End of life care: Delivery of adult services for people in the last year of life
Consultation on draft scope
Stakeholder comments table 1

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37	Affiliation of Crystal Healing Organisations	5	109	Regarding: Areas from the published guideline that will be removed. **Complementary Therapy Services.** On behalf of the Practitioners registered with the Affiliation of Crystal Healing Organisations I am objecting to the removal of complementary therapy services from these NICE guidelines, Crystal Therapy Practitioners may provide calming, comforting treatments to patients who are reaching the end of their lives. These services do not interfere with mainstream medical care. I feel Complementary Therapies in general can provide non-intrusive support to patients who may understandably feel scared and anxious about their final days. Emotional support for patients is an area where Complementary Therapies can be of great benefit. Many Professional therapists also offer their time as volunteers, giving patients time for care and personal interaction that increasingly over-burdened NHS staff cannot provide. We believe that everyone deserves to be treated with dignity at the end of their lives and their spiritual needs should be as fully catered for as far as possible. In this increasingly secular society a large number of people have developed a spiritual outlook and beliefs which are not aligned to any one specific mainstream Religion. Many people have turned to the more spiritually based	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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				complementary therapies such as Crystal Therapy and Reiki for a sense of spiritual connection. Whether the writers of the NICE guidelines are believers in this type of spirituality or dismiss it as 'new age nonsense' spiritual comfort should not be denied to any who wish to receive it, no more than a Priest should be denied access to the dying.	
438	Alliance of Registered Homeopaths (ARH)	4	65-70	This section reference 'Holistic needs assessment', yet later in the document NICE proposes to remove CT services as a recommendation in 'Improving Supportive and Palliative Care'. A care package which fails to consider an integrated approach, cannot refer to itself as 'holistic'. This is a seriously misleading title, which suggests the assessment is patient centred. If CT services are not being offered, any assessment can only be partial, not holistic.	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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place. Consequently, holistic needs assessment will not be specifically addressed by any review question, but

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					may be considered as part of service delivery models, in accordance with available evidence.
439	Alliance of Registered Homeopaths (ARH)	5	92-98	CT services have the potential to be of significant benefit to all the areas listed for updating. To deny patients CT services is to fail to fully consider their individual 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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
440	Alliance of Registered Homeopaths (ARH)	5	109	What is the reason for removing CT services from these guidelines? NICE has failed to provide a reason for making this seriously retrograde decision. The revised guidelines are supposed to improve supportive and palliative care for adults, yet an important group of healthcare interventions are being removed as a recommendation. This does not constitute an 'improvement'. The Health and Social Care Act 2012 clearly stresses 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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published

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				importance of patient focused delivery and patient choice. In sections 3 and 4 of the Act, it outlines how patients will be better able to choose the services which meet their individual needs, including services from charities, or independent sector providers (as long as they meet NHS costs). To remove CT services from adult supportive and palliative care appears to be a direct contravention of the Act. If clinicians and other healthcare providers are no longer able provide patients with the most appropriate treatment for their specific condition, which might include CT services, then clinicians/healthcare providers may find their clinical judgement significantly compromised. There are potentially significant cost implications in removing CT services from supportive and palliative care. They include: • The financial cost of providing alternative treatment options if CT services are withdrawn • The cost to patient wellbeing if a treatment option which addresses their specific needs is withdrawn • The financial cost of managing the adverse reactions so often associated with non CT interventions • The cost to the mental, emotional and physical wellbeing of patients and their carers, if they are denied ongoing access to CT services as part of their overall care plan	guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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441	Alliance of Registered Homeopaths (ARH)	5	112	Extraordinary decision to remove this from the published guideline. How does NICE propose to IMPROVE support and palliative care if it EXCLUDES user participation in planning, delivering and evaluating services? This does not even begin to make sense.	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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. 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
442	Alliance of Registered Homeopaths (ARH)	6	124	NICE has decided to remove CT services, yet claims to be taking economic aspects into account. What substantive comparisons have been made between the provision of CT services versus the provision of conventional services? Where can this information be accessed?	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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous

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					guideline will remain in place.
443	Alliance of Registered Homeopaths (ARH)	8	186-189	There has been little CAM research which specifically relates to supportive and palliative care in adults. However there are a number of published papers which suggest that CT services can be highly effective in improving the health and quality of life of patients with life-limiting conditions. They can also be effective in reducing overall treatment costs, and do not carry the risk of generating adverse reactions. The research includes: • Leckridge, B. (2004). The future of complementary and alternative medicine: models of Integration. J Altern Complement Med, 10(2), 413-6 • Reducing healthcare costs with homeopathy and anthroposophic medicine in Europe. ECHAMP 2014 • Smallwood, C (2005). The Role of *Complementary* and Alternative *Medicine* in the NHS. Freshminds. • Boon, H., Verhoef, M., O´Hara, D. etal (2004). From parallel practice to integrative health care: a conceptual framework. BMC Health Serv Res, 4 (15) • Frenkel, M & Cohen L. (2008). Incorporating complementary and integrative medicine in a comprehensive cancer center. Hematology/Oncology Clin N Am, 22, 727-36 This is by no means a conclusive list	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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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444	Alliance of Registered Homeopaths (ARH)	General	General	In conclusion, it is incomprehensible that NICE proposes to remove CT services from its supportive and palliative care guidelines. This decision: Denies patients meaningful healthcare choice Limits the treatment options which clinicians can prescribe Potentially increases the cost of provision, by relying on conventional interventions that may be more expensive than CT services, and may generate adverse reactions in the patient, thus creating the need for additional care Ignores the well documented benefits of an integrated approach to healthcare	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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
144	Alzheimer's Society	2	38	We are pleased to see that the scope states how the guideline will look at inequalities relating to people with dementia and cognitive impairment to ensure that they have equal opportunities to access services	Thank you for your comment
145	Alzheimer's Society	5	102	We are pleased to see this approach to holistic care and the importance placed on the identification of the needs of the person, their carers and people who are important to 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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency

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					between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. 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.
146	Alzheimer's Society	5	112	With regard to the focus on the provision of holistic support and the aim of supportive care to be related to the needs of the person and those closest to them, we would question why guidance on user involvement in the planning, delivery and evaluation of services is to be removed. In particular, for people with dementia, and their very individual needs, user involvement is essential in the ability to develop and maintain responsive, caring services that meet those 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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. User involvement in planning, delivering and evaluating services has been covered in the NICE Patient experience guideline,

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					more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.
166	Association for Palliative Medicine of Great Britain & Ireland	3	Definitions of palliative care and non-specialist palliative care	The definition of palliative care (as well as the definition of supportive care) should include enabling people to cope with illness, death and bereavement. The differentiation between palliative care and supportive care is unclear in these definitions. Why has 'Quality of Life' disappeared from the definition of palliative care? In the definition of palliative care, the social aspect of care should be included as a distinct section within the integration of psychological and spiritual aspects of care. In the definition of palliative care the term 'holistic' should be included. It does not make sense to not include this word here, but have it first on the list of key areas on page 4 line 65. The definition of non-specialist palliative care: it is confusing to say "professionals … without specialist skills, knowledge or competence in palliative care". Many people may not be specialists in palliative care but have varying levels 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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. 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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				competence / skills in the specialty e.g. GPs with a palliative care diploma. In the definition of specialist palliative care the list of the multi-professional team should not be limited to consultants and clinical nurse specialists, but should also include AHPs.	
167	Association for Palliative Medicine of Great Britain & Ireland	3-4	53-62	It is unclear why there is differentiation between NHS and non NHS units as both deliver palliative care to patients (and often the same patients). Surely standards should be equitable. This could lead to confusion for staff working in both NHS and non NHS palliative care units. Not all hospices have NHS funding. Some acknowledgement of patients being cared for in non NHS settings would be helpful.	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.
168	Association for Palliative Medicine of Great Britain & Ireland	4	65 - 76	Discusses holistic needs assessment & using established tools e.g. SPARC, distress thermometer and the 'pepsi cola' aide memoir. SPARC & the distress thermometer are widely known, but I don't know how widely known the pepsi cola aide memoir is. Any tool used to measure holistic needs must be relevant to patients in all settings. SPARC may be more appropriate to use in the community and less relevant in the acute setting. Care should be taken to ensure that, although there are many similarities between palliative care in the community	Thank you for your comment. **The guideline committee will take note of your observations.**

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				and secondary care, there are important distinctions. A common one is that the relationship between palliative care and patients in the acute setting is often very short, whereas it is more sustained in the community.	
169	Association for Palliative Medicine of Great Britain & Ireland	4	64-76	The word "wellbeing" is used several times in the list of suggested things that may be important to patients. The word "wellbeing" is vague and does not convey what it is we are trying to assess. It may be better to use more simple language and use words which describe loving and being loved or feelings of warmth, comfort and happiness (or their absence).	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, that the meaning of terms uses is explicit, and that vague terminology is avoided.**
170	Association for Palliative Medicine of Great Britain & Ireland	5	108-115	Proposes removing 6 sections from the current guideline and no reasons are given. These are areas that are integral to patient care. Removing research in from the updated guideline particularly feels like a backwards step.	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. 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.

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					User Involvement in planning, delivering and evaluating services, face to face communication and the provision of information have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.
171	Association for Palliative Medicine of Great Britain & Ireland	6	135-148	Clarification is essential on the difference between supportive care needs and palliative care needs – is the differentiation helpful with a practically achievable and meaningful outcome for both professionals and patients?	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, that the meaning of terms uses is explicit, and that vague terminology is avoided.
172	Association for Palliative Medicine of Great Britain & Ireland	6	134-141	Talks about considering what the best tool is to identify & assess holistic needs. This would need to be evidence based. Having one best tool may make the guidelines quite rigid.	Thank you for your comment. The questions will be refined when drafting the full review protocol in conjunction with the guideline committee. Any recommendations will be informed by the evidence identified for each review.
173	Association for	general	general	The document has several other paragraphs proposing to	Thank you for your comment.

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	Palliative Medicine of Great Britain & Ireland			find the "best" model for various things. Again, this should be evidence based. There is a concern that one size may not fit all.	**The guideline committee will take note of your observations.**
174	Association for Palliative Medicine of Great Britain & Ireland	6	142-148	Proposes that the reviewed guideline should include guidance on when & how often supportive / palliative needs should be reviewed. This may be difficult to be prescriptive about as the frequency with which patients' needs are reviewed must be individualised and probably different for each patient.	Thank you for your comment. The guideline committee will take note of your observations.
175	Association for Palliative Medicine of Great Britain & Ireland	8	190-191	Suggests that place of care & death be used as main outcomes to be considered when searching for & assessing the evidence. This can change with time so perhaps shouldn't be a main outcome	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.
176	Association for Palliative Medicine of Great Britain & Ireland	12	256-259	"There is a need to identify & standardise the supportive and palliative care that is need for people…" If the guideline attempts to standardise too much, some of the personalisation of palliative care may be lost	Thank you for your comment. The context section of the scoping document has been amended to reflect these changes.
177	Association for Palliative Medicine	12	277-279	The document says "In practice palliative care is restricted to the last months and weeks of life, while supportive care	Thank you for your comment. The context section of the scoping document has been

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	of Great Britain & Ireland			covers the earlier stages of progressive illness". This is not how palliative medicine physicians view palliative care and no evidence is given to support this statement.	amended to reflect these changes.
178	Association for Palliative Medicine of Great Britain & Ireland	13	294-303	Talks about how palliative care is still very cancer focussed. Is there evidence to support this as it is not what people are anecdotally reporting?	Thank you for your comment. The context section of the scoping document has been amended to reflect these changes.
179	Association for Palliative Medicine of Great Britain & Ireland	13-14	309-316	Many of the examples used sound more appropriate for chronic pain services than palliative care	Thank you for your comment. The context section of the scoping document has been amended to reflect these changes.
180	Association for Palliative Medicine of Great Britain & Ireland	14	337	It is unclear why 'specialist' is in inverted commas	Thank you for your commentThe context section of the scoping document has been amended to reflect these changes.
26	Association for the Advancement of Meridian Techniques, AAMET	5	109	Regarding: Areas from the published guideline that will be removed. Complementary Therapy Services. As a complementary therapist working for the NHS in cancer care I feel the need to state my objection to the removal of the complementary services from the NICE guidelines, Having set up a complementary therapy department for the Dorset Cancer Center at Poole Hospital (NHS trust) Poole Dorset in 1991 feel I speak from experience. Patients either receiving chemotherapy and or radiotherapy	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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not

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				on the ward or as out patients or in the hospice are offered aromatherapy, reflexology and EFT (emotional freedom technique) treatments free of charge. The aim of this service is to support the patient alongside their medical care which has proved over the years to be of great value as we are often called upon to help with anxious patients and stressed staff. I think I speak for the many therapists, paid or as volunteers who offer an invaluable service that fills the need in this for ever more and more technical and burdened NHS system.	being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
258	Association of British Neurologists	1	11	We welcome the move to extend the population to beyond adults with cancer. A number of life limiting neurological conditions such as motor neuron disease, MS, dementia and Parkinson's and related conditions (PSP, MSA) form an important part of the workload of palliative care 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.
259	Association of British Neurologists			The outcomes could be thought through more carefully. For example neither work status nor the 10 metre timed walk is a PROM but could be a measure of good palliative support 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.
317	Association of Reflexologists (AoR)	1	24	This draft document talks of the guidelines being for the use of generalists, specialists, commissioners and 'for other practitioners delivering end of life care services' yet the area	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery

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				that would provide guidelines for a subset of these (**complementary therapists)** is potentially being removed, we disagree with this removal.	within the last 12 months of life for all conditions. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
318	Association of Reflexologists (AoR)	2	41	These draft guidelines are in place to protect vulnerable groups, such as those with dementia or learning disabilities. These are groups where complementary therapies are recognised to fulfil a role in supportive needs and as such should be protected by guidelines.	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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
319	Association of	4	61	While the draft refers specifically to settings where NHS care	Thank you for your comment. Following

