration.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The revised Equalities Monitoring Form lists Socio economic inequalities (people from lower income brackets) as a potential equality issue.
27	**Alliance for Natural Health**	5	109	The proposed removal of complementary therapies from the guideline is not explained. Given the popularity of such services (see for example Palliative Care Funding Review by Hughes-Hallett et al, 2011, p. 56; Mansky & Wallerstedt, Cancer J. 2006 Sep-Oct; 12(5): 425-31; and numerous others), it would be contrary to the intent of the NHS Constitution (principle 4) to remove access to such therapies from NHS services. Forcing the public, especially at such a vulnerable stage of their lives, to pay for complementary therapies privately discriminates against lower socio-economic groups who are likely to	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				not be able to afford such services. Ernst et al (*J Med Ethics* 2004;30:156-159) state: "CAM is by and large private medicine for which consumers pay substantial amounts out of their own pockets. Assuming that CAM does more good than harm, this situation is far from equitable". There is conclusive or plausible evidence for the effectiveness of some complementary therapies in palliative or supportive care (e.g. acupuncture for cancer-related fatigue, chemotherapy-induced nausea and vomiting and leucopenia in patients with cancer, Wu et al, Sci Rep. 2015; 5: 16776; massage in supportive cancer care, Collinge et al Semin Oncol Nurs. 2012 Feb; 28(1): 45-54). For other therapies in which there is evidence from clinical experience, case reports, etc., to dismiss these because of a perceived "lack of evidence" is inappropriate when this may be more a result of a lack of RCTs. Lack of evidence, it should be remembered, cannot be interpreted or assumed to imply lack of effect.	
28	**Alliance for Natural Health**	8	187-188	If those receiving supportive or palliative care indicate that access to complementary therapies are important to them and these cannot be accessed through the NHS, the NHS will have failed in its duty under the NHS Constitution, principle 4.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated

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					within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
29	**Alliance for Natural Health**	10	231-235	Another group for which guidance should be available are those with severe disabilities linked to autism spectrum disorders	Thank you for your comment. Current guidance exists on: Autism in under 19s: recognition, referral and diagnosis further details can be found on the NICE website at the following address: https://www.nice.org.uk/Guidance/CG128. add reference to 2 other guidelines – support and management of autism guideline and autism in adults
30	**Alliance for Natural Health**	14	334	Recognition that care should be based on "individual needs" is entirely appropriate and consistent with principle 4 of the NHS constitution. But exclusion of complementary therapies from the scope of the guidance would be contrary to this intent of this principle given the popularity of public demand for some fo these therapies. It would be appropriate to convene a committee of experts in the field of complementary therapies to evaluate the totality of available evidence based not only on RCTs, which are few in number and not necessarily the most appropriate experimental method in this setting, but also on observational evidence, case reports, etc. It should be remembered that thee are some orthodox treatments offered by the NHS that themselves have a	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the context section of the scoping document has been amended to reflect these changes.

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				limited evidence base or benefit/risk profile.	
115	**Belfast Health and Social Care Trust**	1	11-12	Agree with need to extend and standardise the remit of palliative care to other life-limiting conditions-however how would this be delivered within existing resources/how does this work in relation to core services who are already seeing these clients eg MS/HD/PD-would it be with support from Specialist Team as required on advisory basis?	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. This guideline will not provide recommendations on specific clinical conditions.
116	**Belfast Health and Social Care Trust**	1	15-16	Unfortunate that this guideline development document is coming so soon after the "Care of dying adults in the last days of life. NICE guideline NG31 (2015)" – leading to confusion.	Thank you for your comment. The care of adults in the last days of life addressed clinical issues related to caring for dying adults. NICE was asked by NHS England to develop a guideline focusing on service delivery at the end of life. This guideline will not provide clinical detail related to life limiting conditions.
117	**Belfast Health and Social Care Trust**	1	20-25	It is unclear what the distinction is between providers of supportive and palliative care and other practitioners delivering EOL care services and how they differ from generalist and specialist health care professionals in primary and secondary care. Why will this guidance	Thank you for your comment. Specialist Palliative care service delivery is covered by the guideline and this is relevant to specialist palliative care providers. We have edited the guideline and have listed specialist healthcare professionals in primary and secondary care

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				not include service definitions for specialist palliative care services and be of relevance to specialist palliative care providers?	under the section 'who the guideline is for'.
118	**Belfast Health and Social Care Trust**	2	33-44	Should specific reference be made to prisoners? To Members of Travelling communities	Thank you for your comment. All settings in which National Health services are commissioned and funded are within the remit of NICE guidance and this includes Prisons. Adaptations to recommendations may be relevant, for example due to security concerns, and may be addressed by local decision making and policies and the prison service. We will discuss the equalities issues you raise with the guideline committee who will consider the needs of these populations in terms of recommendations for the delivery of services at the end of life.
119	**Belfast Health and Social Care Trust**	2	45-47	Query re definitions – can you have a guideline which covers supportive and palliative care, when the definition of supportive care includes "cure"??The definition of palliative care is not a particularly good one and reinforces the notion that palliative care is only delivered at "end of life". It differs substantively from the recognised WHO definition – this will lead to confusion especially when referencing other international literature. The definition of supportive	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.

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				care is included within the WHO palliative care definition- if using these definitions – it would need to be clear how and why they differ from the WHO definition of palliative care.Also refers to "integrating the psychological and spiritual aspects of the persons care", but what about the social aspects? The term " Non specialist palliative care" is defined in the table, however the term used later in the document in the section entitled " Who is the guideline for?" refers to "generalist health care professionals", which is not defined anywhere- need to have consistent terminology.	
120	**Belfast Health and Social Care Trust**	3		We welcome the inclusion of spiritual aspects of the person's care in the definition of palliative care.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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121	**Belfast Health and Social Care Trust**	3	48	The definition of non-specialist is not accurate, as most healthcare professionals have specialist knowledge of palliative care to some degree depending on education and experience. There is a gap between these two levels Non Specialist and Specialist. Some staff do have no knowledge i.e. Disability centre which has no or very little exposure to end of life, others are ward nurses, community nurse etc. who deliver palliative care within their normal duties but do not specialise in it. Would a definition such as staff who specialise in palliative care and staff who do not be appropriate	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms, used in the guideline. The terms 'end of life services' and care at the end of life' are now being used within a revised.
122	**Belfast Health and Social Care Trust**	3	49-50	Not sure one overarching guideline can cover of this. Is this scope to broad? See above re definitions.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
123	**Belfast Health and Social Care Trust**	3	51	The fact that the guideline covers adults only is not reflected in the title of the document.	Thank you for your comment. We have added adults into the title

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124	**Belfast Health and Social Care Trust**	3	53-62	Is this for NHS services only? Although the exclusion is for services "without any element of NHS funding"- it will appear not to include e.g. Hospice and specialist palliative care units./ care homes. Are these partners party to the consultation? Can this partnership be stated more clearly?	Thank you for your comment. This is outside of our remit – we can only give guidance for NHS provided care, however Hospices are welcome to adopt this guidance.
125	**Belfast Health and Social Care Trust**	4	61	There are still on-going issues around funding for some professions providing a service to Hospices. Need to consider how this can be best managed.	Thank you for your comment. This is outside of our remit – we can only give guidance for NHS provided care, however Hospices are welcome to adopt this guidance.
126	**Belfast Health and Social Care Trust**	4	62	If a service is commissioned by NHS is it then not funded by it? Who pays the bills?	Thank you for your comment. If an organisation is funded by a charity it is not within the remit as it is not NHS regulated.
127	**Belfast Health and Social Care Trust**	4	65	Whilst "carers assessments" have to be undertaken, is it appropriate to apply the term "holistic" to a carers assessment in the same way that it can for a patient's holistic assessment? Normally a standard carer's assessment proforma is followed which would not include the same tools used for a patient's holistic assessment as advocated in this document. It would not seem appropriate for a professional to be expected to routinely assess the cognitive functioning, sexual functioning etc. of "those important to the patient"??	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					Additionally, holistic needs assessment will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
128	**Belfast Health and Social Care Trust**	4	66-68	Are the tools suggested validated and fully researched? Many tools have been published which have a pragmatic origin. Will there be guidance on best evidence and validation for specific groups- patients, carers etc?	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, holistic needs assessment will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
129	**Belfast Health and Social Care Trust**	4	67-76	caution identifying needs of carers when funding is scanty for services	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new

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					recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
130	**Belfast Health and Social Care Trust**	4	76	We welcome the inclusion of spiritual wellbeing and a cultural and religious need under Holistic needs assessment.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, holistic needs assessment will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
131	**Belfast Health and Social Care Trust**	4	77-83	Will there be evidence of benefit for service models recommended? Will it be established as a right of users and a duty of providers to provide specific types of service?	Thank you for your comment. We do not wish to prejudge the evidence. The guideline committee will make recommendations on the evidence presented to them.

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132	**Belfast Health and Social Care Trust**	4	81,87	Will the guideline establish the duty of providers to ensure access to specialist services, with clearly defined and commissioned services in all care settings?	Thank you for your comment. Any recommendations will be informed by the evidence identified for each review.
133	**Belfast Health and Social Care Trust**	5	88	Identifying the risk of complex bereavement; this will have training/resource implications. It would also require the use of an evidence based tool for assessing the risk etc. Additionally limited services are available – will need to discuss service provision once risk identified – in many places-Cruse available only	Thank you for your comment. Following consideration of all stakeholder comments the guideline will not now include complex bereavement but will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline. The use of an evidence based tool for assessing risk, will be considered when designing the review protocol for the question. The availability of limited services is an implementation issue that is beyond the remit of this guideline.

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					Additionally, please note that
134	**Belfast Health and Social Care Trust**	5	94	We welcome the intention to update information on spiritual support services.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
135	**Belfast Health and Social Care Trust**	5	102-104	We welcome the intention to include information on The role of holistic needs assessment to identify the supportive and palliative care needs of the person, carers and those important to them and Sharing information between multiprofessional teams.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessment will not be

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					specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence. However, information sharing between multiprofessional teams will be covered when we consider the planning and coordination of services for care in the last year of life.
136	**Belfast Health and Social Care Trust**	5	104	Important to recognise information sharing with out of hours services	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. However, information sharing between multiprofessional teams will be covered when we consider the planning and coordination of services for care in the last year of life.