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	Reflexologists (AoR)			is provided, it is often the case that complementary therapies are offered within hospitals yet funded by external agencies such as charities. A research study in 2009 by Corner et al showed that reflexology is offered in 62% of NHS cancer units second only to counselling, with aromatherapy following up a close third at 59%. This data was collected in 2009 and undoubtedly the coverage will have increased since then. It is important therefore that the guidelines should include complementary therapies.	consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
320	Association of Reflexologists (AoR)	5	109	The draft is considering the removal of the guidelines regarding complementary therapies yet no rationale for this removal is provided, it would be expected that there should be a clear reason for removal under NICE protocols. If the lack of evidence base is the unstated underlying issue then it would be expected that a separate research fact finding consultation be put into place as there has been an increase in the research base since the original guidelines were written in 2004. Aside from the research studies carried out, most organisations that offer complementary therapies will have some sort of patient satisfaction data which we would hope would be reviewed. As a therapy organisation	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 Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				we could provide research references if provided with an opportunity to do so– currently adding attachments to this document renders it unacceptable. If the underlying issue is one based on the potential range of complementary therapies and therefore the difficulty in coping with the standards for acceptance the answer is a simple one. The General Medical Council has stated that when referring to a practitioner who is not a doctor or other statutorily regulated health professional, doctors must *'...... be satisfied that systems are in place to assure the safety and quality of care provided – for example, the services have been commissioned through an NHS commissioning process or the practitioner is on a register accredited by the Professional Standards Authority(PSA)'. Therefore any complications regarding the variability of complementary therapies can simply be solved by reference to those therapies on PSA accredited registers such as the Complementary and Natural Healthcare Council (CNHC).* *If the underlying issue for not retaining the guidelines for complementary therapies is economic reasons then under the statement on page 6 line 128, economic analyses should*	

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				be carried out as stated, before the removal of the guidance. *If the underlying issue is something other than these reasons then the central focus of the 'Putting patients first' agenda needs to be taken into account. 'We put people first. Everything we do is directly connected to our purpose of improving outcomes – not a process, not an organisation, not a profession – but the person who needs the NHS to care for them.' Putting people first NHS England. There is no denying that patients enjoy and benefit from complementary therapies. Quote from Dyer et al 2013 patient survey* ***'I only wished I had access to them (complementary therapy sessions) sooner; but thankfully I've had them. The recovery journey is more than outpatient's appointments.*** *' By removing the guidelines here it is likely that it will become more difficult for organisations to provide the support that complementary therapies offer in a safe and well-defined way.*	
321	Association of Reflexologists (AoR)	6	128	The draft document states that *'We will review the economic evidence and carry out economic analyses, using an NHS and personal social services (PSS) perspective, as appropriate.'* Therefore it would be expected that complementary therapies be given a full economic review of benefit prior to the removal of guidance on complementary therapies from the supportive and palliative care guidelines.	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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not

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					updated will remain within the published guideline.
322	Association of Reflexologists (AoR)	8	186-193	The draft document states that some of the main outcomes for assessing the evidence are; • Patient-reported outcomes. • Views and satisfaction of those receiving supportive and palliative care and those important to them. • Health-related quality of life. • Staff satisfaction among providers of supportive and palliative care. • Resource use and costs These outcomes are all relevant to complementary therapies and it is to be assumed that the same processes will be used for the assessment of complementary therapies prior to the removal from the 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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
323	Association of Reflexologists (AoR)	general	general	If the business case for the removal of the guidelines for complementary therapies is to tighten up this guideline in comparison to other more recently produced ones then we suggest that a specific stand-alone guideline for the use of complementary therapies within 'settings where NHS care is provided' should be considered. Complementary therapies are used in many areas of healthcare, not just supportive and palliative care so perhaps an overarching guideline could be produced. As a therapy organisation we would be happy to provide input where required.	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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this

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					guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
324	Association of Reflexologists (AoR)		references	Eur J Cancer Care (Engl). 2009 May;18(3):271-9.Patterns of complementary and alternative medicine use among patients undergoing cancer treatment. Corner J, Yardley J, Maher EJ, Roffe L, Young T, Maslin-Prothero S, Gwilliam C, Haviland J, Lewith G. Complement Ther Clin Pract. 2013 Aug;19(3):139-46. Is reflexology as effective as aromatherapy massage for symptom relief in an adult outpatient oncology population? Dyer J, Thomas K, Sandsund C, Shaw C	Thank you for Bringing these to our attention.
118	Brainstrust	1	12	*"Life limiting conditions"* needs to be defined with the other terms at the top of 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, that the meaning of terms uses is explicit, and that vague terminology is avoided.**
119	Brainstrust	1	15/16	Clarity is needed so that the three phases of supportive, palliative and end of life care are clearly delineated when juxtaposed. End of life is mentioned on page 1 but then	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery

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				virtually disappears. It is not integrated through the whole document like supportive and palliative care.	within the last 12 months of life for all conditions. 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.
120	Brainstrust	2	38 - 44	*Specific groups at risk of exclusion are mentioned. This means that there may be some groups that aren't mentioned that are excluded. This is borne out later by the cataphoric reference to those people who live with sickle cell anaemia – no mention of this group in this list and yet it has been singled out as at risk of exclusion.*	Thank you for your comment. This has been taken into account in our revised Equality Impact Assessment.
121	Brainstrust	2	47	*Definitions of roles. Shouldn't this include family carers, who also provide palliative care without specialist knowledge, skills and competence?* 'Palliative care provided by healthcare professionals within their normal duties, and without specialist knowledge, skills and competence in palliative care.'	Thank you for your comment. The revised scope will adopt a wider focus on service models that provide support for the carers or those important to the people accessing end of life services.

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122	Brainstrust	4	60 - 62	This is short sighted and does not reflect what really happens. People use a mix of services.	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.
123	Brainstrust		88	What is meant by complex bereavement and to whom is this referring? Patients? Caregivers?	Thank you for your comment. The final review question and review protocol will be discussed and agreed with the guideline committee. All 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. Recommendations on bereavement can be found in the 2004 guideline, and will not be updated.
124	Brainstrust	5	91-98	There is a disconnect here. It refers to the areas to be updated: Co-ordination of care Psychological support services	Thank you for your comment. This has been taken into consideration in the redrafting of the scope.

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				Spiritual support services General palliative care services Rehabilitation services Specialist palliative care services Services for families and carers, including bereavement care. But this doesn't relate to the areas to be covered mentioned in lines 71 – 76. Cognition is missing from the above list.	
125	Brainstrust	12	268-269	Supportive care is not related to the patient's condition or prognosis, rather to the needs of the person and those important to them. Why supportive care is not related to the patient's condition? Surely this would be taken into account? Some conditions like brain cancer mean that the patient has progressive neurological deficit. Early palliative interventions can prevent deterioration before it starts.	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. Consequently, the context section of the scoping document has been amended to reflect these changes.
126	Brainstrust	12	271	No reference again to cognition yet this was listed earlier	Thank you for your comment. This has been taken into consideration in the redrafting of the scope.
127	Brainstrust	General	General	Lack of integration of end of life care in this document, which reflects a lack of clarity about what the terms actually mean. Too little real understanding on what aspects guidance is	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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				being given. The document wavers between one list and another - there is no cohesion at all	conditions. . 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.
31	British Acupuncture Council	5	109	The draft scope is proposing to remove complementary therapy services from the updated guideline. It is unclear what the reason for this is. This despite the stakeholder workshop, which included patient groups and health professionals, wanting complementary therapy (CT) to be included in the guideline. Discussion in groups (and the summary of these discussions recorded and reported on the NICE website) showed that a) many of the orthodox health professionals present supported CT services, and b) the majority of groups fed back concerns about CT exclusion – indeed it was the most prevalent single issue. Despite this, the current version of the scoping document appears to be not in favour of CT, but with no rationale	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				given. CT services are no longer just to be 'not covered'; they are to be 'removed from the published guideline'.	
32	British Acupuncture Council	5	109	In addition, section 1.4 from the earlier draft has been taken out. This asked about the most effective interventions to meet supportive needs, but there is now no mention of interventions. A consequence of this is that any comments that focus on the strength of the evidence base for CT will be ruled out of scope, hence requiring no response. Various changes have been made to the draft scope in the light of feedback from the workshop but the powerful voice questioning the CT decision appears to have been ignored (which would not reflect well on the credibility of the exercise). The existing guideline (2004) spells out the various needs/wants of patients and carers, one of which is: *'to know what options are available to them under the NHS, voluntary and independent sectors, including access to self-help and support groups, complementary therapy services and other information'.* Is there now any indication that patients and carers no longer want access to CT services? Quite the opposite. Recent surveys indicate substantial levels of use across Europe, up to 90% in women with gynaecological cancers undergoing	**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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				radiotherapy (Muecke et al 2015). To meet this demand there was said to be growing provision within the NHS, with many hospices and oncology departments offering CT. This continues to be the case (Leng 2013), and orthodox health professional appear to be supportive (Ben-Arye et al 2013), so it is hard to understand why these services are now to be disenfranchised. The old guideline goes on to talk 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 CT 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. In fact they are most useful in precisely those areas/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'.* CT services are used not just to help them live with the side-	

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				effects of conventional treatments but even more so at the 'completed' stage, partly because there is little else on offer then (Matthews et al 2015).	
33	British Acupuncture Council	5	109	The only concern about CT services expressed in the 2004 guideline concerned the weakness of the evidence base. If discourse about evidence is now out of scope then we are in the strange position of not being able to respond to this but we shall make a few brief points nevertheless. The evidence is more extensive and stronger now, certainly for acupuncture, where there are many systematic reviews, primarily for side effects of chemo- and radio-therapy. For example Garcia et al (2015) identified nausea and vomiting as the best supported area for acupuncture use. Other side effect symptoms supported by recent trials were xerostomia, hot flushes, fatigue, lymphoedema and ileus. They saw acupuncture as a viable, low cost option for treating the side-effects of conventional medicine. The US Society for Integrated Oncology has published clinical practice guidelines for CT as supportive care for breast cancer patients (Greenlee et al 2014). They recommend (grade B evidence) acupuncture for nausea and vomiting and selectively recommend it (grade C) 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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				depression, fatigue, quality of life, pain and hot flushes. Several other CTs (meditation, yoga, massage) achieve A or B recommendations for one or more symptoms and others get a C. Similar findings are reported from the UK in an 'over-review' (Towler et al 2013). They concluded that acupuncture should be considered for symptom management where there are limited treatment options. The strength of the acupuncture evidence is much debated, centring on the differing results seen with either sham or usual care comparators. Tellingly, no cancer studies have found sham to be superior to 'true' acupuncture and the end position (given sufficient research accumulation) is likely to mirror that in chronic pain, with small effect sizes (0.2 SD) for sham comparisons and moderate (0.5 SD) for usual care/waiting list (Vickers et al 2012). In this situation very large trials, or well populated meta-analyses, are needed to identify sham comparison effect sizes with confidence, a situation that currently pertains only for nausea and vomiting re cancer. There is much less evidence on CT outside of oncology. An acupuncture example is Tsay's 2004 RCT on fatigue in late stage renal disease patients. A number of observational pilot studies in advanced cancer and haemodialysis populations have demonstrated change over a wide range of symptoms,	

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				alongside improved quality of life (Dean-Clower 2010), safety (Kim 2011), user endorsement of the service (Johnstone 2002), and the capability to stay living at home through the terminal stages (Takahashi 2009). A small RCT of acupuncture compared to nurse-led care in patients with incurable cancer reported global benefits without significant side-effects or other tolerance issues (Lim 2011). It appears that in the real world, outside of the placebo controversies, acupuncture and sham are found to be beneficial by both patients and health care professionals.	
34	British Acupuncture Council	5	109	In addition to the well known general mechanisms underpinning acupuncture's effects various pathways have been identified for specific cancer support areas, for example enhancing levels of vasoactive intestinal polypeptide and calcitonin gene-related peptide for xerostomia and hot flushes (O'Sullivan 2010). A collection of peer-reviewed summary papers of the existing scientific information on CT in cancer is available from the European CAM-Cancer project (hosted by the University of Tromso, Norway).	**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. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous

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				The only substantive objection to CT raised at the workshop was that it is not feasible to differentiate and evaluate individually the different therapies in CT. We would reject that argument on two counts: 1) given the patient demand, to avoid doing this review, simply because there's too much work involved, looks poor; 2) Most NHS CT services operate a bundle of individual therapies, not single ones. These could be evaluated as CT bundles without having to disentangle them. Hospices and hospital departments can provide you with information about how their CT services operate as a whole: how they are organised, how they integrate with orthodox approaches, whom they care for, patient and staff experiences, outcomes data and (possibly) economic data. CT service models used by oncologists are available in the orthodox oncology literature (Ben-Arye et al 2013). The 2004 guideline made these recommendations on CT: *'11.11 Commissioners, NHS and voluntary sector providers and user groups should work in partnership across a Cancer Network to decide how best to meet the needs of patients for complementary therapies where there is evidence to support their use.* *11.12 Commissioners should determine what complementary therapy services they wish to fund and in what setting and whether these should be made available for*	guideline will remain in place.

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				particular groups of patients, ensuring equal access for all patients meeting the relevant criteria. They should take account of the views of patients and health and social care professionals in determining local provision.' It would be useful to know what has been the effect of these recommendations and why it's now being proposed that they are no longer needed. The proposed new guideline differs significantly in its aims from the one it is updating: it is about improving service delivery rather than about improving care. The key questions are restricted to asking how to assess needs and how to organise the services that are meant to meet those needs. There's nothing about what the needs are, nor what should be offered in the services. Again, this makes it impossible to mount an argument against dropping CT services because any such argument is going to be out of scope. CT services may be able to help meet patient needs but we can no longer discuss such needs, nor such services. It would be very helpful to see the reasoning behind the CT exclusion.	
35	British Acupuncture	5	109	**References**	Thank you for bringing these to our attention.

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	Council			Ben-Arye E, Schiff E, Zollman C, Heusser P, Mountford P, Frenkel M, Bar-Sela G, Lavie O. Integrating complementary medicine in supportive cancer care models across four continents. Med Oncol. 2013 Jun;30(2):511. Dean-Clower E et al. Acupuncture as palliative therapy for physical symptoms and quality of life for advanced cancer patients. Integr Cancer Ther 2010; 9: 158-67 Garcia MK, McQuade J, Lee R, Haddad R, Spano M, Cohen L. Acupuncture for symptom management in cancer care: an update. Curr Oncol Rep. 2014 Dec;16(12):418. Greenlee H, Balneaves LG, Carlson LE, Cohen M et al. Clinical practice guidelines on the use of integrative therapies as supporting care in patients treated for breast cancer. Journal of the National Cancer Institute Monographs 2014; 50:346-358 Johnstone PA et al. Integration of acupuncture into the oncology clinic. Palliat Med 2002; 16: 235-9. Kim KH et al. Acupuncture for symptom management in hemodialysis patients: a prospective, observational pilot study. J Altern Complement Med 2011; 17: 741-8	

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				Leng G.Use of acupuncture in hospices and palliative care services in the UK. Acupunct Med. 2013 Mar;31(1):16-22 Lim JT et al. Is there a role for acupuncture in the symptom management of patients receiving palliative care for cancer? A pilot study of 20 patients comparing acupuncture with nurse-led supportive care. Acupunct Med 2011; 29: 173-9. Matthews M, Glackin M, Hughes C, Rogers KM. Who accesses complementary therapies and why?: An evaluation of a cancer care service. Complement Ther Clin Pract. 2015 Feb;21(1):19-25. Muecke R, Paul M, Conrad C, Stoll C, Muenstedt K et al. Complementary and Alternative Medicine in Palliative Care: A Comparison of Data From Surveys Among Patients and Professionals. Integr Cancer Ther. 2015 Jul 26. pii: 1534735415596423. [Epub ahead of print] O'Sullivan EM, Higginson IJ. Clinical effectiveness and safety of acupuncture in the treatment of irradiation-induced xerostomia in patients with head and neck cancer: a systematic review. Acupunct Med 2010; 28: 191-9.	

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				Tsay SL. Acupressure and fatigue in patients with end-stage renal disease-a randomized controlled trial. Int J Nurs Stud 2004; 41: 99-106. Vickers AJ, Cronin AM, Maschino AC, Lewith G, MacPherson H, Foster NE, Sherman KJ, Witt CM, Linde K. Acupuncture for Chronic Pain: Individual Patient Data Meta-analysis. Arch Intern Med 2012;172(19):1444-1453	
434	British Homeopathic Association	5	109	The British Homeopathic Association strongly opposes the removal of Complementary Therapy Services from the NICE guidelines for Improving Supportive and Palliative Care in Adults. Complementary therapies – including homeopathy – provide a valuable adjunct to conventional care, often enabling patients to reduce the amount of pharmaceutical drugs they have to take and cutting the number of times they have to visit their GP or be admitted to hospital. Not only does this benefit patients, it produces a financial saving for the NHS too.1 Although, generally, the evidence base for complementary therapies is inconclusive, this is no different to psychological therapies which the scoping process recommends for continued inclusion in the NICE guidelines. However, it must	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				remembered that "inconclusive" is not synonymous with "no evidence", and any objective review of the research literature will reveal a growing evidence base for the therapeutic benefits beyond placebo for many complementary therapies, including homeopathy.2, 3 Furthermore, it appears that spiritual support is also to be retained in the NICE guidelines, which has, apart from the anecdotal evidence of patients, even less evidence than complementary therapies. Greater choice for patients in healthcare is central to the government's NHS reforms. Complementary therapies are popular among patients and many want to access them on the NHS. If NICE removes Complementary Therapy Services from its guidelines, a range of effective and economical treatment options will be denied to some of the NHS's most vulnerable patients. 1. Witt C, Keil T, Selim D, et al. Outcome and costs of homeopathic and conventional treatment strategies: a comparative cohort study in patients with chronic disorders. Complement Ther Med 2005; 13: 79–86. 2. Mathie RT, Lloyd SM, Legg LA, et al. Randomised	

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				placebo-controlled trials of individualised homeopathic treatment: systematic review and meta-analysis. Syst Rev 2014, 3: 142. 3. Spence D, Thompson E, Barron S. Homeopathic treatment for chronic disease: a 6-year university hospital based outpatient observational study. J Altern Complement Med 2005; 5: 793–8.	
341	CAHSC	5	109	The draft scope currently excludes Complementary Therapy Services, although these were included in previous guidance. CAHSC consider these should not be excluded unless it can be ascertained that these are no longer of interest to the patient groups within the scope, their families or carers particularly within the context of addressing their holistic needs (as defined pa r64-76) social, psychological and spiritual. CAHSC considers that complementary services should be included but updated.	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
342	CAHSC	4	64-76	We note that a holistic needs assessment to identify the supportive and palliative care needs of patients, their carers and those important to them in considered a key area. The	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery

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				question arises once identified how are these to be met for each individual within an overstretched NHS service? We consider that inclusion of complementary therapies would be helpful in this context.	within the last 12 months of life for all conditions. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
343	CAHSC	3	47-48	As supportive care, defined: 'Care that helps the person and people important to them to cope with life-limiting illness and its treatment – from before diagnosis, through diagnosis and treatment, to cure or continuing illness, or death and bereavement' is included in the draft scope, CAHSC questions the rationale for removing complementary therapies from the scope without first ascertaining the extent to which these form part of supportive care It is noted that complementary therapies are specifically listed under supportive care options in the current NICE guidance	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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344	CAHSC	3	47-48	As palliative care is included in the draft scope, CAHSC questions the rationale for removing complementary therapies from the scope without first ascertaining the extent to which these form part of palliative care	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
345	CAHSC	6	134-148	It is stated that 'The guideline will look at inequalities relating to particular groups [p2 line 38-44] yet with regards holistic needs assessment the key questions imply that there is a 'best tool' for all ie does not appear to take the particular needs of these groups into account.	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

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					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.
346	CAHSC	7	150-152	Questions imply a presumption of a 'best model' /'best way/'rather than an openness to different models for different situations/ groups ertc	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. The guideline aims at identifying optimal models of care which could be different for different groups and situations.
347	CAHSC	7	165-169	As above questions imply there is a 'best' model, a 'best way' rather than being open to differing ways that deliver a good outcome for each patient. patients	Thank you for your comment. The guideline aims at identifying optimal models of care which could be different for different groups and situations. Also the guideline may not identify a single best model but some examples of how to best provide end of life care.
348	CAHSC	8	189	Why only focus on health-related quality of life when searching for evidence of outcomes given that the scope of a holistic needs assessment [which is considered key] extends beyond this?	Thank you for your comment. These are the main outcomes. When the full review protocols are developed

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					additional outcomes may also be included after discussion with the Guideline Committee.
349	CAHSC	8	183-194	If the evidence search indicates that complementary therapies or any other intervention not included in the current scope, have a role to play in achieving any of the main outcomes listed, what will be the response? Will there be a reconsideration of the scope of the guidance?	**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.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
350	CAHSC	12	256-257	'There is a need to identify and standardise the supportive and palliative care etc.:We consider that there should be a standard of care but that its delivery should not be 'standardised' but individualised	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer***

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					which are not updated will remain within the published guideline. Consequently, the context section of the scoping document has been amended to reflect these changes.
351	CAHSC	14	334	In direct contradiction to above re standardisation 'supportive care should be based in individual needs'	Thank you for your comment
189	Cavendish Cancer Care	5	109	The draft scope currently recommends that complementary therapies are removed from the revised published guidelines. We feel this is a regressive step at a time when the value of such therapies has never been more relevant. This is sure to place additional negative strain on community based healthcare services at a time when strategically NHS England has highlighted the importance of developing new models of care and partnership working between statutory and charity organisations in order to meet the healthcare needs of the future (for example in *Five Year Forward View)*.	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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190	**Cavendish Cancer Care**	5	109	The 2004 NICE guidance has drawn attention to the extent to which cancer patients seek out support from complementary therapies (up to one third) and the extent to which oncology departments report providing complementary therapy (two thirds). (NICE 2004, p152, 11.22 and 11.24)	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
191	**Cavendish Cancer Care**	5	109	Cavendish Cancer Care has valued the 2004 NICE guidance in developing our care, and in continually moving towards best practice in the use of complementary therapies as a support in cancer care. We should emphasise that our provision is for supportive care, and in no way intended 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. Recommendations from

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				treat cancers, and that this is made clear to clients.	CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
192	**Cavendish Cancer Care**	5	109	Our concern is that a useful support for us in providing our service in the most evidenced and up to date way may disappear if the proposed updated guidance excludes complementary therapies from its scope.	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4.

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					Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
193	**Cavendish Cancer Care**	5	109	The state of the evidence for complementary therapies had advanced since the 2004 guidance, and many organisations beside our own could benefit from updated guidance.	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4.Although the evidence base for complementary therapies may have advanced, reviewing this is not considered a priority. Although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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194	**Cavendish Cancer Care**	5	109	As supportive and palliative care services have always used a wide range of approaches, including complementary therapies, it seems arbitrary to exclude complementary therapies, simply for being complementary therapies.	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
195	**Cavendish Cancer Care**	5	109	Useful interventions could thereby have a decreased exposure to professional attention, with the result that patients have reduced access to therapies that can help reduce symptoms: e.g. acupuncture treatment for nausea and vomiting (NICE 2004, 11.26).	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. Recommendations from

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					CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
196	**Cavendish Cancer Care**	5	109	The 2004 guidance stated its objectives thus: 'To ensure that: - patients are empowered to make their own decisions about complementary therapies and therapists through the provision of high quality information - complementary therapies either commissioned by the NHS or provided in NHS facilities are provided safely by trained practitioners who are sufficiently aware 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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4.

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				clinical problems and psychological issues with which patients with cancer can present.' (NICE 2004, 11.10) These objectives seem to us to be not only still valid, but increasingly important, as we do not envisage that cancer patients' desire for support is likely to decrease in future years.	Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
197	**Cavendish Cancer Care**	5	109	Good information and empowerment of patients will become an even more important issue with the development of different models of service, such as Personal Health Budgets.	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. Recommendations related to information provision can be found in the NICE patient experience guideline. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v.
365	**Childhood Bereavement Network**			We understand the rationale for excluding children with long-term and life-limiting conditions, as they are covered in the separate forthcoming guideline for the care of children at the end of life. This guideline will also cover the needs of siblings	Thank you for your comment. We recognize the very real issues that impact on children when their parent or carer has palliative care needs. Thank you for your

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				of these children However, a separate group of children are affected when their parent or carer (or someone else important) has palliative care needs. This group has specific support needs before and after their parent's death, yet are often overlooked in policy and practice issues. We believe the EIA (and the scope) should make specific reference to this group, in line with the 2004 guidance p24: '*The Guidance concentrates on services for adults, but the needs of children who may be affected by an adult carer or relative with cancer are acknowledged'*. Each year in England and Wales, we estimate that 20,400 parents die, leaving dependent children (CBN, 2015). Many other children and young people are bereaved of someone else important in their lives each year. Children and young people facing the terminal illness of a parent have elevated levels of depression and anxiety: the most stressful time for them seems to be before the death (Seigel et al 1996). Their levels of anxiety are inversely correlated with the quality of communication in the family (Beale et al 2004) and with their perception of the well parent's general openness (Raveis et al 1999).	comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. Those aged under 18 are outside the scope of this guideline. There is current NICE guidance in development on End of life care for infants, children and young people. We will not be able to review the evidence or make specific recommendations for the needs of the children or young people you describe but we will bring your comments to the committee for their consideration in interpreting relevant service delivery evidence

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				Many children are not told when their parent is dying (Barnes et al 2000) and even families with open communication styles can struggle to communicate specifically about the parent's illness and impending death (Siegal et al 1996). Children bereaved of a parent are at increased risk of poor mental and physical health. Compared to their non-bereaved peers they are: a) are at increased risk of **early mortality,** being 50% more likely to die before middle age (Li et al 2014) and more likely to die early once over the age of 65 (indicating a persistent association with early mortality) (Smith et al, 2014). b) are 3 times more likely to have **physical health symptoms** in the clinical range, more likely to have a serious illness or accident, or to have been hospitalised (Worden 1996) c) are more likely to do things that **risk their health** including smoking, drinking (Sweeting et al 1998), not wearing a seat belt, being in a car with a driver who has been drinking, carrying a weapon, being in a physical fight (Hamdan et al, 2012), being	

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				hospitalised for drug or alcohol use (Wilcox et al 2010). Those bereaved suddenly are more likely to have substance or alcohol abuse disorders (Brent et al 2009). d) are 1.5 times as likely to have a **mental disorder** (Fauth et al, 2009); more likely to report **depressive symptoms** at the age of 30 (women) (Parsons 2011); 1.71 times more likely to **attempt suicide** in young adulthood (Jakobsen and Christiansen 2011); more likely to be hospitalised for a psychiatric disorder (Wilcox et al 2010) This group merits specific inclusion.	
366	**Childhood Bereavement Network**	6	139	We would like to see specific mention here of children and young people included in the group that may be important to the person with life-limiting conditions. In our experience, if this group is not explicitly included, they are often overlooked. Alternatively, an addendum could be added to line 148:	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. The list of draft questions included in the revised scope reflects these changes. Holistic needs assessments will not be specifically addressed by any review question, but may be considered as part of

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					service delivery models, in accordance with available evidence.
367	**Childhood Bereavement Network**	6	148	1.7 should also include identification of these people: eg 'When and how often should supportive care needs be reviewed in carers and those (including children and young people) who are important to people with life-limiting conditions? How should these people best be 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. The list of draft questions included in the revised scope reflects these changes. 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.
382	**College of Health Care Chaplains**	3	Table of definitions	The definitions, as separate entities, are good, except that there does not appear to be a recognition that integrating the psychological and spiritual aspects of a person's care is part of holistic care and may be needed all the way through the disease trajectory. This may be implied, but it has not been made explicit.	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. 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

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					the guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.
383	**College of Health Care Chaplains**	3	Table of definitions	Very pleased to see, in the definition of Palliative care, that people should have a support system that allows them to live as actively as possible until their death. It is so important to people's feeling of value and self-worth and therefore to their quality of life.	Thank you for your comment.
384	**College of Health Care Chaplains**	5	107	Very concerned that education and training is not to be covered in the Guidance. Whereas professionals will have access, non-professionals (i.e. carers) may not automatically have the same access, which could then compromise the care they give.	
385	**College of Health Care Chaplains**	5	109	Very concerned that complementary therapy services are being removed. For many people, especially as they come towards the end of their life, receiving complementary therapy enhances their wellbeing in a way that is difficult to put into words. It enables them to cope with the symptoms of their illness, some of which are extremely debilitating. It is a part of holistic care that people may not be able to access if it is removed, because of cost.	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4.