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137	**Belfast Health and Social Care Trust**	5	107-110	Why are Education/ Training and Research being removed from the new guidelines? For Specialist Teams both should be integral part of the job. With regards to SLT there is so little research/best practice evidence available for palliative care at present/would keeping it in the guidance lend weight to protecting time/resources to do this?	.
138	**Belfast Health and Social Care Trust**	5	109	Query -why this is being removed? It would be useful to clarify NICE assessments of benefit or lack of in relation to how these services are funded. Even if controversial	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
139	**Belfast Health and Social Care Trust**	5	109-115	Why are these not being included?	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within

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					CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
140	**Belfast Health and Social Care Trust**	5	113	Query- why this is being removed? if supportive services include telephone review- need to be clear that this is better than face to face contact?	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline; and this includes recommendations on face to face communication.
141	**Belfast Health and Social Care Trust**	6	134-180	Is it expected that there will be movement of patients between supportive and palliative care- how will service models define and manage this? How will service models define access to specialists – presumably in Palliative Care across both definitions? Many clinicians e.g. District Nurses, oncologists etc. provide both palliative care under the WHO definition (which in this document includes both supportive and palliative care) Again there may be a definition issue	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. As such, there is no specific question on the transition

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					between supportive and palliative care, however, the timing and review of service provision is among the key areas covered in the guideline.
142	**Belfast Health and Social Care Trust**	6	135	Introduction of Holistic assessment tools for assessment of non-cancer patients may need to be disease specific. A general tool, such as the excellent Sheffield Profile (SPARC), would capture the physical, psychological, social and spiritual needs of all and could be used as a first assessment of needs. Thereafter, renal patients may benefit from on-going assessment using the Kidney Disease Quality of Life (KDQPL-TM36) or Patient Outcome Scales (POS and POS-s) which would help to highlight renal specific issues such as dialysis access difficulties. Renal patients who have a failing kidney transplant should also be assessed via a nurse-led transplant out-patient clinic.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessment will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
143	**Belfast Health and Social Care Trust**	6	137	The Sheffield Profile tool appears to be very comprehensive. The local specialist palliative care teams may have other preferences. The Belfast Trust has developed an excellent care pathway which they may feel is adequate for assessment.	Thank you for your comment and participation in the consultation process. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End

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					of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
144	**Belfast Health and Social Care Trust**	6	139	Assessment of supportive care for carers needs is undertaken by social workers using the Northern Ireland Single Assessment Tool (NISAT). I am unsure how effective this has been given that the Transforming Your Care Strategy failed to be adequately funded to allow care packages to be fully implemented.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
145	**Belfast Health and Social Care Trust**	6	142	Surely supportive care needs are reviewed on an individual basis? When and how often? Assessment should be initiated when a patient reaches end-stage kidney disease (stage 5 CKD). This is when a patient commences one of three pathways: • preparation to be listed for kidney transplant • preparation for dialysis treatment • chooses a non-dialysis option and	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				commences a conservative management pathway Review Assessment could be completed 6mths following initial assessment OR sooner if patient has a medical event and then perhaps on an annual basis if no changes to circumstances noted.	
146	**Belfast Health and Social Care Trust**	6	144	This will depend entirely on the type and stage of disease process. Commenting from a renal perspective, I feel monthly assessment of palliative care needs is required for those at stage 5 CKD following a conservative management pathway, as this group of patients are known to deteriorate rapidly during their final 1-3 months.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. This includes timing and review of service provision within a service delivery model of end of life care.
147	**Belfast Health and Social Care Trust**	6	146	Identifying needs for carers will be problematic with no funding designated to rectify issues identified.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
148	**Belfast Health**	7	179	We need to improve transition of young adults from children's services to the adult service.	Thank you for your comment and your participation in the consultation process. The remit and scope of the

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	and Social Care Trust			Currently young adults receive education and support via the renal nurses in RBHSC. Thankfully most of the children and young adults are eligible for a transplant via living organ donation from a parent. However for those very few transferring to the adult dialysis ward or to the adult out-patient transplant clinic; earlier referral form RBHSC, could improve a more robust system of support and preparation for these young adults. There are plans to move all nephrology clinics in to the dialysis unit, so this move should help improve transition, as a full team of renal support services will be allocated in one area. It may also help accommodate the introduction of young adult clinics. Renal Patient Education have attempted to run a young people's forum, but this has not been well supported by the young adults to date.	guideline have changed and this work will now focus on the delivery of services to adults in the last year of life. Transition from paediatric to adult services will no longer be addressed in the guideline as an individual review question. NICE has produced a guideline on Transition from children's to adults' services for young people using health or social care services (NG43).
149	**Belfast Health and Social Care Trust**	10	231-246	Confusion with standards/ guidelines/ pathways – can they all be updated together and included in one reference document?	Thank you for your comment, NICE's guidance takes several forms, all accessible online and developed on a prioritised schedule. We are happy to clarify that: Quality Standards are concise sets of statements, with accompanying metrics, designed to drive and measure priority quality improvements within a particular area of care. These are derived from the best available evidence, particularly NICE's own guidance and, where this does not exist, from other evidence sources

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					accredited by NICE. NICE guidelines make evidence-based recommendations on a wide range of topics, from preventing and managing specific conditions, improving health and managing medicines in different settings, to providing social care to adults and children, and planning broader services and interventions to improve the health of communities. The pathways are an online tool which provides quick and easy access, topic by topic, to the range of guidance from NICE, including quality standards, technology appraisals, clinical, public health and social care guidelines and NICE implementation tools.
150	**Belfast Health and Social Care Trust**	11	-	The context and facts figures and current practice should perhaps be at the beginning not the end.	Thank you for your comment. The guideline's scope is based upon a standardised NICE template. We will pass your feedback on to the NICE editing team.
151	**Belfast Health and Social Care Trust**	12	260-277	The distinctions made between supportive care and palliative care are confusing and at times misleading and really reinforce the notion that palliative care is only for end of life. This in fact contradicts the graphic (Figure 1) on page 7oft the APM 2012 Commissioning	Thank you for your comment. The remit and scope of this guideline has been changed and the context section of the scoping document has been amended to reflect these changes. The guideline will now focus on the delivery of services to adults in the last year of life.

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				Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives where palliative care is provided in increasing need as disease advances. It also may lead to confusion in the referral to specialist palliative care providers when there are supportive care challenges. The distinction between supportive and palliative care is artificial in some settings e.g. Community as referenced in 134-180. It may be in some locations that providers provide palliative care only e.g. Hospices but community and hospital specialist palliative care teams may provide both. This applies to cancer in particular – may be less developed in non- cancer. Definitions are challenging. Resourcing will be challenging.	
152	**Belfast Health and Social Care Trust**	13	284-287	Is this the focus of this guideline- will there be guidelines for specialist palliative care- for which there should be "24/7 access for advice?" If not – where will this be provided?	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Out of hours, weekend and 24/7

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					availability of services have being included in the key areas to be covered in the revised scope.
153	**Belfast Health and Social Care Trust**	13	303	There are more referrals coming through to Palliative Team for clients with end stage dementia-how can this be sustained given the anticipated increase? How would it overlap with core services-would it be more complex cases and how would this be decided? It is also likely to generate increased training needs within Palliative Teams if the focus has previously been more on cancer.	Thank you for your comment and for participating in the consultation process. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Dementia has been highlighted as an important equalities issue for this guideline and the committee will consider the needs of this population in terms of recommendations for the delivery of services at the end of life.
154	**Belfast Health and Social Care Trust**	General	General	We would hope that the role of chaplaincy (within hospice and acute settings) and the wider Faith communities will be acknowledged and encouraged as part of the holistic, multidisciplinary team in the outworking of these guidelines.	Thank you for your suggestion on Committee membership. The developers are mindful of the need for ensuring that a broad range of experience and knowledge is represented on the group. This has to be balanced with the need to ensure that the guideline committee is a workable size and as such enables

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				Will NI data and figures be provided for NI if adopted here? Generally the proposals to widen palliative care are welcome. The concern would be in terms of resourcing etc. but not sure if the guideline is the right forum for expressing?? Once the Guideline has been developed it may be easier to comment on specifics. Within Nephrology in Belfast Trust we are currently exploring the best model for planning, coordinating and sharing information between our multi professional teams. We are also very keen to introduce the Trust's documentation on advance care planning. A Specialist nurse has been appointed to lead this service which incorporates care and support for the following five categories of patients and is paramount in the delivery of education for nursing staff: - 1. CKD patients not progressing to renal replacement therapy - 2. Patients with a failing transplant who are not returning to dialysis - 3. Patients on dialysis who have increasing symptom burden - 4. Patients withdrawing from dialysis	individuals to contribute effectively. When convening the guideline committee the developers have followed the principles outlined in the NICE technical manual. NICE's role is to improve outcomes for people using the NHS and other public health and social care services nationwide. Decisions on how the guidelines apply in Northern Ireland are made by ministers in the Northern Ireland Executive. The roll out and use of this guideline in Northern Ireland is therefore an implementation issue which, unfortunately is outside the remit of the guideline. Thank you for participating in the consultation process.

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				- 5. Patients who have been commenced on a Palliative care pathway	
5	**Department of Health**			**Has no substantive comments to make, regarding this consultation**	Thank you for your participation in the consultation process.
155	**Faculty of Pain Medicine of the Royal College of Anaesthetists**	General	General	The Faculty of Pain Medicine of the Royal College of Anaesthetists would be grateful for the opportunity to both register as a Stakeholder and seek full membership of our organisation in the committee updating this guideline.	Thank you for your comment and for contributing to the consultation process. Details on how you can further get involved with the development of NICE guidance can be found at the following link: https://www.nice.org.uk/get-involved/join-a-committee/professional-member-applications.
156	**Faculty of Pain Medicine of the Royal College of Anaesthetists**	General	General	We believe pain management is a fundamental priority in the care of the patients covered by the guideline and in particular the patients groups detailed by the scoping document as needing special consideration.	Thank you for your comment. The management of pain for dying adults was addressed in the clinical guideline on the Care of Dying adults in the last days of life. This guideline can be found at the following link: https://www.nice.org.uk/guidance/ng31.
157	**Faculty of Pain Medicine of the Royal College of Anaesthetists**	General	General	The Faculty of Pain Medicine welcomes the broadening of scope to encompass people who are at end of life, whether they have cancer or other end of life conditions.	Thank you for your comment and for contributing to the consultation process. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where

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					recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
158	**Faculty of Pain Medicine of the Royal College of Anaesthetists**	General	General	Pain is indeed referenced in the actual definition of palliative care. It is a symptom most feared by patients and their carers. It affects around half of patients at diagnosis of cancer and affects up to 75% of patients with advanced disease. Historically often under recognised and under treated, it remains prevalent and of moderate to severe intensity. Despite the use of the World Health Organisation's analgesic ladder, almost half of patients with cancer do not receive adequate analgesia to control their pain.	Thank you for your comment. NICE has published a guideline on Care of dying adults in the last days of life that addresses the clinical aspects of care of dying adults, including the management of pain – details on this guideline can be found at: https://www.nice.org.uk/guidance/ng31. Currently another guideline is being developed on End of Life care for infants, children and young people which includes both clinical care and service delivery – further details can be found at: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0730. Further guidelines specific to a range of life-limiting illnesses and conditions are also available on the NICE website: http://www.nice.org.uk/Guidance.
159	**Faculty of Pain Medicine of the Royal College of Anaesthetists**	General	General	Pain at the end of life is often very complex and often present in multiple sites, often from multiple aetiologies and pain types, such as somatic, visceral, neuropathic or mixed. Specialist pain management input, with our multiprofessional team approach and utilising all treatment modalities including	Thank you for your comment and for contributing to the consultation process. NICE has published a guideline on Care of dying adults in the last days of life that addresses the clinical aspects of care of dying adults, including pain management – details on this guideline can be found at: https://www.nice.org.uk/guidance/ng31.

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				pharmacological and non-pharmacological treatments, including interventional pain management, is crucial to its treatment.	
160	**Faculty of Pain Medicine of the Royal College of Anaesthetists**	General	General	Close collaboration between supportive and palliative care and pain services is an important feature of current working practice in many areas.	Thank you for your comment and contribution to the consultation process. NICE has published a guideline on Care of dying adults in the last days of life that addresses the clinical aspects of care of dying adults, including pain management – details on this guideline can be found at: https://www.nice.org.uk/guidance/ng31.
161	**Faculty of Pain Medicine of the Royal College of Anaesthetists**	General	General	The Faculty of Pain Medicine would welcome the opportunity to update and help improve this important guideline, and we believe our full participation would facilitate this process.	Thank you for your comment and continued contribution to the consultation process.
10	**Hospiscare**	1	4	We are interested that only service delivery is included in this version of the guidance. Are there due to be other areas of guidance issued? And if so, what are they likely to be?	Thank you for your comment. NICE has published a guideline on Care of dying adults in the last days of life that addresses the clinical aspects of care of dying adults – details on this guideline can be found at: https://www.nice.org.uk/guidance/ng31. Additionally, another guideline is currently being developed on End of Life care for infants, children and young people which includes both clinical care and service delivery – further

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					details can be found at: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0730. Further guidelines specific to a range of life-limiting illnesses and conditions are also available on the NICE website: http://www.nice.org.uk/Guidance.
11	**Hospiscare**	1	26	Why is the "may also be relevant for" used to head a section including charitable sector organisations delivering supportive and palliative care? These guidelines will be highly relevant to such charitable organisations and we would prefer to see the "may also be relevant" heading removed.	Thank you for your comment. We recognize that some NHS services are provided by the charitable sector and these providers will be directly impacted by the recommendations of relevance to their services. However, non NHS or other care funded settings are beyond the remit of NICE in relation to guidance provision and for these settings, we use this text in line with the NICE house style. .
12	**Hospiscare**	4	66-70	We would argue that the holistic needs assessment tools are not "established" and would value a clear review of the evidence for the wealth of tools available.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, holistic needs assessment will not be specifically addressed by any review question, but may

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					be considered as part of service delivery models, in accordance with available evidence.
13	**Hospiscare**	5	109	It is not clear to our organisation why complementary therapy should be excluded from this latest review, where it was present in the 2004 document. We have a small team of paid complementary therapists and a large team of volunteers working for our organisation. They provide very valuable care which we consider to be an important part of the delivery of our service. There is growing evidence that this is helpful and appreciated by patients and to remove this area of guidance without reassessing the evidence seems unwise. We undertake regular audit of the work of our complementary therapy team at Hospiscare and have also published research in the field. "Hypnotherapy for relief of pain and other symptoms in palliative care patients: A pilot study". Harlow et al. Contemporary Hypnosis and integrative therapy 30(4): 163-174 (2015)	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				We would argue for inclusion of complementary therapy in this NICE review.	
14	**Hospiscare**	5	113	This seems a key area of supportive and palliative care – but maybe this has been excluded because it doesn't fit with "service delivery" review and will be covered in another section of NICE guidance. It would help to clarify why this has been removed.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Face to face communication is covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.
15	**Hospiscare**	7	176	The provision of 24/7 services is a hugely important area in Palliative Care. A key issue which needs to be addressed is how will this be funded? Maybe economic modelling could be undertaken to look at the cost benefits of 24/7 Palliative Care?	Thank you for your comment. We agree this could be an important economic issue; areas for original economic modelling will be prioritised by the Guideline Committee during guideline development. If this area is identified as a high priority area, an original economic analysis may be conducted.

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16	**Hospiscare**	8	191	We have reservations about using preferred and actual place of death as an outcome measure. There is significant evidence that too much concentration on preferred and actual place of death is misplaced as a measure of anything important. "The results of this study, and the results of similar studies, suggest that place of death may not be a good marker of the quality of end of life care" From: "Opinions of patients with cancer on the relative importance of place of death in the context of a 'a good death'" Melanie Waghorn, Holly Young and Andrew Davies BMJ Supportive and Palliative Care 2011; 1:310-314 "A substantial number of people do not specify a preference" "Current assumptions that home is the best and preferred place of death oversimplify patient and public attitudes and preferences for death and dying. Preoccupation with dying at home as an indicator of a good death deflects attention from improving the quality of care available in other places. It is more	Thank you for your comment. These are the main outcomes. When the full review protocols are developed appropriate outcomes for each review questions will be discussed and determined for inclusion after discussion with the Guideline Committee. The issues around preferred and actual place of death as outcomes will be discussed and if included for the review will be considered alongside other outcomes and published evidence.

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				important to focus on the experience of dying than the place of death. Hospitals will remain the place where most people die and need to provide excellent end of life care" "Preferences for place of care are rarely clearly differentiated from place of death. When they are, preference for care at home is greater than for death at home" "An unreflective focus on place as the determining factor of a good death distracts attention from the experience of dying" "Evidence suggests that place of death is not the over-riding priority. Control of symptoms, especially pain, and being accompanied by loved ones are more important". "When home death becomes normatively prescribed there is a risk that it becomes increasingly difficult for patients to express alternative preferences". "Given the projected increase in institutional deaths, the hospital needs to be reinvested as a viable alternative and place of excellent care for dying	

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Stakeholder comments table 2

31/12/15 to 29/01/16

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				patients and their families". Ref: Is home always the best and preferred place of death? Kristian Pollock – BMJ 2015; 351:h4855 We would therefore appreciate a full review of the evidence for preferred and actual place of death as an outcome measure.	
17	**Hospiscare**	12	277	We would suggest replacing "restricted" with "may be limited to". Restricted is not a good word to use here and certainly does not reflect the care given to Hospiscare patients. We provide care for longer than months, sometimes stretching into years where needed. We would suggest that this is a somewhat outdated view of palliative care. There is now a wide consensus that palliative care is driven by need, not by diagnosis or time. The conflation of palliative care and end of life care is misleading.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the 'context' section of the scoping document has been removed as this is no longer an update of the existing guidance. Thank you for contributing to the consultation process.

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18	**Hospiscare**	13	296	As a charity, we have always provided care to non-cancer patients. Our charity has been well established for 34 years.	Thank you for your comment and contributing to the consultation process.
19	**Hospiscare**	14	325-330	We would suggest that this paragraph is a little "clunky" and requires a rethink. We do not accept that the provision of supportive care to cancer patients is "mainly confined to large teaching hospital trusts". Hospiscare has a 34 year history in the provision of specialist palliative care and is one of a number of charities which provides supportive care to cancer patients in our local area. At least two other charities are long established to offer supportive care to patients with haematological and solid organ malignancies from the time of diagnosis. Hospiscare has always existed to support non-cancer patients, but we still see a relatively small proportion of non-cancer patients on our books. We are trying to encourage use of Hospiscare's services by non-cancer patients as best we can with collaborative work across the local area. We agree that the provision of both supportive and palliative care to non-cancer patients therefore remains	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the 'current practice' section of the scoping document has been removed as this is no longer an update of the existing guidance. Thank you for contributing to the consultation process.

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				inequitable. In a survey covering the years 1993-2012, the overall proportion of people with non-cancer diagnoses dying in English hospices was 5.2%. Only 0.8% of non-cancer deaths in 2012 occurred in hospices, compared with 6% of all deaths in England (Palliative Medicine 2015, doi: 10.1177/0269216315585064). We would value a review of the evidence around the best ways to encourage increased uptake of community palliative care services by patients with non-cancer illness.	
20	**Hospiscare**	14	333	We do not restrict our services to those in the last year of life. We assess patients and support them according to their need. The challenge for us will be providing such care for an expanding pool of patients with limited extra financial resources.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					Consequently, the 'current practice' section of the scoping document has been removed as this is no longer an update.
21	**Hospiscare**	14	337	We question why the term "specialist" is placed in quotation marks. They seem inappropriately used in this context as they appear to cast doubt on the specialist nature of some palliative care services. We would suggest that this sentence should be rewritten	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the 'current practice' section of the scoping document has been removed as this is no longer an update.
22	**Hospiscare**	General	General	Thanks to the NICE team for reviewing the evidence again. We look forward to being involved in the process.	Thank you for your comment and for participating in the consultation process.
68	International Federation of	General	General	Wilkinson et al (2007) found that aromatherapy & massage helps anxiety & depression in the short term following treatment. Complementary therapies (CT)	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all

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	Professional Aromatherapists			are also currently considered to be a core component of care for both patients & carers towards the end of life. The past two decades have seen complementary therapy provision in hospitals and hospices, which provide emotional support and respite from the effects of cancer, raising the morale of patients while supporting cancer sufferers to manage their conditions. Wilkinson et al. (2007). Effectiveness of Aromatherapy Massage in the Management of Anxiety and Depression in Patients With Cancer: A Multicenter Randomized Controlled Trial. Available: http://jco.ascopubs.org/content/25/5/532.long. Last accessed 28/01/2016.	conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
69	International Federation of Professional Aromatherapists	4	61-62	CTs are currently provided in situations that do not always require NHS funding. Removing them completely from guidelines will exclude individuals who do not have the economic power to self- fund. Similarly in the current trend for autonomous health care removing CTs will also eliminate any patient choice.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
70	International Federation of Professional Aromatherapists	4	65	Holistic support must include the patient and take into account not only the physical but also spiritual and emotional needs.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the

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					new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessments will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
71	International Federation of Professional Aromatherapists	5	102-104	The "Wholistic Assessment" should continue to include CTs but must only be made and supported by professionals registered with the CNHC and qualified to carry out complementary therapies. The assessment and consideration should both cover all forms of holistic support already used within the NHS and private healthcare in this country.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
72	International Federation of Professional Aromatherapists	5	109	CTs are a core component of supportive and palliative care both in the NHS and in the majority of hospices throughout the UK. Removing them will take away from patients already anxious and distressed any possibility in alleviating the symptoms from oncology interventions	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care

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					for adults with cancer, they will remain within the published guideline.
73	International Federation of Professional Aromatherapists	5	110-111	There is an emerging, though as yet small, body of evidence regarding how these practices support patients, their carers' and bereaved families cope with the myriad stresses and strains an illness, such as cancer or motor neurone disease, place on them.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended.
74	International Federation of Professional Aromatherapists	6-7	131-182	Tools and models are available and in use in large cancer centres such as the Royal Marsden Centre and the Dimbelby Centre. Any mulit-disciplinary intervention should take into account patient choice & autonomy	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the