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					Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
386	**College of Health Care Chaplains**	6	123 ff	Economic aspects are an important factor in health care and the cost of treatment cannot be ignored. We would urge the committee to look at the evidence for how spiritual care interventions can help in reducing drug bills.	Thank you for your comment. This guideline will focus on the effectiveness and cost effectiveness of service delivery aspects of end of life care; therefore we will not be looking at the cost effectiveness of individual interventions such as spiritual care but we will look at different ways to deliver care, which may or may not include spiritual care.
387	**College of Health Care Chaplains**	6 – 7	179 -180	Overall, an excellent section. However, there is nothing about supporting those who are important to young adults as they move from children's to adults' palliative and end of life services. It is a very stressful time for them. Would it be possible to include a clause in 3.8, or have a 3.9: "How should those important to young adults be supported during this time of transition?"	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. The scope includes draft questions that reflect the key areas covered by the scope document, the technical team looks

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					forward to refining the more detailed, review questions when drafting the protocols with the assistance of the guideline committee.
388	**College of Health Care Chaplains**	8	186	As well as looking at patient-reported outcomes, we think that patients' experience should also be included as experience has an effect on outcome. Again, this might be implied but it is not explicit.	Thank you for your comment. These are the main outcomes. When the full review protocols are developed additional outcomes may also be included.
389	**College of Health Care Chaplains**	8	189	Instead of restricting quality of life to those things that are health-related, we think this should be a holistic quality of life, to include the met needs for the person and those who are important to them.	Thank you for your comment. These are the main outcomes. When the full review protocols are developed additional outcomes may also be included.
390	**College of Health Care Chaplains**	8	192	We think it important that staff safety, quality and effectiveness is included as these contribute to their feelings of satisfaction (or lack of satisfaction) and should be made explicit in this outcome.	Thank you for your comment. These are the main outcomes. When the full review protocols are developed additional outcomes may also be included.
391	**College of Health Care Chaplains**	9	213	There is Guidance on the transition between inpatient hospital settings and community or care home settings for adults with social care needs and are puzzled as to why this has been omitted from this section.	Thank you for your comment. The NICE scoping template only requires that related guidance, currently in development be included on the document. We are unable to make reference to the guideline in your suggestion.

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392	**College of Health Care Chaplains**	11	325 – 330	It would be helpful to know the evidence that shows that the "provision of supportive care for people … [is] mainly confined to a few large teaching hospital trusts … ", as this is a very broad statement.	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. Consequently, the context section of the scoping document has been amended to reflect these changes.
393	**College of Health Care Chaplains**	14	339 ff	It is disappointing that there is no mention of "Ambitions for Palliative and End of Life Care", the document that replaces the 2008 End of Life Care Strategy, as being relevant in informing the development of this 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. Consequently, the context section of the scoping document has been amended to reflect these changes. Additionally, we are unable to cross refer to non-NICE guidance. However policy document and strategies will inform the guidance and be referenced in the full guideline.

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380	College of Medicine			Thank you for this opportunity to submit our response. As a College, we cannot see the logic of removing complementary therapy services from this guidelines, when they are frequently part of service delivery for patients and their relatives/carers and clearly therefore something that both patients and the clinicians looking after them will need and want to know about. In my own hospital for instance, The Royal Devon Exeter Hospital, many patients and relatives receive help from an attacked charity FORCE, while many others use private complementary services or those available at a subsidised rate at my own NHS GP surgery. Some complementary services – e.g. for pain – are, as you know, provided within the NHS. Though we describe these services as complementary, they are often the most important treatment as far as patients are concerned, when facing the realities of palliative care. The desired outcomes of such patients are, of course, quite different from those, where cure is possible and that is why complementary treatments are particularly relevant in this area. We contend that the NICE guidelines need to reflect the reality of patient care, which is integrating both conventional	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				and complementary therapies. Omitting complementary medicine from the guidelines will create an "either/or" culture between "accepted" conventional practice and excluded complementary medicine. It will do nothing for the credibility of NICE as provider of unbiased material seeking to maximise the benefit for patients and clinicians. I would be very grateful to know the rationale of this decision and willing to provide input to any further debate/decisions on this subject.	
325	**Complementary and Natural Healthcare Council**	5	109	The draft scope is proposing to remove complementary therapies from the guidelines and we are responding to challenge this proposal. The provision of complementary therapies is demanded by patients hence the services provided. Approximately 40% of breast and prostate patients use complementary therapies and 20% of patients with other cancers. The evidence and audits are very patient-centred and almost always supportive of the service and what it has to offer (especially the qualitative work and audits). We provide further details in the comments that follow.	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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326	**Complementary and Natural Healthcare Council**	5	109	Complementary therapies are provided for patients, service users, carers and family members in almost every cancer and palliative care service in the country. Some of the most renowned cancer and palliative centres such as the Royal Marsden NHS Foundation Trust, Guy's and St Thomas's NHS Foundation Trust, St George's University Hospital NHS Foundation Trust, the Christie NHS Foundation Trust and a wide range of hospices and Macmillan cancer centres provide complementary therapies as an integral part of their supportive and palliative care 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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
327	**Complementary and Natural Healthcare Council**	5	109	Comment 2 continued Complementary therapies represent a patient-centred holistic approach to supportive and palliative care which precisely meet the definitions included at line 48 of the draft scope: *Supportive care: Care that helps the person and people important to them to cope with life-limiting illness and its treatment – from before diagnosis, through diagnosis and treatment, to cure or continuing illness, or death and bereavement.* *Palliative care**:** Care towards the end of life that aims 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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline,

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				provide relief from pain and other distressing symptoms, integrate the psychological and spiritual aspects of the person's care, and provide a support system that allows people to live as actively as possible until their death.	recommendations relating to complementary therapies in the previous guideline will remain in place.
328	**Complementary and Natural Healthcare Council**	5	109	Our representative at the NICE stakeholder workshop held on 2 December 2015 expressed concern about the proposal to remove complementary therapies at the workshop, along with many others present including patient representatives, a senior nurse operational manager and a palliative care consultant, and yet this seems to have been disregarded. We understand that one of the reasons provided at the workshop for the removal is that the term 'complementary therapies' covers a wide spectrum of approaches which would be difficult to include. To address this we would suggest confining the scope to those disciplines represented by practitioners on Accredited Registers such as CNHC's. In order to be approved by the Professional Standards Authority for Health and Social Care as an Accredited Register, the organisation concerned must provide details of the knowledge-base and risks posed by discipline(s) on its register. This ensures that all disciplines represented by Accredited Registers for complementary therapy will meet minimum national standards and will have a clearly defined knowledge-base.	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				As well as providing a clear rationale for which therapies could be included, the Accredited Registers Programme also ensures that service providers can point service users, carers, families and staff towards practitioners who are suitably trained and qualified. CNHC is the holder of an Accredited Register and is also the UK voluntary regulator for complementary therapies that was set up with Department of Health support. As such CNHC registration has been a requirement for complementary therapists in many NHS and other supportive and palliative care services around the country to address these very issues. Examples include Guy's and St Thomas's NHS Foundation Trust, the Royal Marsden NHS Foundation Trust, St George's University NHS Foundation Trust, Harrogate and District NHS Foundation Trust and many more.	
329	**Complementary and Natural Healthcare Council**	5	109	Comment 3 continued NICE may wish to be aware of the statement by Parliamentary Under Secretary of State for Public Health Jane Ellison MP speaking in the House of Commons on 3 November 2015: "*Both the Government and the Professional Standards Authority (PSA) recommend that when a patient or service user chooses to visit a health or care practitioner who is*	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain**

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				unregulated, only those on an accredited register are consulted." Rather than remove complementary therapies from the guidelines, surely it would be in the interest of public safety and a duty of care for organisations providing supportive and palliative care services, to have clear guidance about how best to find suitable practitioners, as well as how best to direct service users and their families. Complementary Therapies are now so embedded in the culture of cancer and palliative care that without proper guidance the door will be left open for ad hoc and unsafe practice, without reference to an evidence base. This would be a retrograde step and impinge on patient care and safe practice.	**within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
330	**Complementary and Natural Healthcare Council**	5	109	In terms of evidence, we note that the requirement for research in supportive and palliative care is being removed from the guidelines at line 110, which would appear to mitigate against some of the strongest challenges to the use of complementary therapies in NHS services. Nonetheless, whilst the original guideline acknowledges there are challenges with the evidence-base for complementary therapies it does state at (11.25): "*One Cochrane review, however, suggests that aromatherapy*	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.**

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				and/or massage confer short-term benefits for patients with cancer in terms of psychological well-being and, probably, a reduction in anxiety and some physical symptoms12 [A]. Another found positive benefits for patients with cancer from reflexology in breathing, reduction in anxiety and reduced pain13 [A].” It also notes at 11.26: *“...There is some indication that therapies might have the ability to improve patients’ general sense of well-being and quality of life through, for instance, reductions in distress, anxiety, pain and nausea [B].”* This evidence still stands and backs up the rationale for the use of complementary therapies in line with the definitions provided of supportive and palliative care at line 48. We provide below a number of references for more recent research into the use of complementary therapies in supportive and palliative care. (Please continue to next page)	Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
331	**Complementary and Natural Healthcare Council**	5	109	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	Thank you forbringing these to our attention.

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				• 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 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*	

ID	Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				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 (Please continue to next page)	
332	**Complementary and Natural Healthcare Council**	5	109	Comment 4 continued. Further references for relevant research studies below: Cassileth, B. R. and A. J. Vickers (2004). "Massage therapy for symptom control: outcome study at a major cancer center." *Journal of Pain and Symptom Management* 28(3): 244-9. Ernst, E 2009 Massage therapy for cancer palliation and supportive care: a systematic review of randomised clinical trials. *Supportive Care in Cancer* 17(4):333-7. Lee, S.-H., J.-Y. Kim, et al. (2015). "Meta-Analysis of Massage Therapy on Cancer Pain." *Integrative Cancer Therapies* 14(4): 297. Mackereth P Hackman E Knowles R Mehrez A (2015) The value of stress relieving techniques. *Cancer Nursing Practice*. 14(4): 14-21.	Thank you for bringing these to our attention.

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				Mackereth P Campbell G Maycock P Hennings J Breckons M (2008) Chair massage for patients and carers: a pilot service in an outpatient setting of a cancer care hospital. *Complementary Therapies in Clinical Practice*. 14:136-142. Samuel, A. and Ebenezer, I. (2013) 'Exploratory study on the efficacy of reflexology for pain threshold and tolerance using an ice-pain experiment and sham TENS control', *Complementary Therapies in Clinical Practice* 19, pp. 57-62. Seers, H.E., Gale, N., Paterson, C., Cooke, H.J., Tuffrey, V., Polley, M.J. Individualised and complex experiences of integrative cancer support care: combining qualitative and quantitative data. *Supportive Care in Cancer* 2009; 17(9): 1159-1167. (In collaboration with Penny Brohn Cancer Care). Sharp, D. Walker, M. Chaturvedi, D. Upadhyay, S. Hamid, A. Walker, A. Bateman, J. Braid, F. Ellwood, K. et al (2010) 'A randomised, controlled trial of the psychological effects of reflexology in early breast cancer', *European Journal of Cancer*, 46, pp. 312-322. So PS, Jiang JY, Qin Y. Touch therapies for pain relief in adults. *Cochrane Database of Systematic Reviews* 2008,	

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

ID	**Stakeholder**	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
				Issue 4. Art. No.: CD006535. DOI: 10.1002/14651858.CD006535.pub2. Stringer J Donald G Knowles R Warn P (2014) The Symptom Management of Fungating Malignant Wounds Using a Novel Essential Oil Cream. *Wounds UK* 10(3):30-38. Stringer J Donald G (2011) Aromasticks in Cancer Care: An innovation not to be Sniffed at. *Complementary Therapies in Clinical Practice*. 116-21 Stringer J, Swindell R, Dennis M 2008 Massage in patients undergoing intensive chemotherapy reduces serum cortisol and prolactin. *Psycho-Oncology* 17(10):1024-31. Tsay, S. Chen, H. Chen, S. Lin, H. and Lin, K. (2008) 'Effects of reflexotherapy on acute postoperative pain and anxiety among patients with digestive cancer', *Cancer Nursing*, 31, pp. 109–115.	
333	**Complementary and Natural Healthcare Council**	5	109	Comment 4 continued Further reference for relevant research articles Wilkinson SM, Love SB, Westcombe AM, Gambles MA, Burgess CC, Cargill A, Young T, Maher EJ, Ramirez AJ. 2007 Effectiveness of aromatherapy massage in the management of anxiety and depression in patients with	Thank you for bringing these to our attention.