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					published guideline. Additionally, the scope includes draft questions that reflect the key areas covered by the scope document. The more detailed, review questions will be refined when drafting the protocols with the assistance of the guideline committee.
75	International Federation of Professional Aromatherapists	8	186-187	Without taking into account patient recorded outcomes from those receiving support from complementary therapists, either within the NHS framework or privately, the reports will not be conducive to be fully informative and therefore the consideration of the reported outcomes will be not be truly representative of the holistic aspect.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, these are the main outcomes. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee.
76	International Federation of Professional	11	247	Complementary therapies are able to provide important support within this overview. Care for the patient with a life limiting illness must include care for those who are doing the caring from within the	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the

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	Aromatherapists			patient's own family.	new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
77	International Federation of Professional Aromatherapists	12-13	249-287	Continuing to include a level of CTs within the NICE guidelines will allow such interventions to be transparent in the holistic approach to patient care. Concerns raised are invariably regarding safety and medication interaction, by forcing CTs out of guidelines, the opportunity for open and frank discussions with GPs, oncologists & other carers will be lost. By failing to include complementary therapies in any guidelines, NICE will be disadvantaging a significant number of individuals as only those who have the financial means can commission and fund their own private complementary healthcare support; whilst others who do not have access to adequate private funds must rely solely on an overstretched system which does not take into account the full scope of holistic practice available to the general public. Currently doctors are facing the re emergence of	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				complementary therapies not only with their own professional development into the holistic sphere, but within the scope of public demand. The general public is becoming more aware and seeking complementary healthcare support. It is prudent of such a consultation that the consideration has a wide and valid scope of reporting from which the very basis of assessment is made "Holisitic".	
3	**Interstitial Lung Disease Interdisciplinary Network**	5	104	In particular, integration of care with clinical specialists for patients continuing with possible curative treatment, i.e. those on transplant lists. It is important for patients nearing end of life who might be on transplant lists to not miss out on symptom management and supportive care as transplant teams may view palliative involvement as the 'dying' phase and remove them from the waiting lists if they do not understand the nature of the supportive/palliative support. Equally, some clinical specialists still view palliative care as dying care and in most instances supportive care is taking place locally and communication is good within primary care but not currently with specialist clinicians.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The guideline will include evidence related to supportive care needs of people in the last year of life where it is found but specialist clinical aspects of care, including the administration and delivery of transplant services are excluded from this scope.
4	**Interstitial Lung Disease**	13	307-316	Could you add here Idiopathic Pulmonary Fibrosis (IPF) (see NICE guidelines [CG163]) which causes	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on

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	Interdisciplinary Network			extreme breathlessness in the weeks/months prior to death often resulting in an unpredictable respiratory arrest if palliation has not been initiated. Thanks	service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the 'key facts and figures' section of the scoping document has been amended to reflect these changes.
111	**Julie Duffy Aromatherapy**	5	109	It is proposed that Complementary Therapy Services is an area that will be removed from the current published guideline. We feel that this proposal should be reconsidered or at the very least supported with a greater clarification. Whilst Section 11 of the current guidance is dedicated to complementary therapy (CT) services, CT is also mentioned elsewhere through the guidance, e.g. Introduction (definitions of supportive care) Point 19 and Co-ordination of Care (page 39) Points 1.18 and 1.24. The argument for retaining a section dedicated to complementary therapies encompasses voluntary	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				regulation; prevalent provision of complementary therapies within all areas of the sector, their widespread use by patients and carers and the information available to patients to make decisions about this use and an increasing evidence base to support their use. Since the publication of the current guidelines, and in line with recommendations made within the document, there has been a strengthening of the voluntary regulation of many complementary therapies. The establishment of the Complementary and Natural Healthcare Council (CNHC) via initial government support has further secured protection for the public by providing a UK voluntary register of complementary therapists. Additionally, the CNHC register has been approved as an Accredited Register by the Professional Standards Authority for Health and Social Care. The engagement of therapists meeting the requirements of either the CNHC or a relevant professional body member will ensure that patients and carers are able to access the best level of complementary therapy care. This will minimise the risk of individuals accessing unregulated holistic support from wider sources, which is more likely to occur if complementary therapy services are not	

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				included within the guidance. The current guidance acknowledges the fact that complementary therapies are widely used by patients to provide psychological and emotional support and '*the fact that these therapies are already in wide and effective use in the NHS and voluntary sector may be taken as a significant indication of their value'.* Complementary therapies are also used extensively to support carers in the significant role they play to support patients with a range of life-limiting conditions. The volume and quality of the evidence base supporting the use of complementary therapies for improved quality of life and well-being for individuals with cancer and other chronic life-limiting conditions is increasing. The cost effectiveness of complementary therapy intervention is an area that should be evaluated more extensively before recommendations for its removal from the guidelines are implemented. Supporting patients' wellbeing holistically via complementary therapies eases pressure on an already over-burdened supportive and palliative care service. Continued integration of complementary therapies into the range of supportive care measures available will enable the evidence base to be augmented by good quality research conducted by	

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				experienced professionals working in the field. The focus of this NICE guideline is on supportive and palliative care involving a holistic approach including spiritual and psychological issues. This must surely incorporate patients wishing to seek support from a range of non-medical interventions such as complementary therapies. An integrated assessment of the patient and carer's needs would therefore include complementary therapies. We would welcome a re-evaluation of the decision to remove Section 11 devoted to complementary therapies. At the very least we would expect that complementary therapies would continue to be included in a holistic and integrated manner at relevant points throughout the document.	
112	**Julie Duffy Aromatherapy**	8	186	In order to fully assess and evaluate current care provision complementary therapies should be included in any survey of patient-reported outcomes.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the

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					published guideline.
113	**Julie Duffy Aromatherapy**	8	187	Complementary therapies should be included in any survey of the views and satisfaction of those receiving supportive and palliative care and of those important to them to enable a full assessment and evaluation of current care provision	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
114	**Julie Duffy Aromatherapy**	8	189	To fully assess and evaluate the impact of current care provision, complementary therapies should be included in any survey of health-related quality of life.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
106	London North West Healthcare NHS Trust	Pg4	general	Holistic needs assessment: special consideration needs to be given to the role of nutrition in terms of nutritional assessment and addressing e concerns of patients and carers regarding food intake , enjoyment and appetite. The key issue is that food and nutrition foes not sit within any one of the dimensions of the HNA but	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within

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				uniquely spans the whole of it. 1. evidence exists to support the effect of malnutrition on physical function 2. Eating and nutrition has a fundamental role in social, psychological and emotional well-being. 3. Nutrition affects and is affected by cognitive functioning especially in dementia 4. Food has a key role in meeting the cultural and religious needs of people of all ethnicities. Not being able to eat can lead to people feeling marginalised from their culture and religious obligations. 5. There are key issues around Artifical Nutrition Support, its provision and withholding and withdrawing which are not adderessed on either the NICE guidelines for end of life care or the NICE guidelines for nutrition support	CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The guideline will not address the clinical issues raised in your comment. The General Medical Council's 2010 guidance on End of life care: clinically assisted nutrition and hydration, provides guidance in this area. Additionally, holistic needs assessment will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
107	London North West Healthcare NHS Trust	Pg7	general	The composition of multidisciplinary teams need to address how services from professions underrepresented in palliative care can be realistically commissioned and provided, particularly for dietitians and for speech and language therapists. Speech and language therapists have an essential role on supporting patients with compromised swallowing and in supporting patients with impaired	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for

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				communication. Dietitians have an essential role in supporting patients and carers in 1. Maximising enjoyment of food for as long as possible 2. Addressing reversible causes of malnutrition using a patient centred approach 3. Recognising and coming to terms with reduced food intake which is often part of the dying process	adults with cancer, they will remain within the published guideline. The guideline will not address the clinical issues raised in your comment however; the revised scope includes the following draft question: Who should be involved in providing end of life care services and how should these services be configured (for example the organisation and composition of the multidisciplinary team). Evidence will be searched for covering models of service delivery, including different compositions of multidisciplinary teams. The guideline will not address the clinical issues raised in your comment. The General Medical Council's 2010 guidance on End of life care: clinically assisted nutrition and hydration, provides guidance in this area.
108	London North West Healthcare NHS Trust	Pg 7	Line 181	At the scoping meeting, mention was made of the reluctance by NICE to include qualitative research in evidence reviews. This may preclude key evidence in many areas of research in palliative and supportive care especially when considering quality of life.	The pertinence of qualitative evidence within a service delivery guideline will be evaluated, and if appropriate and relevant for a question will be included and quality assessed in accordance with the NICE guidelines manual.
109	London North West Healthcare				

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	NHS Trust				
110	London North West Healthcare NHS Trust		General	I would hope that all professions will be represented in having an input to the guidelines. It would not be possible for each of the allied health professions to be represented on the committee as the committee would become too large and unwieldy, but it would not be possible for one allied health professional to represent the other profession as they would lack a full understanding of the other profession's roles. I would propose that a sub group be convened to enable the allied health professionals not represented on the committee to be able to contribute from their own unique professional perspective	Thank you for your comment. Recruitment for the guideline committee was advertised on the NICE website and stakeholders contacted to alert them to the roles being sought, 2 allied health professionals were hired to join the committee, not to represent their specialist roles, but (as this guideline will not focus on the clinical aspects of care) to instead bring to the table their experiences related to the delivery of services for adults in the last year of life.
54	**NCRI Brain Clinical Studies Group**	general	general	Clarity is required when the three phases of supportive, palliative and end of life care are juxtaposed. End of life care is not as well integrated within the document as the terms supportive and palliative. There is a risk of confusing non-professionals or creating unease in service users if the term 'palliative' is immediately equated with end of life care rather than with an earlier phase of support.	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.
55	**NCRI Brain Clinical Studies Group**	1	12	The term life limiting condition needs to be defined with the other terms in the table on page 3.	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline.

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56	**NCRI Brain Clinical Studies Group**	3	47	The table defines non specialist palliative care as provided by professionals. Shouldn't this role definition also include informal caregivers who provide palliative care as defined?	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.
57	**NCRI Brain Clinical Studies Group**	4	61	The scope fails to defend the exclusion of non NHS funded settings which may provide important aspects of care; exclusion of these settings may not reflect the reality of care provision and discriminates against those models of care.	Thank you for your comment. We recognize that some services in this setting are provided by the charitable sector and these providers may find the recommendations of relevance to their services however, non NHS or care funded settings are beyond the remit of NICE in relation to guidance provision.
58	**NCRI Brain Clinical Studies Group**	4 and 5	82 and 89	We strongly support the inclusion of transitional care for young adults.	Thank you for your comment and for contributing to the consultation process. Transition from paediatric to adult services will no longer be addressed in the guideline as an individual review question. NICE has produced a guideline on Transition from children's to adults' services for young people using health or social care services (NG43)..
59	**NCRI Brain Clinical Studies Group**	5	88	The term 'complex bereavement' should be defined and to whom it refers.	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline.

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					Recommendations on bereavement can be found in the 2004 guideline.
60	**NCRI Brain Clinical Studies Group**	5	91	Cognitive functioning is missing from the areas to be updated, with the list therefore not accurately reflecting the areas of interest in the holistic assessment list (lines 71-76).	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, holistic needs assessment will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
61	**NCRI Brain Clinical Studies Group**	5	108	It is unclear why areas such as complimentary therapies and social support services are being excluded – particularly for example when economic considerations will include personal social services	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within

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					CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
62	**NCRI Brain Clinical Studies Group**	5	117	It seems remiss to exclude condition specific needs assessment tools where reliable tools exist.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. As the guideline does not cover clinical aspects of care condition specific needs assessment tools will not be covered in our reviews. However, NICE has published a guideline on Care of dying adults in the last days of life that addresses the clinical aspects of care of dying adults – details on this guideline can be found at: https://www.nice.org.uk/guidance/ng31. Additionally, recommendations related to all life limiting conditions, could be found on the NICE website at the following link: http://www.nice.org.uk/Guidance.

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63	**NCRI Brain Clinical Studies Group**	6	123	Economic considerations should include return to work and out of work benefits.	Thank you for your comment. We will adopt an NHS and Personal and Social Services perspective when assessing the cost and cost effectiveness of care models; a wider societal perspective (including productivity costs) will not be adopted since if this was adopted in NICE Guidelines, those interventions aimed at the working population would be favoured and we would discriminate against the elderly, children, unemployed people and people with disabilities.
64	**NCRI Brain Clinical Studies Group**	6	131	No consideration has been given to the assessment of complexity to guide skill mix and assessment frequency within models of care.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The section on 'key issues and questions' has been amended and includes questions on the composition of the multidisciplinary team and timing and review of service provision.

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65	**NCRI Brain Clinical Studies Group**	8	183	Objective outcomes should be considered in relation to physical function and cognitive function. Work status should also be considered as a supportive care outcome,as should educational status for young adults.	Thank you for your comment. These are the main outcomes. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee.
66	**NCRI Brain Clinical Studies Group**	12	268	The phrase: 'supportive care is not related to the person's condition or prognosis' is ambiguous and perhaps should be re-phrased as 'the provision of supportive care is not reliant on a person's diagnosis or prognosis...'	Thank you for your comment. The remit and scope of this guideline has been changed and the context section of the scoping document has been amended to reflect these changes. The guideline will now focus on the delivery of services to adults in the last year of life.
67	**NCRI Brain Clinical Studies Group**	12	271	Physical and cognitive functioning is missing from the description of palliative care service remit.	Thank you for your comment. The remit and scope of this guideline has been changed and the context section of the scoping document has been amended to reflect these changes. The guideline will now focus on the delivery of services to adults in the last year of life.
89	NICE - Quality standards	4	82	The topic Transition from children's to adults' services has been referred to the quality standards library so this guidance could potentially be used during its development.	Thank you for your comment. Transition from paediatric to adult services will no longer be addressed in the guideline as an individual review question. NICE has produced a guideline on Transition from children's to adults' services for young people using health or social care services (NG43).
90	NICE - Quality standards	7	179	This should focus on issues specific to young adults using palliative and end of life services to avoid overlap with the Transition from children's to adults' services	Thank you for your comment. Transition from paediatric to adult services will no longer be addressed in the guideline as an individual review question. NICE

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				guidance.	has produced a guideline on Transition from children's to adults' services for young people using health or social care services (NG43). The scope has however been revised to include adaptations to adults' services for young adults thought to be entering the last year of life.
39	**Phyllis Tuckwell Hospice Care**	2	33	Include people in prisons	Thank you for your comment. All settings in which National Health services are commissioned and funded are within the remit of NICE guidance and this includes Prisons.
40	**Phyllis Tuckwell Hospice Care**	4	65	There are many different tools for holistic needs assessment and it is unlikely that consensus on one specific tool will be gained. As long as an appropriate tool is used competently and consistently by a service provider the actual tool used is academic. A specification for a tool might be useful to drive more detailed assessment in areas of concern, such as a pain, psychological, breathlessness, fatigue etc.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, holistic needs assessment will not be specifically addressed by any review question, but may be considered as part of service delivery models, in

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					accordance with available evidence.
41	**Phyllis Tuckwell Hospice Care**	5	109	Complementary Therapies are integral to the holistic care provided by Phyllis Tuckwell Hospice Care and have been part of service delivery for over 20 years helping to meet the supportive and palliative care needs of patients and families/carers. Current staffing is 2.8 wte paid Complementary Therapists and a team of over 20 volunteers. Complementary Therapies are embedded in all aspects of hospice care, including inpatient, day hospice, outpatient and community patient settings. Approximately 300 patients and carers receive complementary therapy input per month. As well as offering emotional and psychological support, Complementary Therapies also help in the management of distressing symptoms such as pain, stress, insomnia, oedema, skin problems, breathlessness, anxiety, panic and depression. Therapies include Aromatherapy, Reflexology, Indian Head Massage, Spiritual Healing, Acupressure, Acupuncture, Relaxation and Visualisation amongst others. There is now increasing evidence to show how Complementary Therapies can help relieve symptoms	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				and encourage emotional and psychological wellbeing. While the majority of this evidence is qualitative, this type of research should not be dismissed and has value. The Complementary Therapy Service is regularly evaluated. The most recent evaluation, using Measure Yourself Concerns and Wellbeing (MYCAW), showed 100% patients (n= 80) derived a benefit from a Complementary Therapy intervention with stress and pain being reported as the symptoms most positively impacted. The establishment of regulatory bodies including the Complementary Therapists Association (CthA) and the National Association for Complementary Therapies in Palliative Care (NACTPC) promote safe practice, provide a professional code of conduct and require all complementary therapists to belong to a governing body and have relevant insurance. The NACTHPC are currently rewriting the guidelines first published by The Prince of Wales Foundation and these are due out in the near future. The inclusion of Complementary Therapies in 'Improving Supportive and Palliative Care for Adults	

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				with Cancer, 2004', was justified as a reflection of the holistic nature of a patients care and offered increasing patient choice. This recognition assisted in establishing regulation and standardising the ongoing safe delivery of Complementary Therapies. Exclusion from the revised guideline would constitute a backwards step with regard to the safe delivery of Complementary Therapies in Supportive and Palliative Care. There is no rationale given for the removal of Complementary Therapies from the guideline.	
42	**Phyllis Tuckwell Hospice Care**	5	110	There is no rationale given for the removal of Research in Supportive and Palliative Care from the guideline. As the scope of the guideline is expanding to include life limiting conditions, support for research into this area of healthcare for this patient population becomes more necessary.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered

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					to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended.
43	**Phyllis Tuckwell Hospice Care**	5	112	There is no rationale given for the removal of user involvement from the guideline. Again, with the expansion of the guideline to include life limiting conditions support for user involvement becomes more necessary.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. User involvement in planning, delivering nad evaluating services has been covered in the NICE patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.
44	**Phyllis Tuckwell Hospice Care**	5	113	There is no rationale given for the removal of face to face communication from the guideline. Enhanced communication skills for staff working in supportive and palliative care as a key factor in delivering successful	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We

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				outcomes. Removal of this aspect from the guideline removes the impetus to ensure all staff have appropriate training and competencies in this skill.	will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Face to face communication is covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
45	**Phyllis Tuckwell Hospice Care**	5	114	There is no rationale given for the removal of social support services from the guideline. The complexity of patients accessing current supportive and palliative care services requires the full range of multi-disciplinary intervention including the skills of social support services to enable patients and carers to access the correct interventions/services to meet their needs.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. .
46	**Phyllis Tuckwell Hospice Care**	5	115	There is no rationale given for the removal of information from the guideline. With the expansion of	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on

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				the guideline to include life limiting conditions support for information services becomes more necessary, especially as patients/carers not previously accessing supportive and palliative care services will be completely naïve to what such services can offer them.	service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
47	**Phyllis Tuckwell Hospice Care**	7	156	The multi professional team should include complementary therapies and social care services.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
48	**Phyllis Tuckwell Hospice Care**	7	166	Is there a best model for co-ordinating palliative care services, or should this be about principles of best practice, prioritisation and locally care delivery; one overall provider or a consortium type approach with common aims, operational working, responsiveness etc. There is a need for home documentation to share	Thank you for your comment. The planning and coordination of services, including sharing information between multiprofessional teams have been included on the scope. More detailed review questions will be refined when drafting the protocols with the assistance of the guideline committee Any recommendation will be

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				information and/or one IT system for all providers and/or access to each providers IT system to enable up to the minute communication and information sharing.	based on critical appraisal of the evidence and precise wording reflecting the quality of findings. However, the development and delivery of electronic information systems is beyond the remit of this guidance.
49	**Phyllis Tuckwell Hospice Care**	General		Should service delivery in Care Homes have similar standards/expectations to the home setting? How can this be regulated given that many homes are private and do not have NHS or Social Care funding?	Thank you for your comment. The guideline committee hopes that this guideline will articulate standards for providing supportive and palliative care anywhere that NHS funded care is provided. This includes private home settings, care homes in instances where resources, funding and commissioned services are available to support the person's care in a range of settings or their wishes to die in their own home.
50	**Phyllis Tuckwell Hospice Care**	General		There is a need for a rapid response supportive and palliative care provision alongside planned care delivery within palliative care services 7 days a week and 24 hours a day.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Out of hours, weekend and 24/7 availability of services

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					are among the key areas to be covered in the revised scope.
51	**Phyllis Tuckwell Hospice Care**	General		There should be access to equipment 7 days a week.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Out of hours, weekend and 24/7 availability of services are among the key areas to be covered in the revised scope.
52	**Phyllis Tuckwell Hospice Care**	General		Access to palliative care medicines 7 days a week needs strengthening.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					Out of hours, weekend and 24/7 availability of services are among the key areas to be covered in the revised scope.
6	**Solace of Souls Care and Training**	5	97	There are some extremely good quality, specialist services, such as Solace of Souls, who are able to work with NHS services, for the promotion of excellent, efficient palliative care. These services need to be acknowledged and included in the care/support choices that are offered to patients, and honed, equally, to provide the best palliative services possible in all areas of the UK.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
7	**Solace of Souls Care and Training**	5	98	Currently, services such as bereavement support, particularly pre-bereavement, for families, are very sparse in many areas. Studies have shown that healing from grief can often be more effective when it begins (and is formally supported) before the death of a loved one. It is clear that all bereavement services need to be improved and extended, so that individuals are able to work through their grief, to be able to function effectively in their day to day life and contribution of society. It can assist in reducing the risks of long-term depression / post-traumatic stress, which can be extremely damaging. It will also reduce	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.