ID	Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				cancer: a multicenter randomized controlled trial. *J Clin Oncol* 25:532-539 Wyatt, G. Sikorski, A. Rahbar, M. Victorson, D. and You, M (2012) **'**Health-related quality-of-life outcomes: A reflexology trial with patients with advanced-stage breast cancer', *Oncology Nursing Forum*, 39(6), pp. 568–577.	
334	**Complementary and Natural Healthcare Council**	3	48	Complementary therapies are provided in many supportive and palliative care settings precisely because they meet the definitions of 'Supportive Care' and 'Palliative Care' set out at line 48. We welcome these definitions but question why complementary therapies have been removed from the draft scope.	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** . Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
335	**Complementary and Natural Healthcare**	3 - 4	58 - 62	Line 59 proposes that all settings where NHS care is provided or commissioned be included in the scope.	Thank you for your comment. We believe that any NHS setting will be covered by the guideline as they would receive NHS

ID	Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
	Council			However, at lines 61 – 62 the proposal states that 'supportive and palliative care services commissioned and provided without any element of NHS funding' will not be covered. The exclusion of services which do not receive any element of NHS funding will not be helpful to those delivering services within NHS settings where the services are funded by other sources such as NHS charitable funds. Many complementary therapy services are provided as an integral part of NHS services, and staff are employed on NHS contracts even if the funding is from an NHS charitable or other source. For example, the Sir Robert Odgen Macmillan Cancer Centre in Harrogate is funded through NHS Charitable funds and employs a 0.8WTE complementary therapist on NHS terms and conditions. The same is true of many other services in this sector. We therefore suggest that lines 60 – 62 be removed. To specify the setting as set out at line 59 should be sufficient. (Please continue to the next page)	funding by definition. Therefore we do not think the settings covered by the guideline should be edited.
336	**Complementary and Natural Healthcare**	8	186	We note that at line 186 patient-reported outcomes may be considered when searching for and assessing the evidence. We agree that if services are to be patient-focused then this	Thank you for your comment. Thank you for your comment. These are the main outcomes. When the full review protocols

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	Council			is an appropriate way to assess the impact of supportive and palliative care services. To demonstrate some of the results already being achieved by the use of complementary therapies in supportive and palliative care we include details of two services below. The complementary therapies referred to are provided by CNHC registrants. 1) The Sir Robert Ogden Macmillan Centre, Harrogate and District NHS Foundation Trust This complementary therapy service is set within a new NHS day chemotherapy clinical unit in Harrogate, which opened in March 2014. From the outset, complementary therapies were seen as a key service to be incorporated within the original building design and integral to the health and wellbeing supportive services to be provided. Complementary Therapy Service Data collected since 2014 which reflects the complementary therapy activity and outcomes for patients and carers who have accessed the service. • Number of treatments given = 375 (Average of 5.5 per day) • Number of people treated = 93 • Number of Patients treated = 88	are developed additional outcomes may also be included after discussion with the Guideline Committee. Although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				- Number of Carers treated = 5 Percentage breakdown of the treatments given; Reflexology = 64% Massage = 24% Bowen = 7% Reiki = 5% Reasons for Referral Stress / Pain / Lethargy / Insomnia / Anxiety / Low Mood / Hot Flushes / Peripheral Neuropathy / Relaxation / Panic Attacks / Mobility / Swelling / Watery Eyes / Needle Phobias / Exhaustion Sources of Referral Clinical Nurse Specialists (For 7 different cancer sites) SROMC Chemotherapy Unit Consultant Oncologist Clinical Psychologist York Hospital Evidence impact of Complementary Therapy service *Treatment Outcomes using the 'Measure your concerns and Wellbeing' (MYCAW) Tool* – an evidence-based, validated tool designed specifically for evaluating complementary therapies in cancer support care (Paterson et al, 2013; Jollife et al, 2014). Patients reported Concern 1 improved by 58.4% following	

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				treatment Patients reported Concern 2 improved by 57.4% following treatment Patients reported their wellbeing improved by 57.7% following treatment The impact on need for this service has been demonstrated by a 4 month waiting list of over 40 patients requesting treatment.	
337	**Complementary and Natural Healthcare Council**	8	186	Comment 7 continued 2) The Dimbleby Cancer Care Complementary Therapy service at Guy's and St Thomas's NHS Foundation Trust supports patients with a cancer diagnosis to manage the physical and psychological impact the disease and its treatments. To evaluate the service and adhere to recommendations by the London Cancer Alliance, outcome measures were implemented into practice in May 2015. Below are summary results following seven months of outcome measure use. Completion rate and scope of this summary report During 19/05/2015 and 31/12/2015, 155 first forms and 48 follow-up forms were completed. There are fewer follow-up	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				forms because they are only completed if the patient attends their fourth and final appointment. The results below present the findings of the complete sets where both first and follow-up MYCaW forms have been sufficiently completed by patients who have attended the complementary therapy outpatient clinics at either the Guy's or St. Thomas' sites during this time-frame. Forms were included in this analysis if the patient had scored at least one concern (concern 2 is optional) on both the first and follow-up forms. Four sets of forms were not included in this report because they were insufficiently completed by the patient. The therapies offered in the outpatient clinic include aromatherapy, massage, reflexology and reiki. During their course of four sessions, the patients may have received the same therapy or a combination of different therapies; been seen by the same therapist or different therapists; and accessed the service at the same site or both sites. Results: Quantitative data analysis The pre- and post-treatment scores for patients' concern 1, concern 2 and well-being were compared using a paired-samples t-Test with a cut-off value for statistical significance of $p = 0.05$ (two-tailed). Concern 1: statistically significant improvement	

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				For concern 1, the average pre-treatment score of 4.05 ± 1.26 (mean ± SD) decreased to 2.24 ± 1.40 ($p < 0.0001$, n = 44). Concern 2: statistically significant improvement For concern 2, the average pre-treatment score of 4.19 ± 1.01 (mean ± SD) decreased to 2.35 ± 1.80 ($p < 0.0001$, n = 32). Well-being: statistically significant improvement For well-being, the average pre-treatment score of 2.86 ± 1.34 (mean ± SD) decreased to 1.98 ± 1.19 ($p < 0.0001$, n = 44). References for comment 7: - Paterson, C., Thomas, K., Manasse, A., Cooke, H., Peace, G. (2007) Measure Yourself Concerns and Well-being (MYCaW): An individualised questionnaire for evaluating outcome in cancer support care that includes complementary therapies. *Complementary Therapies in Medicine.* 15, pp.38-45. - Jollife, R., Polley, M., Jackson, S., Caro, E., Weeks, L., Seers, H. (2014) The responsiveness, content and convergent validity of the Measure Yourself Concerns and Well-being (MYCaW) patient reported outcome measure. *Integrative Cancer Therapies*.14,1, pp.26-34.	

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338	**Complementary and Natural Healthcare Council**	8	187	We agree that the views and satisfaction of those receiving supportive and palliative care and those important to them should be taken into account. We provide examples below. All complementary therapy services are provided by CNHC registrants. 1) The Royal Marsden NHS Foundation Trust Figures for RMH (last full year) April 2014 - March 2015 Aromatherapy Massage: 2,850 contacts / 1,083 patients Reflexology: 368 contacts / 190 patients The massage therapy service has been in existence at The Royal Marsden since 1988. It has grown to become 5 part time therapists over the two sites which is the clinical equivalent of 2 therapists offering massage / reflexology to In, Out and Day patients Monday to Friday every week, 9-5, one on each hospital site. In addition there are three extra days for the Clinical Lead for Complementary Therapies to organise research, audit, teaching, management etc. Patients are referred by any member of medical staff, nursing staff, rehabilitation staff or self. Reasons are: pain,	**Thank you for bringing this to our attention. A**lthough they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place. .

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				anxiety, poor sleep, low mood, nausea, breathlessness, fatigue and other related symptoms. Reflexology was introduced following a non inferiority randomised control trial involving 115 patients which was conducted to ascertain whether or not reflexology would offer the same benefits to patients as the existing service (ie the aromatherapy massage). As the results showed no statistically significant difference between the two therapies reflexology was introduced three years ago. '*In other words we listened to our patients' requests for reflexology, designed a study to compare the two therapies taking into account the sort of problems our patients bring to the complementary therapy team, and then put the results into practise.*' (Jeannie Dyer – Clinical Lead for Complementary Therapies). This research has been published. (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). Sample comments from the patients on this study are included below: "*The fact that the massage has been provided by the hospital makes it more connected to my condition. I felt comfortable enough to talk about my pain. Thank you.*"	

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				"The improvement in my lower back pain has been staggering" *"Being able to totally relax and de-stress and not think about my problem. Each treatment left me much more able to take things in my stride and rationalise. Great thinking time in a very positive way. Thank you for letting me be part of this trial, I can't emphasise enough the benefits of this to a patients wellbeing*."	
339	**Complementary and Natural Healthcare Council**	8	187	Comment 8 continued: 2) Some patient comments taken from the Sir Robert Ogden Macmillan Cancer Centre reported at comment 6 above. All services were provided by CNHC registrants: *"The treatments were tailored to side effects and symptoms of treatment and they helped alleviate symptoms for me – in particular peripheral neuropathy and watery eyes."* *"It helped me to relax and helped to get rid of feelings of depression. Generally improved mood and improved wellbeing."* *"Made me as a carer feel cared about."* *"My experience was brilliant, it helped with many physical symptoms I was experiencing."* *"Reduced anxiety, helped with insomnia."*	Thank you for bringing this to our attention.

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				"Fantastic service really helped manage side effects." *"Relaxing, Improvement in digestion following treatment."* *"Very relaxing environment and therapist. Feeling so much better on a daily basis, feeling more in control and stopped crying! Thank you Julie, a thoroughly enjoyable experience"* *"Knowing that after my chemotherapy treatment, I could look forward to deep relaxation during my reflexology session of ¾ to an hour for myself, escaping from the world"* *"Very good and has helped a lot. Would recommend to other people with chemotherapy, Thank you"* *"I think it is a wonderfully, humanising therapy to be able to prescribe and aid promotion of wellbeing"* *"Julie has been extremely kind, caring and supportive. I have been grateful for the chance to talk to her about my concerns and have some relaxing, helpful treatments"* *"The treatment was wonderful, relaxing and the music is very soothing. Lynn is excellent. Coming for treatments … it really has helped me"* *"Whilst it did not ease any of my symptom, (as mine were severe), it did help coming to see Julie for treatment. It was a nice treatment and one I could choose, which is important when you lose control with cancer. It was a very enjoyable and important treatment"* (Please continue to the next page)	
340	**Complementary**	8	192	We agree that staff satisfaction is an important measure.	Thank you for bringing this to our attention.

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	and Natural Healthcare Council			Here we provide some comments from staff about the supportive therapy service provided by CNHC registrants as part of the Full Circle Supportive Therapy service at St George's NHS Foundation Trust in London. The Full Circle team delivers therapies including reflexology, massage therapy and relaxation training as part of the Trust's Oncology, Haematology and Paediatrics services. Referrals are authorised by the patient's clinical or nursing team only. If a patient wishes to self-refer consent is requested and assessed by the clinical or nursing team prior to authorisation of therapy. *"Full Circle Fund therapy team has made a fantastic difference to the wellbeing of our patients. There is no doubt that chemotherapy and particularly bone marrow transplantation create huge anxieties in anyone who is faced with the need. Even with the best clinical care and explanation these tensions remain and the professional expertise of the Full Circle Fund's Therapy Team has helped so many to relieve the fear and relax the tension."* Professor Ted Gordon-Smith, MD, FRCP, FRCPath, FMedSci Professor of Haematology, St George's Healthcare NHS Trust *The St George's Transplant programme benefits greatly from*	

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				the work of the Full Circle Therapy Team who provide a much needed service integral to the well-being and health of my patients. Stem Cell Transplantation is a complex procedure which requires a multidisciplinary team working closely together. I receive extremely positive feedback from my patients regarding the role that Full Circle play in their recovery process. I am certain that the excellence of our transplant programme is in part due to the wonderful and professional work performed by the Full Circle Therapy team. Dr Mickey Koh, MD, PhD, MRCP, FRCPath, Director Stem Cell Transplantation, Consultant Haematologist/Hon Senior Lecturer, St George's NHS Foundation Trust and Medical School. *"The supportive therapies provided by Full Circle Fund provide patients with a lifeline and often become the highlight of the week. The provision of supportive care therapies is an essential to the holistic management of cancer patients and patients with chronic lifelong debilitating haematological conditions."* Dr Fenella Willis, MD, FRCP, FRCPath, Consultant Haematologist. St George's Healthcare NHS Trust *"The beneficial effects of massage therapy, reflexology and breathing techniques have been demonstrated in adult*	

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				patients with sickle cell disease, who have reported improved well being and have experienced fewer and shorter hospitalizations. We are looking forward to working with Full Circle Fund's Therapy Team and empowering more young patients and their carers with strategies to allow them to cope with this chronic disease." Dr Maria Pelidis, MD. Consultant Paediatric Haematologist/ Oncologist, St George's Healthcare NHS Trust	
14	**Crystal Therapy Council (CTC)**	5	109	Regarding: Areas from the published guideline that will be removed. Complementary Therapy Services. As a complementary therapist working for the NHS in cancer care I feel the need to state my objection to the removal of the complementary services from the NICE guidelines, Patients either receiving chemotherapy and or radiotherapy on the ward or as out patients or in various hospices are offered aromatherapy, reflexology and other treatments free of charge. The aim of this service is to support the patient alongside their medical care which has proved over the years to be of great value as we are often called upon to help with anxious patients and stressed staff. I think I speak for the many therapists, paid or as volunteers who offer an invaluable service that fills the need in this for ever more and more technical and burdened NHS system.	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 Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				Sue Lilly CTC Chairperson	
445	**East & North Hertfordshire NHS Trust**	1	11	Positive that the scope includes people with all life limiting conditions and not just those with cancer	Thank you for your comment.
446	**East & North Hertfordshire NHS Trust**	1	15-16	Consideration needed about the use of the proposed guideline to update the NICE Quality Standard for end of life care. Palliative and end of life care are not synonymous and this needs to be further clarified.	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. Consequently, only information relating to the provision of services in the last 12 months of life will be used to update the end of life care quality standard. 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, that the meaning of terms uses is explicit, and that vague terminology is avoided.
447	**East & North**	2	41-44	Good to specify those with dementia and other increasingly	Thank you for your comment.