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				the strain on mental health services, which are already hugely over-stretched.	
8	**Solace of Souls Care and Training**	5	107	As the head of an organisation that puts education high on its agenda for palliative care, I strongly believe it is important for the guidelines to promote the need for effective education in two very important areas: 1. Across the board for all carers and professionals who work in any form with palliative care patients, to ensure they have a thorough knowledge of holistic care and support and all options that are available to individuals facing the end of their lives. 2. To offer services / promote services that offer education for patients and their families to understand what is available for them, how to access it, and how forward planning may be extremely important in utilising the appropriate services for their personal wishes and needs.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
9	**Solace of Souls Care and Training**	5	109	As a highly experienced health and social care professional and CEO of a specialist, holistic palliative care organisation, I have received numerous correspondence raising concerns, from holistic health practitioners and complementary therapists (CT's), regarding the proposal to remove CT's from the new recommended NIHCE Guidelines document. As I have	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care

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				worked in palliative care for many years, I also share these concerns because CT therapies have been clearly show to provide a major benefit to patients. CT's have been well documented and witnessed as being very effective in offering physical, psychological and spiritual wellbeing. This is particularly important at a time when patients and their loved ones are going through an extremely traumatic experience. These complementary therapies offer a variety of non-invasive 'treatments' that assist in promoting relaxation and peace, which may otherwise be difficult for many people at the end of life to achieve. The fact that there are already extremely limited, natural options that promote the feeling of wellbeing, for palliative patients, means that removing these services as an approved form of alternative therapy, will greatly reduce choice and options that are available to patients and their families. In addition to this, it has taken many years for complementary therapies to be accepted as valuable additions to traditional medicine in many mainstream medical settings. It is therefore a major concern to all CT's and health professionals, that work in end of life	for adults with cancer, they will remain within the published guideline.

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				care that removing complementary therapies from the NIHCE Palliative Care Guidelines, will send out negative signals. This is likely to damage the reputation of these highly valuable services in mainstream healthcare, particularly amongst professionals and Trusts that already have doubts about the positive effects of these therapies. At the end of the day, the people who will then be most negatively affected by the removal of CT's from the Guidelines document are the patients, who will have another helpful choice taken away from them. In an age when we are all agreed on the importance of holistic choice and support at the end of life, is it really in the best interests of our patients and their families, to remove CT's from this extremely important and respected document?	
91	South Tyneside NHS Foundation Trust	1	19-29	I think the categories of whom the guidance is for is clearly listed however feel that as an introduction to the whole document it needs to be absolutely explicit that supportive and palliative care is everyone's business as the general feeling following the 2004 guidance was that it belonged to specialist palliative care only despite the speciality only having 1 chapter out of the guidance	Thank you for our comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published

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					guideline. Consequently we have edited the 'who the guideline is for' section to include: Generalist and specialist healthcare professionals in primary and secondary care, commissioners, providers, other practitioners and people using end of life care services in the last year of life.
92	South Tyneside NHS Foundation Trust	1	12	Positive move is extending the scope of the guidance to all life limiting conditions in terms of equity of access	Thank you for your comment.
93	South Tyneside NHS Foundation Trust	4	82	positive to identify this group	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Transition from paediatric to adult services will no longer be addressed in the guideline as an individual review question. NICE has produced a guideline on Transition from children's to adults' services for young people using health or social care services (NG43).

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94	South Tyneside NHS Foundation Trust	4	65	it would be helpful to include some outcome measurement as part of the assessment process	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Main Outcomes are listed later in the scope, please see section 1.6 for further details. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee.
95	South Tyneside NHS Foundation Trust	5	107	It may be beneficial to set some baseline standard for education and training being mandatory for staff delivering care to this group of patients / carers	
96	South Tyneside NHS Foundation Trust	5	109	Can see why this has been removed however for services with only partial NHS funding this guidance would be helpful	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service

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					delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
97	South Tyneside NHS Foundation Trust	5	112	am assuming this be inherent throughout the document? Think it is an important aspect and quite difficult to engage this patient group	Thank you for your comment. User involvement in planning, delivering and evaluating services has been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.
98	South Tyneside NHS Foundation Trust	6	134-148	this needs to specified as a minimum	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
99	South Tyneside NHS Foundation Trust	8	186-194	Does there need to be inclusion of the national minimum data set and the categories of patients as suggested by the palliative care funding review – stable, unstable, deteriorating and dying	Thank you for your comment. These are the main outcomes. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee.

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100	South Tyneside NHS Foundation Trust	7	164-180	Needs to make reference to EPaCCS Does there need to be reference to how palliative care will be funded?	Thank you for your comment. The NICE scope will only refer to other NICE products in this section. Regarding, the funding of palliative care, we recognize that some services in this setting are provided by the charitable sector and these providers may find the recommendations of relevance to their services however, non NHS or care funded settings are beyond the remit of NICE in relation to guidance provision.
101	South Tyneside NHS Foundation Trust	3	57	As a lot of palliative care is provided via the charity sector, do we need an extra point here for clarity?	Thank you for your comment. We recognize that some services in this setting are provided by the charitable sector and these providers may find the recommendations of relevance to their services however, non NHS or care funded settings are beyond the remit of NICE in relation to guidance provision.
102	South Tyneside NHS Foundation Trust	7	169-170	Mention hospices specifically.	Thank you for your comment. The guideline will cover all settings where NHS care is provided or commissioned, however we have edited the question and removed the examples.
103	South Tyneside NHS Foundation Trust	General		Fully agree with the repeated references to transition from children's to adult's services. This is a difficult issue and recent advances in care have brought it to the fore. Cystic fibrosis and congenital heart disease are two good examples.	Thank you for your comment. Transition from paediatric to adult services will no longer be addressed in the guideline as an individual review question. NICE has produced a guideline on Transition from children's to adults' services for young people using health or

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					social care services (NG43)..
104	South Tyneside NHS Foundation Trust	12	250-259	Does there need to be a distinction between "end of life care" delivered as a person is dying and the type of palliative care referred to which is needed "long before the last 12 months of life"?	Thank you for your comment. The remit and scope of this guideline has been changed and the context section of the scoping document has been amended to reflect these changes. The guideline will now focus on the delivery of services to adults in the last year of life.
1	**SOUTH WEST AMBULANCE SERVICES NHS FOUNDATION TRUST**	General	General	The ambulance service has a unique, significant and increasing role in the supportive and palliative care for adults with Long Term Conditions (LTC's) and their concomittent life limiting components. Since the changes to the GP contract in 2004, ambulance services have become the main urgent care provider which includes out of hours (OOH) care and unscheduled care (USC) in addition to emergency (999) services. This changing and increasing role is often underestimated or overlooked in the planning and	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. One of the areas included in the revised scope is the delivery of unplanned 24/7 care.

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				delivery of NHS services by other stakeholders.	
2	**SOUTH WEST AMBULANCE SERVICES NHS FOUNDATION TRUST**	General	General	South West Ambulance Services NHS Foundation Trust (SWAST) is currently running a 3 year project to improve cancer care. The Cancer Care Improvement Project is an innovative joint venture between Macmillan Cancer Support and SWAST that recognises the unique and increasing interface that ambulance services have with cancer patients. Current challenges in cancer care include ensuring that cancer patients receive support from the right person at the right time and with the right level of skills to meet their individual needs. A significant part of this work concerns palliative and end of life care. Initial thematic analysis of complaints from cancer patients and their families alongside staff feedback related to our Right Care initiative suggest that there is also a role for frontline staff with supportive care (paramedics who see patients 1:1 as well as staff who speak to patients on the telephone via the 999, 111 services) . The project recognises cancer as a LTC and anticipates that the model of care that will be developed over the next 3 years will be applicable to all LTC's. The project will report in September 2018 and will be	Thank you for your comment and for contributing to the consultation process. The developers are mindful of the need for ensuring that a broad range of experience and knowledge is represented on the guideline 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. When convening the guideline development group the developers have followed the principles outlined in the NICE guidelines manual. Further, a guideline committee is never designed to represent the interest of any specific interest group, nor could all be represented. It is clinicians and professionals with knowledge of the field who are tasked with evaluating evidence when such evidence exists. The guideline committee members do not represent a professional body.

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				able to make a valuable contribution to the work of the guideline committee. and should have full committee representation rather than co-opted status	
162	**St Joseph's Hospice**	2	44	We suggest include people in prisons	Thank you for your comment. All settings in which National Health services are commissioned and funded are within the remit of NICE guidance and this includes Prisons.
163	**St Joseph's Hospice**	3	Box	We do not like the definitions. The PC definition focuses on end of life care whereas the supportive care definition is really what PC is. Why has the established WHO definition not been used? There should always be a need for us to provide care to patients longer than the last year of life as symptom control experts may be needed at an earlier point in their condition. PC can always discharge patients when they no longer require our specialist input. This does not help our quest to reduce the fear associated with PC and only being about death & dying. For us PC is much more than that.	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.
164	**St Joseph's Hospice**	3	Box	We find the definition of non-specialist palliative care very limiting – we would expect generalists to have some competence and basic knowledge in palliative care.	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline. The terms 'end of life services' and 'care at the end of life'

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					are now being used within a revised scope.
165	**St Joseph's Hospice**	4	83	We would like to see something included regarding outcome measures / measuring performance of services as a topic	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
166	**St Joseph's Hospice**	5	104	We believe that survivorship should also be included as we are looking at prognosis being much longer	Thank you for your comment. The guideline covers services delivery of the dying adult in the last year of life. Survivorship will not be specifically addressed by any review question as it is outside the remit of the guideline.
167	**St Joseph's Hospice**	6	145	We believe that patients should be reviewed according to needs so this is not a question that can be answered by one time measure. This should include outcome measures, emphasizing patient centred care and an assessment of their level of distress.	Thank you for your comment. The scope includes draft questions that reflect the key areas covered by the scope document. The more detailed, review questions will be refined when drafting the protocols with the assistance of the guideline committee.
168	**St Joseph's**	7	170	We are not sure about this question. We presume it is connected to moving services away from institutions	Thank you for your comment. The scope includes draft questions that reflect the key areas covered by the

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	Hospice			and into the community / OP setting??	scope document. The more detailed, review questions will be refined when drafting the protocols with the assistance of the guideline committee.
169	**St Joseph's Hospice**	12	269	This explanation does not make 'supportive care' clearer. We don't agree that PC is restricted to the last months & weeks of life – we consider efforts are being made in ensure PC is adopted much earlier in the disease trajectory as it was meant to be. On the point about prolonged survival the Temel, et al (2010) study showed that PC (not referred to as supportive care) was associated with longer survival.	Thank you for your comment. The remit and scope of this guideline has been changed and the context section of the scoping document has been amended to reflect these changes. The guideline will now focus on the delivery of services to adults in the last year of life.
24	**St Raphael's Hospice**	General	General	The hospice is concerned that the focus appears related to palliative care supporting an increasing number of patients from across the healthcare spectrum ranging from elderly care, frail elderly and chronic conditions. The ageing population will naturally increase the workload of palliative care however the specialty will not have the resources to look after 100% of people who die; nor will 100% of people require specialist palliative care but rather access to excellent social care, who understand the	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The guideline will cover the planning and coordination