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	Hertfordshire NHS Trust			common co-morbidities.	
448	**East & North Hertfordshire NHS Trust**	3	47 - 48	Whilst it is very useful to have included definitions of supportive & palliative care (specialist and non-specialist), there are already a number of established, nationally agreed definitions of end of life care, palliative care and specialist palliative care. For clarity, these should be used in the current NICE document rather than developing conflicting variants. Definitions listed in *One Chance to get it Right* https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf	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. Consequently, 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.
449	**East & North Hertfordshire NHS Trust**	3	65	Review choice of holistic assessment tools to align with national work on clinical outcome measures (National Clinical Database for Palliative Care and Palliative Care Currency). Robust tools, such as those from the Outcomes Assessment Complexity Collaborative (OACC) have gone through a much more rigorous assessment process than aide memoirs such as PEPSI COLA. As services are required to use OACC tools for national reporting these need to be included. http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/re	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. Holistic needs assessments will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance

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				search/studies/oacc/index.aspx https://www.england.nhs.uk/wp-content/uploads/2015/03/dev-new-apprch-pallitv-care-fund.pdf http://www.endoflifecare-intelligence.org.uk/national_information_standard/palliative_care_dataset/	with available evidence.
450	**East & North Hertfordshire NHS Trust**	4	82	Good that it will identify transitional care for young adults	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).
451	**East & North Hertfordshire NHS Trust**	4	86	Service delivery should also include cross-organisational models as in the supportive care section *"Service delivery models, including those covering both acute and community settings."*	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. The revised scope will look at service delivery models for end of life care, including those covering both acute, community and third sector settings.

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452	**East & North Hertfordshire NHS Trust**	5	88	Good that identification and referral of people at risk of complex bereavement will be included; disappointing that management of bereavement will not be covered.	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. Recommendations on bereavement can be found in the 2004 guideline. In addition the scope of this guideline does not include care after death.
453	**East & North Hertfordshire NHS Trust**	5	108	Realistic to remove complementary therapies from the guideline due to the lack of evidence base.	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to

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					complementary therapies in the previous guideline will remain in place!
454	**East & North Hertfordshire NHS Trust**	5	112	User involvement never really took off in this guidance as difficult to keep current 'users' so better to move this to patient experience	Thank you for your comment. The guideline on patient experience covers this and will be cross referred to in the guideline: https://www.nice.org.uk/guidance/cg138.
455	**East & North Hertfordshire NHS Trust**	6	123	Please clarify in the economic section whether only NHS funding will be reviewed or also charitable contributions in voluntary sector organisations where dual funding applies.	Thank you for your comment. The perspective adopted for this guideline will be that of the NHS and PSS and the cost impact and cost-effectiveness of recommendations will be formally assessed for these bodies only, as the guideline recommendations apply to these only. We acknowledge, however, that the cost of end of life care is only partially borne by the NHS and PSS and that the funding arrangements in this area are complex. The guideline committee will therefore consider the potential cost impact on other sectors more informally (i.e. without explicit quantification).
456	**East & North**	7	161 & 176	As specialist palliative care is covered in the section of	Thank you for your comment. This and

ID	Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
	Hertfordshire NHS Trust			palliative care services consider removing this as an example from the supportive care section to avoid duplication.	others has been taken into account in the redrafting of the scope.
457	**East & North Hertfordshire NHS Trust**	8	193	Please ensure that resource use and costs of hospice admission and use of voluntary sector community palliative care services is included. This commissioned by the NHS and with the implementation of the new Palliative Care Currency will now be funded by it as well.	Thank you for your comment. The section you refer to lists the main outcomes for the guideline. When the full review protocols are developed, additional outcomes may also be included after discussion with the Guideline Committee.
458	**East & North Hertfordshire NHS Trust**	12	252	Is the reference to the LCP essential for context? The risk of including it is that this keeps the focus on the past and not the future. It could just be stated that recent national policy documents have reviewed the needs for end of life care.	Thank you for your comment. We feel that the recent withdrawal of the LCP is an important piece of context which should remain in the scope.
459	**East & North Hertfordshire NHS Trust**	12	268	*Supportive care is not related to the patient's condition or prognosis, rather to the needs of the person and those important to them.* This is equally true of palliative care. The two should not be differentiated by the point in the disease pathway at which they are provided but by the clinically complexity / level of need and the breadth of service required to meet this.	Thank you for your comment. This has been taken into consideration in the redrafting of the scope.
460	**East & North Hertfordshire NHS Trust**	12	277	Palliative care is not limited to the last weeks or months of life. Many services offer medical support to patients with complex needs pre-diagnosis or to those who have long term but not currently life limiting conditions.	Thank you for your comment.

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461	**East & North Hertfordshire NHS Trust**	13	309	Key facts and figures The wording of this section appears emotive rather than factual. There is a lack of figures to highlight why particular clinical conditions are referenced. For example, whilst sickle cell disease is common in certain population groups, what is the national incidence / prevalence or comparative severity of symptoms that mean that it is included as an example of unmet need as opposed to other conditions?	**Thank you for your comment.** This has been taken into consideration in the redrafting of the scope.
462	**East & North Hertfordshire NHS Trust**	14	334	*Supportive care provision should be based on individual needs, not the stage of disease or prognosis, determined by consistent and comprehensive holistic needs assessment.* As should palliative care.	**Thank you for your comment.** This has been taken into consideration in the redrafting of the scope.
209	**Eden Valley Hospice**	3	59	Eden Valley Hospice is within the appropriate settings to submit supportive evidence as NHS care is provided within the hospice	This is noted.
210	**Eden Valley Hospice**	4	72	The draft scope identifies that key areas to be covered include Social Wellbeing – an area supported by Complementary Therapy, specifically Reiki, with evidence from the research paper including: 1. Baldwin AL, Vitale A, Brownell E, Scicinski J, Kearns M, Rand W. The Touchstone Process: an ongoing critical evaluation of reiki in the scientific literature. Holist Nurs Pract. 2010 Sep-Oct;24(5):260-76. 2. Bowden D, Goddard L, Gruzelier J. A randomised	Thank you for bringing these to our attention.

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				controlled single-blind trial of the effects of Reiki and positive imagery on well-being and salivary cortisol.Brain Res Bull. 2010 Jan 15;81(1):66-72. 3. Bullock M. Reiki: a complementary therapy for life. Am J Hosp Palliat Care. 1997 Jan-Feb;14(1):31-3. 4. Burden B, Herron-Marx S, Clifford C. The increasing use of reiki as a complementary therapy in specialist palliative care. Int J Palliat Nurs. 2005May;11(5):248-53. 5. Crawford SE, Leaver VW, Mahoney SD. Using Reiki to decrease memory and behavior problems in mild cognitive impairment and mild Alzheimer's disease. J Altern Complement Med. 2006 Nov;12(9):911-3. 6. Miles P. Reiki for Mind, Body, and Spirit Support of Cancer Patients. Adv Mind Body Med. 2007 Fall;22(2):20-26. 7. Rivera C. Reiki therapy--a tool for wellness. Imprint. 1999 Feb-Mar;46(2):31-3, 56. VanderVaart S, Gijsen VM, de Wildt SN, Koren G. A systematic review of the therapeutic effects of Reiki. J Altern Complement Med. 2009Nov;15(11):1157-69. 8. Shore AG. Long-term effects of energetic healing on symptoms of psychological depression and self-	

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				perceived stress. Altern Ther Health Med. 2004 May-Jun;10(3):42-8. 9. Yapp V. Reiki. Complement Ther Nurs Midwifery. 2002 May;8(2):118	
211	**Eden Valley Hospice**	4.	73	The draft scope identifies that key areas to be covered include Psychological and emotional wellbeing – an area supported by Complementary Therapy with evidence from the research papers include: 1. Crawford SE, Leaver VW, Mahoney SD. Using Reiki to decrease memory and behavior problems in mild cognitive impairment and mild Alzheimer's disease. J Altern Complement Med. 2006 Nov;12(9):911-3. 2. Burden B, Herron-Marx S, Clifford C. The increasing use of reiki as a complementary therapy in specialist palliative care. Int J Palliat Nurs. 2005May;11(5):248-53. 3. LaTorre MA. The use of Reiki in psychotherapy. Perspect Psychiatr Care. 2005 Oct-Dec;41(4):184-7. 4. Miles P. Preliminary report on the use of Reiki HIV-related pain and anxiety. Altern Ther Health Med. 2003 Mar-Apr;9(2):36. (b) 5. Miles P. Reiki for Mind, Body, and Spirit Support of	Thank you for bringing these to our attention.

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				Cancer Patients. Adv Mind Body Med. 2007 Fall;22(2):20-26. 6. Nield-Anderson L, Ameling A. The empowering nature of Reiki as a complementary therapy. Holist Nurs Pract. 2000 Apr;14(3):21-9. 7. Richeson NE, Spross JA, Lutz K, Peng C. Effects of Reiki on anxiety, depression, pain, and physiological factors in community-dwelling older adults. Res Gerontol Nurs. 2010 Jul;3(3):187-99 8. Shore AG. Long-term effects of energetic healing on symptoms of psychological depression and self-perceived stress. Altern Ther Health Med. 2004 May-Jun;10(3):42-8. 9.	
212	**Eden Valley Hospice**	4	76	The draft scope identifies that key areas to be covered include Spiritual Wellbeing and cultural and religious needs – an area supported by Complementary Therapy with evidence from the research paper including: 1. Baldwin AL, Vitale A, Brownell E, Scicinski J, Kearns M, Rand W. The Touchstone Process: an ongoing critical evaluation of reiki in the scientific literature.Holist Nurs Pract. 2010 Sep-Oct;24(5):260-76. 2. Burden B, Herron-Marx S, Clifford C. The increasing	Thank you for bringing these to our attention.

ID	Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				use of reiki as a complementary therapy in specialist palliative care. Int J Palliat Nurs. 2005May;11(5):248-53. 3. Miles P. Reiki for Mind, Body, and Spirit Support of Cancer Patients. Adv Mind Body Med. 2007 Fall;22(2):20-26.	
213	**Eden Valley Hospice**	5	94	The draft scope identifies that the guidelines will be updated in relation to Spiritual Support Services which are supported by Complementary Therapy with evidence from the research paper including: 1. Baldwin AL, Vitale A, Brownell E, Scicinski J, Kearns M, Rand W. The Touchstone Process: an ongoing critical evaluation of reiki in the scientific literature.Holist Nurs Pract. 2010 Sep-Oct;24(5):260-76. 2. Burden B, Herron-Marx S, Clifford C. The increasing use of reiki as a complementary therapy in specialist palliative care. Int J Palliat Nurs. 2005May;11(5):248-53. 3. Miles P. Reiki for Mind, Body, and Spirit Support of Cancer Patients. Adv Mind Body Med. 2007 Fall;22(2):20-26.	Thank you for bringing these to our attention.

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214	**Eden Valley Hospice**	5	102	The draft scope identifies that an area not currently published in the guideline that will be included in the update is the role of holistic needs assessment to identify the supportive and palliative care needs of the person, carers and those important to them. We believe this should be included as such an assessment is crucial to the delivery of care service in the hospice.	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. 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.
215	**Eden Valley Hospice**	5	109	The draft scope states that Complementary Therapy is an area that will be removed from the published guidelines. We do not believe this is a valid decision as there is strong evidence to support the benefits of Complementary Therapy (including Reiki therapy) to the wellbeing, psychological and emotional wellbeing as well as Spiritual Wellbeing of patients, carers and those important to them within the supportive and palliative care services. Research to investigate that substantiates the importance of Complementary Therapy within Supportive and Palliative Care include: **1.Touch therapies for pain relief in adults – Cochrane Review** Pui Shan So1, Johnny Y Jiang2, Ying Qin3	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** **Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.**

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				1Surgery, Prince of Wales Hospital, Hong Kong, China. 2Chinese Academy of Medical Sciences & Peking Union Medical College, Beijing, China. 3School of Public Health, The Chinese University of Hong Kong, Hong Kong, China Contact address: Pui Shan So, Surgery, Prince ofWales Hospital,Ward 3D, Prince ofWales Hospital, Ngan Shing Street Shatin, Hong Kong, Hong Kong, HKSAR, China. Sophiaso@gmail.com. **Editorial group:** Cochrane Pain, Palliative and Supportive Care Group. **Publication status and date:** Edited (no change to conclusions), published in Issue 8, 2012. **Review content assessed as up-to-date:** 29 July 2008. **Citation:** So PS, Jiang JY, Qin Y. Touch therapies for pain relief in adults. ***Cochrane Database of Systematic Reviews*** 2008, Issue 4. Art. No.: CD006535. DOI: 10.1002/14651858.CD006535.pub2. 2. Bowden D, Goddard L, Gruzelier J. A randomised controlled single-blind trial of the effects of Reiki and positive imagery on well-being and salivary cortisol.Brain Res Bull. 2010 Jan 15;81(1):66-72. 3. Burden B, Herron-Marx S, Clifford C. The increasing use of reiki as a complementary therapy in specialist palliative care. Int J Palliat Nurs. 2005May;11(5):248-53.	

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				4. Miles P. Reiki for Mind, Body, and Spirit Support of Cancer Patients. Adv Mind Body Med. 2007 Fall;22(2):20-26. 5. Olson K, Hanson J, Michaud M. A phase II trial of Reiki for the management of pain in advanced cancer patients. J Pain Symptom Manage. 2003Nov;26(5):990-7. 6. Richeson NE, Spross JA, Lutz K, Peng C. Effects of Reiki on anxiety, depression, pain, and physiological factors in community-dwelling older adults. Res Gerontol Nurs. 2010 Jul;3(3):187-99. 7. VanderVaart S, Gijsen VM, de Wildt SN, Koren G. A systematic review of the therapeutic effects of Reiki. J Altern Complement Med. 2009Nov;15(11):1157-69. 8. Vitale A. An integrative review of Reiki touch therapy research. Holist Nurs Pract. 2007 Jul-Aug;21(4):167-79.	
216	**Eden Valley Hospice**	5	110	The draft scope states that an area within the guidelines that will be removed includes Research in Supportive and Palliative care: current evidence and recommendations for direction and design of future research. We believe strongly that this area needs to be included in the guidelines as we believe this supports best practice and provides valid foundation to ensure continued development of supportive and palliative care.	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. The standards for drafting and including research recommendations established by NICE will be adhered to during the

ID	Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					development of this guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended.
217	**Eden Valley Hospice**	8	186	The draft scope states that one of the main outcomes to be considered includes Patient-reported outcomes. With respect to Complementary Therapy, we strongly advise that results from MYCAW (Measure your concerns and wellbeing) research is considered including: **MYCAW (measure your concerns and wellbeing) references:** Peace G,.Mannasse A. The Cavendish Centre for intergrated cancer care: assessment of patients' needs and responses. Complement Ther Med 2002;10:33-41. Cooke H. Is the adapted Measure Yourself Medical Outcome Questionnaire an appropriate tool to evaluate the Bristol Cancer Help Centre's supportive programme? Dissertation. University of Exeter. 2000. Paterson C, Thomas K, Manasse A, Cooke H, Peace G. Measure Yourself Concerns and Wellbeing (MYCaW):an individualised questionnaire for evaluating outcome in cancer	Thank you for bringing these to our attention. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place. This also implies that outcomes from complementary therapies will not be reviewed.**

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				support care that includes complementary therapies. Complementary Therapies in Medicine 2007;15: 38-45 Polley M, Seers H, Cooke H, Hoffman C, Paterson C. How to summarise and report written qualitative data from patients: a method for use in cancer support care. Supportive Care in Cancer 2007; DOI 10.1007/s00520-007-0283-2 Vaghela C, Robinson N, Gore J, Peace B, Lorenc A. Evaluating healing for cancer in a community setting from the perspective of clients and healers: a pilot study. Complementary Therapies in Clinical Practice 2007;13:240-249 Seers H E, Gale N, Paterson C, Cooke H J, Tuffrey V, Polley M. (2009) Individualised and complex experiences of integrative cancer support care: combining qualitative and quantitative data. Supportive Care in Cancer. 17:1159–1167 Harrington J E, Baker B S, Hoffman C J. (2012) Effect of an integrated support programme on the concerns and wellbeing of women with breast cancer: A national service evaluation. Complementary Therapies in Clinical Practice, 18:10-15	

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				Jolliffe R, Polley M, Jackson S, Caro E, Weeks L, Seers H. The responsiveness, content and convergent validity of the Measure Yourself Concerns and Wellbeing (MYCaW) patient reported outcome measure. *Integrative Cancer Therapies*, 2014. (Epub ahead of print).	
218	**Eden Valley Hospice**	8	187	The draft scope states that one of the main outcomes to be considered includes Patient-reported outcomes. With respect to Complementary Therapy, we strongly advise that results from MYCAW (Measure your concerns and wellbeing) research is considered including: **MYCAW (measure your concerns and wellbeing) references:** Peace G,.Mannasse A. The Cavendish Centre for intergrated cancer care: assessment of patients' needs and responses. Complement Ther Med 2002;10:33-41. Cooke H. Is the adapted Measure Yourself Medical Outcome Questionnaire an appropriate tool to evaluate the Bristol Cancer Help Centre's supportive programme? Dissertation. University of Exeter. 2000. Paterson C, Thomas K, Manasse A, Cooke H, Peace G.	Thank you for bringing these to our attention. 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 **Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place. This also implies that outcomes from complementary therapies will not be reviewed.**

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				Measure Yourself Concerns and Wellbeing (MYCaW):an individualised questionnaire for evaluating outcome in cancer support care that includes complementary therapies. Complementary Therapies in Medicine 2007;15: 38-45 Polley M, Seers H, Cooke H, Hoffman C, Paterson C. How to summarise and report written qualitative data from patients: a method for use in cancer support care. Supportive Care in Cancer 2007; DOI 10.1007/s00520-007-0283-2 Vaghela C, Robinson N, Gore J, Peace B, Lorenc A. Evaluating healing for cancer in a community setting from the perspective of clients and healers: a pilot study. Complementary Therapies in Clinical Practice 2007;13:240-249 Seers H E, Gale N, Paterson C, Cooke H J, Tuffrey V, Polley M. (2009) Individualised and complex experiences of integrative cancer support care: combining qualitative and quantitative data. Supportive Care in Cancer. 17:1159–1167 Harrington J E, Baker B S, Hoffman C J. (2012) Effect of an integrated support programme on the concerns and wellbeing of women with breast cancer: A national service evaluation. Complementary Therapies in Clinical Practice,	

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				18:10-15 Jolliffe R, Polley M, Jackson S, Caro E, Weeks L, Seers H. The responsiveness, content and convergent validity of the Measure Yourself Concerns and Wellbeing (MYCaW) patient reported outcome measure. *Integrative Cancer Therapies*, 2014. (Epub ahead of print).	
394	Faculty of Homeopathy	5	109	As the registering body for statutorily regulated healthcare professionals who integrate homeopathy into their practice, the Faculty of Homeopathy opposes the removal of Complementary Therapy Services from the NICE guidelines for Improving Supportive and Palliative Care in Adults. Several of our members specialise in palliative care and have found complementary therapies – including homeopathy – to have clinical and psychological benefits for patients. They report that patients can often reduce the amount of conventional drugs they need to take and have fewer GP appointments and hospital admissions. This not only benefits patients, it produces a financial saving for the NHS.1	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.**

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				There is a growing evidence base from Patient Recorded Outcome Measures2 and meta-analyses to support the therapeutic benefits of homeopathy and other complementary therapies. The most recent meta-analysis in individualised homeopathy found there was a significant treatment effect beyond placebo.3 Removing complementary therapies from the NICE guidelines would limit the clinical options available to healthcare professionals and be detrimental to patient care. 1. Witt C, Keil T, Selim D, et al. Outcome and costs of homeopathic and conventional treatment strategies: a comparative cohort study in patients with chronic disorders. Complement Ther Med 2005; 13: 79–86. 2. Spence D, Thompson E, Barron S. Homeopathic treatment for chronic disease: a 6-year university hospital based outpatient observational study. J Altern Complement Med 2005; 5: 793–8. 3. Mathie RT, Lloyd SM, Legg LA, et al. Randomised placebo-controlled trials of individualised homeopathic treatment: systematic review and meta-analysis. Syst Rev 2014, 3: 142.	

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152	**General Council for Massage Therapies**	5	109	The draft scope recommends that complementary therapy services be removed from the published guideline. No rationale is provided for this recommendation so in responding we are unaware if this suggestion has been driven by financial reasons, patient feedback or other reasons—this makes it very difficult to respond in a constructive and informed manner. Complementary therapies have long been provided as part of the supportive and palliative care package bringing comfort and relief to individuals with life limiting or terminal conditions. It would seem a cruel and somewhat arbitrary decision to remove these services, particularly if this has been done without reference to what the patients actually want (and surely this must be the most important consideration). We are also unclear if the proposal is to remove the therapy or the therapist from the guidelines. To give a couple of examples—massage is often provided as part of a Physiotherapy, Osteopathic or Chiropractic treatment---are you suggesting that massage should no longer form part of that treatment or that it would be acceptable if delivered by one of the above but not a trained massage professional? Acupuncture is used extensively by Physiotherapists and GPs—again the same question applies i.e. if the treatment is delivered by one of the above group it is acceptable (even though they may lack adequate training), but if delivered by a specialist it is not acceptable? As we have said it is difficult	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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.**

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				to respond without a rationale being provided, but we hope that you will give our comments due consideration and would be delighted to discuss with you further.	
199	Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network	2	41	Confirm that this guidance scope will link to other NICE guidance already in place for other relevant disease groups	Thank you for your comment. The section of the scope entitled 'Links with other NICE guidance, NICE quality standards and NICE Pathways' will provide this information, but not list every life limiting condition/disease. Further information on all condition specific guidance provided by NICE can be found at: http://www.nice.org.uk/Guidance.
200	Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network	3	48	Relating to the table – there needs to be a clear definition of what is 'towards the end of life'	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.
201	Greater Manchester, Lancashire and	3	59	Does this include voluntary sector organisations part funded by NHS commissioning?	Any settings in which NHS commissioned services are provided, are covered.

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	South Cumbria Strategic Clinical Network				
202	Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network	4	72	financial concerns need adding as well	Thank you for your comment. This section of the scope has now been redrafted.
203	Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network	4	87	Will there be a description of modelling around whether supportive and palliative care should be provided through one seamless model or through two separate models with collaboration and handover? As currently the scope describes the two elements but not the interface	Thank you for your comment. This is not currently on the list of key issues for economic modelling, but if the deliberations of the committee suggest it would be of value, it will be done.
204	Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network	5	107	It is key that education and training is part of the scope still and is not removed – or where this will sit if not within NICE guidance	
205	Greater Manchester, Lancashire and South Cumbria Strategic Clinical	5	112	given the nature of integration of services moving forward nationally, it is key that social support remains part of the scope	Thank you for your comment. This will be considered by the committee.

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	Network				
206	Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network	5	113	Will there be anywhere within the scoping where communication issues are picked up specifically as this has been highlighted as an area of focus in all the recent national documents	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. 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.
207	Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network	12	252	it is unclear why last days of life and withdrawal of Liverpool Care Plan is mentioned specifically here given the scope of the just approved NICE Care of the Dying Adult guidance – it seems that the scope of this document should therefore be wider than this and not placed in this context	Thank you for your comment. Our view is that the recent withdrawal of the Liverpool Care Pathway is an important piece of context which should remain.
208	Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network	12	253	it is unclear why last days of life and withdrawal of LCP is mentioned specifically here given the scope of the just approved NICE Care of the Dying Adult guidance – it seems that the scope of this document should therefore be wider than this and not placed in this context	Thank you for your comment. Our view is that the recent withdrawal of the Liverpool Care Pathway is an important piece of context which should remain.
266	**Greenwich &**	general	general	The draft scope seeks to provide guidance on Supportive	Thank you for your comment.

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	Bexley Community Hospice			and Palliative Care for all conditions, whereas the previous guidance looked specifically at Cancer; whilst I applaud this in principle, the practicalities and enormity of the task concern me. I wonder if this piece of work could be more focused to enable the make up of the guideline development committee to better reflect the expertise needed for the range of conditions, as the evidence base varies quite significantly for different conditions.	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 individuals to contribute effectively. When convening the guideline committee the developers have followed the principles outlined in the NICE technical manual.
267	**Greenwich & Bexley Community Hospice**	2	27	The distinction between charitable providers and providers (line 23, page 1) is unhelpful and unnecessary. Charities provide commissioned services and other providers provide non-commissioned services. n.b. note P.4 line 61 supports this	Thank you for your comment.
268	**Greenwich & Bexley Community Hospice**	2	33-44	The needs of LGBT people, BAME people and the older old may also need review as there is considerable evidence that they have less access to services	Thank you for your comment. 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.
269	**Greenwich &**	3	48	The definitions provided by NCPC or in the Palliative Care	Thank you for your comment. The

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	Bexley Community Hospice			Funding Review may be useful here	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.
270	**Greenwich & Bexley Community Hospice**	5	88	This should include children – as they are supported in services providing services to adults	Thank you for your comment. Those aged under 18 are outside the scope of this guideline. There is current NICE guidance in development on End of life care for infants, children and young people.
271	**Greenwich & Bexley Community Hospice**	5	113	Communication is a vital element of palliative care and should in some way reference guidance relating to this, in particular the issues relating to mental capacity and best interests decisions, communicating with families when patients have lost capacity	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. Face to face communication and information provision are covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.

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272	**Greenwich & Bexley Community Hospice**	general	general	More guidance on at what point supportive and palliative care services should be available for different conditions would be helpful. The scope suggests SPC services are still seeing people with non-malignant disease at 2004 levels, this is simply not the case, with some notable examples of excellent practice. The guidance should explore these models.	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. The revised scope will cover service delivery models for end of life care and address timing and review of service provision .
377	**Guy's and St Thomas NHS Foundation Trust**	3		Supportive care is stated as referring to patients with life-limiting illness. It would be better to include "life-threatening" as "life-limiting" excludes cancer patients being treated with curative intent or patients that have been cured (some of these patients benefit hugely from supportive care)	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. 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.
378	**Guy's and St**	4	66	Consider including POS and other measures from OACC:	Thank you for bringing these to our

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	Thomas NHS Foundation Trust			http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/outcome/index.aspx	attention.
379	**Guy's and St Thomas NHS Foundation Trust**	6	119	Would be useful to define "end of life" for the purposes of this guidance (ideally with the other definitions 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. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.
260	Helen and Douglas House		39	The examples here of life-limiting conditions are, in the main, disease or single-organ/system specific. It is the case that many of the young people graduating from children's palliative care services have multi-system conditions (including, for example, metabolic, genetic, congenital or even undiagnosed conditions) which are either progressively life-shortening or that render them extremely vulnerable to unpredictable life-threatening acute crises. At the other end of the age spectrum, adults suffering chronic illness often with multiple co-morbidities or multi-organ/system failures also need to access supportive and palliative care services. Could some different examples be used so that it is clear that the guideline is focussing on the promotion of person-	Thank you for your comment. The use of organ specific examples has now largely been removed from the scope, and the need to consider multi-organ diseases will be borne in mind by the committee.