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				requirements of caring for a person at the end of life. The guideline does not proactively reflect the development of collaboration and joined up working between specialities. Educating the wider workforce to support social care in the delivery of generic palliative care is key to supporting an increasing number of people to have good EoLC, this is not reflected in the guidance (**line 107**) as education and training are areas that will not be covered. It feels like the guideline is focused on supporting a failing NHS provision of care by pushing supportive care onto the voluntary palliative care services that are locally valued for the quality of care they deliver. The dilution of quality service provision will lead to palliative care having long waiting lists where appropriate patients will not get the services they require or would benefit from. Too little too late is not what hospice wants to be associated with in care for	of services, and this includes sharing information between teams and exploring the composition of the multidisciplinary teams. Education will not be addressed in this NICE guidance as guidelines on this area are the remit of the NHS led Health Education England. Further information can be found about this organisation at: https://hee.nhs.uk/. As recommendations in this area will no longer be updated please see the original guideline, CSG4 Improving supportive and palliative care for adults with cancer, for further details. This guideline aims to describe end of life (in the last year of life) care services for all conditions and diseases. It will review service models provided in the acute setting by disease-specific specialists and their supportive services, or by primary care or specialists in palliative care Face to face communication, information provision and user involvement in planning, delivering and evaluating services are covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v The patient experience guideline focuses on generic patient experiences and is relevant for all people who use adult NHS services in England and Wales. The

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				people with life limiting illness. In our opinion it is not in keeping with the Cecily Saunders approach to patient focused holistic care. Within current resourcing there is no clarity about how palliative care are to treat and support the new cohort of patients plus those that are currently being seen – particularly as there is to be a loss of emphasis on face to face communication (**line 113**). We feel there is lack of coherence within the guideline related to the areas that the guideline will not cover. In point **1.1 line 55** carers and those important to people accessing SPC are noted, yet at **line *112*** user involvement in planning, delivering and evaluating services are to be removed, as is information (**line 115**). Other areas of NICE Guidance state that every borough must have a user led forum (substance abuse and addictions), where as this guidance seems to be moving away from this important area of developing a	aim of the guidance is to provide the NHS with clear guidance on the components of a good patient experience. We are pleased to be able to list this guidance as related to the scope subject to this consultation process. The outcomes listed in the scope are the main outcomes. When the full review protocols are developed, additional outcomes may also be included after discussion with the guideline committee. User involvement in planning, delivering and evaluating of services is covered in the NICE Patient experience guideline and details can be found at the following link: https://www.nice.org.uk/guidance/cg138v. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended. Thank you for participating in the consultation process.

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				service. The removal of Complementary Therapies is also a concern. The benefit to patients and carers can be scientifically evidenced and there is also a large body of anecdotal evidence related to the benefits that are derived from these therapies. It is acknowledged that it is difficult in the palliative care setting to undertake long term studies that facilitate follow up as patients die. However we question whether the removal of these therapies is related purely to cost factors. We also note that there appears to be a mismatch between Outcomes and the Guidelines revised suggestions **– Line 186 & 187** Patient reported outcomes and views and satisfaction and **line 112** related to user involvement in planning…and evaluating services which is to be removed? The removal of Research in supportive and palliative	

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				care (**line 111**) is of serious concern. We questioned whether palliative care in this guideline was viewed as "woolly" and not "scientific"? Every speciality requires R&D to expand knowledge and support best practice. We consider this to be very short sighted. Is there a plan to highlight R&D within palliative care in any other NICE document? As an organisation we feel that there needs to be further examination of the guideline and clarification related to who has been involved in its construct as there are a number of aspects of the guideline that we feel need to be redefined.	
25	**St Raphael's Hospice**	General	General	The removal of Complementary Therapies is also a concern. The benefit to patients and carers can be scientifically evidenced and there is also a large body of anecdotal evidence related to the benefits that are derived from these therapies. It is acknowledged that it is difficult in the palliative care setting to undertake long term studies that facilitate follow up as patients	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care

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				die. However we question whether the removal of these therapies is related purely to cost factors. We also note that there appears to be a mismatch between Outcomes and the Guidelines revised suggestions – Line 186 & 187 Patient reported outcomes and views and satisfaction and line 112 related to user involvement in planning…and evaluating services which is to be removed? The removal of Research in supportive and palliative care (line 111) is of serious concern. We questioned whether palliative care in this guideline was viewed as "woolly" and not "scientific"? Every speciality requires R&D to expand knowledge and support best practice. We consider this to be very short sighted. Is there a plan to highlight R&D within palliative care in any other NICE document? As an organisation we feel that there needs to be further examination of the guideline and clarification related to who has been involved in its construct as there are a number of aspects of the guideline that we feel need to be redefined	for adults with cancer, they will remain within the published guideline. Further, please note that the outcomes listed in the draft scope are the main outcomes. When the full review protocols are developed, additional outcomes may also be included after discussion with the Guideline Committee. Regarding the removal of research in supportive care. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended. User involvement in planning, delivering and evaluating services has been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
105	**The Confederation of Healing**	5	109	We do not understand the reasoning behind the suggestion to remove complementary therapy services from the published guideline. It is our experience that	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all

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	Organisations			complementary therapies are a valued and respected service within healthcare. Specifically, we write about the complementary therapy of Healing, which service is often provided freely to patients within hospitals, hospices and nursing homes. Healing supports patients, their carers and the bereaved to cope with the many stresses and strains a life limiting illness can place upon them. We have members amongst our organisation who are working within palliative care, indeed we have match-funded a healer working in Derriford Hospital, Plymouth. These practitioners of Healing are getting regular positive feedback from their patients, who are receiving benefit from their services, and from the healthcare personnel with whom they work that their service is valued. Last year we held a presentation at Portcullis House, Westminster of two meta-analyses into non-contact healing, which had been published in the peer reviewed journal "Explore". These showed evidence of a significant effect size above chance that Healing can work. The publication is available on our website for reference. To sum up, we feel that removing complementary therapies from the guideline would be a step backward for an already burdened National Health Service.	conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				Patients should be given the right to choose their treatment.	
53	**The Homeopathy College**	5	109	This is a Freedom of Choice issue. Complementary Therapy Services are widely used in this area. Complementary Therapies are always going to be in difficulty when getting funding for good research as those organisations with sufficient money to fund research have no incentive to help prove that Complementary Therapies are effective. Despite this situation, there is a growing small body of evidence suggesting they are effective. A paucity of research indicating the value of these services does not mean that there is no value to them and most definitely should not be used as a reason to limit the freedom of choice of the public by removing them. Freedom of choice should never be curtailed in this country without extremely sound and compelling reasons.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
78	**The Mulberry Centre**	5	109	The draft scope is proposing to remove complementary therapies from the guidelines and we are responding to challenge this proposal. The Mulberry Centre has been running for nearly 15 years. We are an independent charity that provides complementary therapies, counselling and information and support services to people affected by cancer	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care

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				(patient, carer) and those at end of life or bereaved. We currently have 35 volunteer therapists delivering a range of complementary therapies including aromatherapy, massage, reflexology, shiatsu, acupuncture and yoga classes. We are concerned about complementary therapies not being included in the Supportive and palliative care in adults (update). We are unsure of the implications of this decision and how this may impact on the provision and quality of complementary therapies for patients in end of life care?	for adults with cancer, they will remain within the published guideline.
79	**The Mulberry Centre**	5	109	Comment 1 continued The old guideline talks about how patients and carers want good face to face communications and support for physical, emotional and spiritual needs. Meeting such desires is very much characteristic of complementary therapy services. They are patient centred and individualised; work well with multi-morbidity, functional disorders and combined physical/mental/spiritual issues; improve wellbeing and help people to develop better coping behaviour. *"I am much better able to cope physically and*	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				mentally." In fact, they are most useful in precisely those areas or aspects where conventional approaches may struggle. These were exactly the sentiments expressed in the recommendations of the 2004 guideline: *'Patients with cancer use complementary therapies because they feel the remedies are non-toxic and holistic, allow them more participation in their treatment and involve supportive relationships with practitioners'* *"The complementary therapy massage made an enormous difference to my ability to cope with my physical condition and the very depressed state of mind and anxiety which were not improved by drugs. This therapy also alleviates the sometimes very painful muscle aches and cramps associated both with my condition and the stress resulting from suffering from it. It is a life saver for people like me."*	
80	**The Mulberry Centre**	5	109	The only concern about complementary therapy services expressed in the 2004 guideline concerned the weakness of the evidence base. The current	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all

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				evidence is more extensive and stronger. We are aware of numerous articles that have been published by the Christie team. We have listed some examples here: Bardy J Finnegan-John J Molassiotis A Mackereth P (2015) Providing acupuncture in a breast cancer and fatigue trial: the therapists' experience. Complementary Therapies in Clinical Practice.21:217-222 Donald G Lawrence M Lorimer K Stringer J Flowers P (2015) The meaning and perceived value of mind-body practices for people living with HIV: a qualitative synthesis. Journal of the Association of nurses in AIDS care. 26(5): 660-672. Mackereth P Hackman E Knowles R Mehrez A (2015) The value of stress relieving techniques. Cancer Nursing Practice. 14(4): 14-21. Mackereth P Maycock P (2014) Aromatherapy and the SYMPTOM model. In Essence 13(3):9-12. Mackereth Bardy J Finnegan-John J Molassiotis A (2014) Receiving or not receiving acupuncture in a trial: the experience of participants recovering from breast cancer treatment Complementary Therapies in Clinical Practice. 20(4): 291-296. Mackereth P Hackman E Knowles R Mehrez A (2014) The value of complementary therapies for carers	conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				witnessing patients' medical procedures. Cancer Nursing Practice. 13(9):32-38. McLaren N Mackereth P Hackman E Holland F (2014) Working out of the 'toolbox': an exploratory study with complementary therapists in acute cancer care Complementary Therapies in Clinical Practice. 20(4): 207-21. Roberts D Wilson C Todd C Long Af Mackereth P Stringer J Carter A Parkin S Caress a-L (2013) Complementary therapies in cancer: Patients' views on their purposes and value pre and post receipt of complementary therapy—A multi-centre case study. European Journal of Integrative Medicine. 5: 443-449. Mackereth P Chaudhry S (2013) On reflection. International Therapist. October Edition 106: 20-22 Hackman E Mak T Mackereth P Tomlinson L Mehrez A (2013) Reducing "Bert's" distress: a CALM model of dementia care in oncology . British Journal of Nursing. 22(4) S20-24. Molassiotis A, Bardy J, Finnegan-John J, Mackereth P, Ryder DW, Filshie J, Ream E, Richardson (2012) Acupuncture for cancer-related fatigue in patients with breast cancer: a pragmatic randomized controlled trial. A.J Clin Oncol. 2012 Dec 20;30 (36):4470-6. Mackereth P (2012) Pandiculation: releasing anxiety during procedures. Anxiety Times. 83:14.	

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				Mackereth P Tomlinson L Maycock P Donald G Carter A Mehrez Lawrence Stanton T (2012) Calming panic states in the Mould Room and beyond: a pilot complementary therapy head and neck service. Journal of Radiotherapy in Practice. 11(2):83-91 Carter A Maycock P Mackereth P (2011). Aromasticks in clinical practice. In Essence. 10(2): 16-19. Donald G Tobin I Stringer J (2011) An evaluation of acupuncture in the management of chemotherapy induced peripheral neuropathy. BMJ Acupuncture in Medicine. 29(3):230-233. Mackereth P Mehrez A Maycock P (2011) At the cutting edge: the role of reflexology pre-& post-surgery. International Therapist. 96: 10-12. Stringer J Donald G (2011) Aromasticks in Cancer Care: An innovation not to be Sniffed at. Complementary Therapies in Clinical Practice. 116-21 Mackereth P A Parkin S Donald G Antcliffe N (2010) Clinical supervision and complementary therapists: an exploration of the rewards and challenges of cancer care. Complementary Therapies in Clinical Practice. 16: 143-148. Mackereth P Carter A Parkin S Stringer J Roberts D Long A Todd C Caress A (2009) Complementary therapists' training and cancer care: a multi-site study.	

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				European Journal of Oncology Nursing. 13: 330-335. Mackereth P Marland L (2009) Clive O'Hara (1948-2008) – pioneer of reflexology. Complementary Therapies in Clinical Practice.15:52. Stringer J Swindell R Dennis M (2008) Massage in patients undergoing intensive chemotherapy reduces serum cortisol and prolactin Psycho-Oncology. 17: 1024-1031. Mackereth P (2007) Touch Therapies: the curious researcher Journal of Holistic Healthcare Journal of Holistic Healthcare 4(4) 32- 36. Bott J (2007) An analysis of paper-based sources of information on complementary therapies. Complementary Therapies in Clinical Practice. 13, 53-62. Mackereth P Carter A (2006) Clinical leadership: developing the role of complementary therapy coordinators. Complementary Therapies in Clinical Practice. 12, 80-82. Mackereth P Carter A (2006) Nurturing Resilience: touch therapies in palliative care. Journal of Holistic Healthcare.3 (1), 24-28.	

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81	**The Mulberry Centre**	5	109	Comment 2 continued Below is a selection of recent research / audit / case studies from the Royal Marsden Hospital. • Dyer J, Cleary L, McNeill S, Ragsdale-Lowe M, Osland C. 2016 The use of aromasticks to help with sleep problems: A patient experience survey. *Complementary Therapies in Clinical Practice* 22:51-8 • Dyer J, Cleary L, Ragsdale-Lowe M, McNeill S, Osland C. 2014 The use of aromasticks at a cancer centre: A retrospective audit. *Complementary Therapies in Clinical Practice* • 20(4):203-6 • Dyer J, Sandsund C, Thomas K, Shaw C 2013 Is reflexology as effective as aromatherapy massage for symptom relief in an outpatient oncology population? *Complementary Therapies in Clinical Practice* 19(3):139-46 • Dyer J, McNeill S, Ragsdale-Lowe M, Cleary L, Cardoso M, Cooper S 2010 The use of aromasticks for nausea in a cancer hospital. *International Journal of Clinical Aromatherapy* 7(2):3-6 • Ragsdale-Lowe, M. 2009. Supporting a young girl	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				through radiotherapy, following resection of a brain tumour: Case study. *International Journal of Clinical Aromatherapy* 6(1):23-5 • Dyer J, Ashley S, Shaw C 2008 A study to look at the effects of a hydrolat spray on hot flushes in women being treated for breast cancer. *Complementary Therapies in Clinical Practice* 14:273–79 • Dyer J, McNeill S, Ragsdale-Lowe M, Tratt L 2008 A snap-shot survey of current practice: the use of aromasticks for symptom management. *International Journal of Clinical Aromatherapy* 5(2):17-21 • McNeill, S. 2007 Essential oils and massage used to support a patient with a compromised airway: a case study. *International Journal of Clinical Aromatherapy* 4(1):40-2	
82	**The Mulberry Centre**	5	109	Here at the Mulberry Centre from 1/6/15 – 31/12/15 our therapy team saw 226 clients. We collate feedback and it is clear how this addition to their care is valued for the difference it can make. Recent feedback (11/1/16/- 22/1/16) from 24 clients (18 cancer patients, 5 carers and 1 bereaved) showed	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated

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				that the symptoms clients most hoped to get help with were relaxation (15), anxiety (12), stress (10) and depression (8). These clients received a range of complementary therapies with all 24 reporting a slightly (7) or greatly improved (17) quality of life after treatment. For just over half (14) this improvement was continued to be felt more than a week after their treatment. *"It has helped me tremendously in coping with my condition. I have better mobility now and am more active because of this."*	within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
83	**The Mulberry Centre**	5	109	Comment 3 continued Longer term feedback kept by The Mulberry Centre shows that client overall wellbeing (score range, 1-5) went from a score of 1 or 2 (poor or very poor), to a 4 or 5(better or much better) for over 40% of clients – this was for both emotional and physical wellbeing. All respondents to the questions as to whether they would recommend our complementary therapies to another person, gave a 4 or 5 indicating they would definitely recommend us. *"The complementary therapy has been very helpful, it has helped me to relax, eased pain,*	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				improved mobility for a few days and also relieved stress. All in all it has been a wonderful experience." Some of the specific comments received by the Centre, including those in this response, show the additional impact the therapies have had for our clients. Some clients have been helped in their return to work, some have increased their mobility and activity levels, while many have found they are able to cope better with their diagnosis. *"I have been receiving the best care. Every time I leave I am relaxed, I sleep better and if I had headaches I will wake up the next day feeling wonderful and optimistic. Thank you."* *"It has helped me with pain and also given me confidence to start walking."*	
84	**The National Council for Palliative Care**	General	General	Whilst NCPC supports the continuation of supportive care, we recommend that the name of the guideline be changed to 'Improving palliative care and bereavement support'. NCPC recommends removing "supportive care"	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery

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				because the inclusion of the term is confusing: the distinctions between supportive and palliative care are not clear. Furthermore the framing of the guideline in terms of supportive care is very specific to those with cancer (as supportive care has primarily been used in relation to care for people with cancer). As the draft scope suggests (page 1, lines 11-12; page 14, lines 331-3) NICE recognises the need to extend this guideline to all adults with life-limiting conditions. Removing "supportive care" would make clear that this guideline applies to all life-limiting conditions, rather than just cancer. Bereavement support is an essential part of high quality care and support at the end of life. Whilst it is welcome that this will be updated in the revised guideline, it should be given much more prominence. NCPC therefore recommends including "bereavement support" in the title of the guideline.	and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline. Subsequently, the title of the guideline has been changed to: End of life care: Service delivery for adults in the last year of life.
85	**The National Council for Palliative Care**	5	98	Please see above regarding our recommendations on the prominence of bereavement support.	Thank you for your comment and for contributing to the consultation process. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where

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					recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Clinical management and bereavement support are therefore outside the remit of the guideline and may be misleading if included in the title of the guideline for users seeking advice on service delivery for end of life care across all conditions. Recommendations on bereavement can be found in the 2004 guideline.
86	**The National Council for Palliative Care**	5	104	NCPC supports the addition of sharing information between multiprofessional teams – in particular, there is a need to accelerate the uptake of Electronic Palliative Care Co-ordination Systems (EPaCCS). The Review of Choice in End of Life Care recommends 100% coverage of EPaCCS or equivalent systems by April 2018.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The planning and coordination of services, including sharing information between multiprofessional teams will be covered by the guideline when evidence is reviewed on service organisation for care in the last

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					year of life. Full review of the published evidence relating to service delivery, including information sharing will be conducted. This may include consideration of EPaCCs if published evidence is available.
87	**The National Council for Palliative Care**	5	109	Complementary therapies should not be removed from the guideline as they are important aspects of psychological and emotional support for people with life-limiting conditions and those who are important to them. They are part of the end of life care service in many care settings: according to the 2014/15 Minimum Data Set for Specialist Palliative Care, 72.8% of services who responded were providing complementary therapies as one of their services.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
88	**The National Council for Palliative Care**	5	112	NCPC considers "user involvement" in planning, delivery and evaluating services to be essential, although would recommend using the language of public participation, and co-production with people with lived experience. Person-centred care is at the heart of palliative care, and this must include co-design in service provision and evaluation. If it is removed, NCPC would strongly recommend the inclusion of this area in another appropriate guideline.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Further, user involvement in planning, delivering and evaluating services has been

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					covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.
23	**The Reiki Connection**	5	109	CAM has become an accepted and often requested service for those in palliative care and at The Reiki Connection we are concerned at the NICE proposal, in the area of public guidelines that complementary therapy services will be removed. Reiki, practitioners have been well received in this environment and appear to have been greatly appreciated judging on feedback from both the client and their family members. Many Reiki Practitioners have gone through a very robust form of verification, based on the National Occupational Standards (NOS) for the giving of Reiki in a professional Setting, NOS having been agreed with Skills for Health.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
170	**Thelma Rogers Practising as St Mary's Reiki**	5	109	The Draft Scope excludes Complementary Therapy. My opinion is that they should be included within the guidance because of the following reasons. Nowhere have you given any reason for excluding Complementary Therapies. I am a CNHC registered Practitioner who is about to commence work with MacMillan as a Complementary Therapist, my specialism is Reiki. I will be working within a facility attached to an NHS hospital in the SW	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				of England, where referrals are made by the Doctors and Specialists in charge of the patients' conventional care. My experience of the use of Complementary Therapy in palliative care and elsewhere in the NHS is both on a professional level and as an observer. Complementary Therapy is already available within the NHS and needs to be recognised and governed as part of patient's treatment and care plan within palliative care. Otherwise it will be only available to a small elite who can afford it and not the general population. The Scope speaks about the importance of treating the patient and their carers holistically. Complementary Therapy does just that it treats the person on physical, psychological and spiritual levels. In fact, the practise of Complementary Therapy echo's very strongly the whole ethos of your Draft Scope. It works to alleviate distress and symptoms towards the end of life and where remission is achieved. In the long run it is cost saving because of the holistic nature of the therapy and because the patient participates and plans the therapy with the practitioner. The improved wellbeing of the patient, reduced levels of complications and reduction in drug use for symptoms mean that the patient and the budget	

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				benefit. Complementary Therapists that work within the NHS and other closely related organisations are members of professional institutions, federations and the CNHC. Their standards of professionalism and training can be measured, monitored and policed and this needs to be visible within the NHS, not happening undercover as will happen if they are removed from the Draft Scope. Whereas a lot of Complementary Therapists do give their time to the NHS and other organisations on a voluntary basis, they are dedicated, trained and sincere people who still need to earn a living. This exclusion seeks to bring Complementary Therapy back to the dark ages and could lead to the demotivation of therapists and a whole tier of practical, cost effective and effective treatment being lost to the general population. There is a growing amount of evidence which shows that Complementary Therapies is effective both for patients, their carers and families. The families of Patients also benefit from Complementary Therapies especially in the area of coping where bereavement eventually happens. On a personal level I have observed the passing of two brothers with bone cancer a very long and painful journey for both of them, one having access to	

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				complementary therapy one who did not have access. If I were given a choice of which path towards my own death I could follow, I would walk the path which allowed me to access Complementary Therapy.	