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				centred, holistic supportive and palliative care across specialties and care-settings, rather than on disease/organ/specialty specific illness? This will help to emphasise the inclusion of non-malignant illnesses as well as younger adults in the guideline.	
261	Helen and Douglas House		48	Many of the young people with life-limiting illness graduating from children's services are using special schools or colleges (day or residential) or live in supported environments such as those for people with learning disabilities. The care around these young people is very often NHS commissioned through CHC (Continuing Health Care), personal budgets with or without SEND (Special Educational Needs and Disability) reform EHC (Education and Health Care) plans (up to 25 years of age).	Thank you for your comment. The revised guideline will cover service organisation for end of life care services and address how young adults moving from children's to adults' end of life services should be supported.
262	Helen and Douglas House		62	Holistic needs assessment needs to include social functioning	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. 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.

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263	Helen and Douglas House		139	In order to inform recommendations regarding service organisation I would suggest co-opting a member to the guidance committee who has knowledge of both children's and young person's palliative medicine services as well as the process of transition.	Thank you for your comment. The revised scope will address the service delivery needs of adults in the last year of life, only. 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**. 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). .
264	Helen and Douglas House		287	As well as seeking to improve provision for an ageing population, the increasing numbers of young people graduating from children's palliative medicine services also need to be accounted for. More specifically so too do the increasing numbers of patients being supported by more and more sophisticated medical technology and complex care	**Thank you for your comment.** The revised guideline will cover service organisation for end of life care services and address how young adults moving from children's to adults' end of life services should be supported, which will

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				packages. Again could these last be included in terms of awareness raising generally and also to ensure that the guideline covers these issues?	take into account any complex care packages in place.
265	Helen and Douglas House		298	In keeping with my previous comments about the importance of choosing representative examples in the introduction to the guideline, I'm not sure that Sickle Cell Disease appositely demonstrates the difficulties that young people face in accessing supportive and palliative care services. Indeed, I have worked in two acute hospital trusts where the adult palliative care advisory team as well as the chronic pain team have routinely seen Sickle Cell patients as outpatients or on the wards. A wider disconnect is often experienced outside the acute hospital setting: for example, there are well recognised difficulties for young people with degenerative neuromuscular conditions or vulnerable cerebral palsy patients in translating comprehensive community paediatric and/or children's hospice support into adult supportive and palliative care services. The same young people often do not have one identifiable adult medical specialty team coordinating their healthcare in the hospital. Their access to support services is therefore truly lacking as they will not have access to specialty specific support services such as the specialty nurses or social workers that run alongside cystic fibrosis, renal, diabetes or Sickle clinics, for example. Adult palliative medicine services across all settings have a potential role here.	**Thank you for your comment.** The revised guideline will cover service organisation for end of life care services and address how young adults moving from children's to adults' end of life services should be supported, which will take into account any complex care packages in place.

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291	**Isabel Hospice**	4	66 - 76	As The Outcome Assessment and Complexity Collaborative (OACC) initiative is seeking to implement outcome measures into routine palliative care nationally, will the guideline scope consider this tool to identify supportive care and palliative needs?	Thank you for your comment, which is noted.
292	**Isabel Hospice**	5	109 - 114	Please advise the reasoning for removing these areas from the updated guidelines? Specifically:	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. Further, 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, face to face communication and the provision of information have been covered in the NICE Patient experience guideline, more details can be found at the following link:

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					https://www.nice.org.uk/guidance/cg138v. Social support services: Thank you for your comment. Guidelines related to the provision of social support are the remit of the Social Care Institute of Excellence. More details on this agency and its published work can be found at: http://www.scie.org.uk/.
293	**Isabel Hospice**	5	109	Complementary therapy services. This is an established provision for both patients and carers and Isabel Hospice strongly recommends the continuation of this service. Evidence exists to support the benefit of complementary therapy in line with the psychological and emotional wellbeing needs identified as being important to the person and carers (Line 73). The Complementary Therapy Service has policies and guidelines which are adhered to rigorously and all therapists subject to qualification and background checks. The positive contribution made by complementary therapies to the wellbeing of patients is supported by a large body of research carried out in supportive and palliative care settings.	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. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
294	**Isabel Hospice**	5	112	User involvement in planning, delivering and evaluating services. How is it proposed that the main outcomes of	Thank you for your comment. Following consideration of all stakeholder comments

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				Patient-reported outcomes (line 186) and Views and satisfaction of those receiving supportive and palliative care and those important to them (line 187) be achieved without this aspect included within the guideline?	the guideline will focus on service delivery within the last 12 months of life for all conditions. Additionally, 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.
295	**Isabel Hospice**	5	114	Social support services. How can the 24/7 provision of care and access to specialist services (line 81) and the Co-ordination of care (line 92) be achieved without this critical support service included within the 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. The revised scope will cover service delivery models for end of life care and address out of hours, weekend and 24/7 availability of services.
296	**Isabel Hospice**	5	109, 112, 114	The Ambitions for Palliative and End of Life Care national framework notes six ambitions to achieve person-centred and coordinated care which include:	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery

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				➢ Maximising comfort and wellbeing through a holistic approach. ➢ Each person gets fair access to care through community partnerships and person centred outcome measurement. ➢ Care is coordinated through a system-wide approach and continuity in partnership. Removal of these areas from the updated guideline would not therefore align with the national framework.	within the last 12 months of life for all conditions.
273	Jewish Care	1	12	A positive development to include people with life-limiting conditions. However, once people have been identified through supportive care (as should be the case if appropriate training and education is obtained), as needing specialist palliative care, will the hospice movement be able to cope?	Thank you for your comment. The overall cost impact of any recommendations made will be borne in mind when they are drafted.
274	Jewish Care	2	33	Equalities are also on ethnicity, religion, gender etc. Unfortunately we cannot see the impact assessment to see if there is an opportunity to cross these with the areas that are highlighted as needing special consideration. For us and other ethnic and minority groups, identity plays a huge role in end of life considerations and may influence how and where people choose to be towards the end of their lives. A lot of people with unidentified palliative care needs are supported by generalist health care professionals in the voluntary sector and statutory social care workers with no	Thank you for your comment. 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

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				awareness of palliative or end of life care knowledge. Why are they not receiving regulated training across the UK?	
275	Jewish Care	4	60	For many people with dementia, those receiving care at home, or in a care home at the end of their lives, they are not receiving funding from NHS – why is this excluded? Could it at least be a best practice recommendation?	Thank you for your commentWe 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.
276	Jewish Care	5	106	Clinical aspects of care. Understanding symptom control (pain management) is paramount to recognising when it is appropriate to refer to specialist palliative care professionals. Therefore Line 107, Education and Training, should be covered.	Thank you for your comment. Following consideration of all
277	Jewish Care	5	109/112/ 114	Complementary therapies/ user involvement/ social support Why are these being removed? Is this purely a move to a medical model or has this been included elsewhere?	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End

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					of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place. 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.
278	Jewish Care	5	113	Why is User involvement being removed as we need to hear from people for improvement and development?	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.
279	Jewish Care	6	131	The Care Act 2014 promotes prevention and sound information and advice of support in the community. All	Thank you for your comment.

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				generalist health care workers involved with a person and their carer who may have a life limiting illness, should have a basic awareness to recognise when someone has palliative or end of life care needs. With this basic knowledge, they are then in a position to communicate to other more specialist health care professionals, within a multi-disciplinary team, who can assist more appropriately. Too often, people with palliative and end of life care needs are overlooked, as health care workers have failed to recognise holistic individual needs; the situation then develops into a crisis and people find themselves dying in settings which cause emotional distress and can often result in complicated bereavement issues. As Dame Cicely Saunders said, "How someone dies, remains in the memory of those that live on."	
280	Jewish Care	336	14	Where NHS funding is received, specialist palliative care services may not always be already involved. Therefore, if non specialist workers/generalist workers have not received some basic training to recognise the holistic needs of the person and their carer, then there is a higher probability of needs being overlooked and personal outcomes not being met.	Thank you for your comment. .
281	Jewish Care	General	General	Care at the end of life should be specific and culturally appropriate. Spirituality is an important part of dying and should form part of any holistic system.	Thank you for your comment, which isnoted.
381	**Kilbryde Hospice**	5	109	Complementary Therapies are an important and growing part of the person centred care we provide within the	Thank you for your comment. Following consideration of all stakeholder comments

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				hospice. We feel we should be working towards greater integration within palliative care and inclusion within guidelines, recognising this as an integral part of many services is the way forward. These guidelines should be updated and expanded to reflect how popular and effective they are proving to be, rather than removed. Currently our evidence base is purely qualitative however patient feedback is invaluable and complementary therapies often are successful where pharmacological interventions fail. There is an expanding evidence base re complementary therapies. The Cochrane collaboration – Touch therapies for pain relief in adults – So PS, Jiang JY, Qin Y 2012 Authors conclusions: Touch therapies may have a modest effect in pain relief. More studies on Healing Touch and Reiki are needed. Also Health related quality of life outocmes: A reflexology trial with patients with advanced stage breast cancer (Gwen Wyatt, RN, PhD, Alla Sikorskii, PhD, Mohammed Hossein Rahbar, PhD, David Victorson, PhD, and Mei You, MS 2012 Found: A longitudinal comparison revealed significant improvements in physical functioning for the reflexology group compared to the control group. Implications:	the guideline will focus on service delivery within the last 12 months of life for all conditions. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline.** **Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.**

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				Reflexology can be recommended for safety and usefulness in relieving dyspnea and enhancing functional status among women with advanced stage breast cancer.	
426	**Leeds Teaching Hospitals NHS Trust**	12	General	Supportive care: there needs to be a statement about the importance of remaining active, the importance of regular exercise (this does not need to be exhaustive) on general well being – physical and psychological, for which there is an evidence base. Psychological interventions may be key to changing behaviours in relation to healthy eating and exercise. I am aware that this is to be included in the recovery programme for cancer 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. Consequently, we do not wish to pre-judge the evidence, but are focussing on service delivery rather than clinical interventions. Also, the context section referred to in this comment, has been amended to reflect the changes to the final scope.
427	**Leeds Teaching Hospitals NHS Trust**	7	General	For those with long-term conditions it will probably depend on the specific needs of the individual as to which organisation(s) deliver that care and it should be multidisciplinary. The focus probably needs to be on primary or community care but for those with more complex needs then there might be a need for more specialist input. There should be more collaboration between organisations and teams should be multidisciplinary.	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. The revised scope will aim to explore the service delivery components, including specialist input and multidisciplinary approaches.

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428	**Leeds Teaching Hospitals NHS Trust**	12	269	It is imperative to include those who care for those with long-term conditions	Thank you for your comment. The needs of carers will be given due consideration.
429	**Leeds Teaching Hospitals NHS Trust**	3	47-48	Definition of supportive care should be broader to include the symptoms of the life-limiting disease and the impact of treatment including side effects	Thank you for your comment, which is noted. Consequently, 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.
430	**Leeds Teaching Hospitals NHS Trust**	4	General	Holistic needs tools need to be all encompassing. In mental health rehabilitation a useful tool is the 'The Tree of Life', which might be helpful for some as their needs change with time.	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. 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. Also, guidance related to the provision of

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					psychological services are the remit of the National Clinical Centre for Mental Health, which is tasked by NHS England and NICE to develop products to support the Achieving Better Access to Mental Health Services programme. Guidance related to condition specific psychological needs can be found on the NICE website at: http://www.nice.org.uk/Guidance.
431	**Leeds Teaching Hospitals NHS Trust**	4	73	Psychological and emotional wellbeing underpins physical, social and cognitive functioning, and should perhaps be at the top of the list	Thank you for your comment, which is noted.
432	**Leeds Teaching Hospitals NHS Trust**	6	134	Holistic needs assessment tools: is it necessary to 'dictate' which tool should be used? I am aware of a number in use, which cover broadly the same issues. However, it should 'belong' to the patient / carer and be portable – to be viewed by health professionals across organisations and to be updated to reflect continuing and changing 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 do not wish to pre judge the evidence. An evidence review will take into account clinical and cost effectiveness to determine if one or any of these tools are beneficial. Recommendations will then be made by the guideline committee, taking into account the evidence.

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433	**Leeds Teaching Hospitals NHS Trust**	6	142	Care including follow up and review needs to be tailored to the individual needs and wishes (patients and carers alike). The decision should be the result of a 2-way discussion between the individual and health care professional.	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. Additionally, we do not wish to pre judge the evidence. An evidence review will take into account clinical and cost effectiveness to determine when and how follow up and review are most appropriate. Recommendations will then be made by the guideline committee, taking into account the evidence. The revised scope will adopt a wider focus on service models that provide support for the carers or those important to the people accessing end of life services.
395	**London Cancer**	General	General	The previous NICE Guidance addressed only cancer and we welcome the change in focus to include all life-limiting illness and a focus on inequalities. However, we feel it is not clear to what extent the proposed Guidance will address the supportive care elements associated with living with 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.

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				beyond cancer. It is not consistently obvious that guidance pertains is to supportive care for *all* cancer patients (not just those who are only receiving palliative care) *and* people with other conditions that are 'life-limiting'. The term 'life-limiting' is problematic as it is then inaccurately used throughout the document to refer to everyone supposedly covered by the guidance. Also will the guidance address the supportive care needs of individuals who no longer have cancer but are living with the long term effects of treatment? Many of these individuals have significant resultant physical/psychological issues thus we would be concerned if they were not encompassed within this document.	The scope has been revised to reflect these changes. Among the groups that will be covered are: adults (over 18) with progressive life-liming conditions thought to be entering the last year of life. Further, guidance related to the provision of psychological services are the remit of the National Clinical Centre for Mental Health, which is tasked by NHS England and NICE to develop products to support the Achieving Better Access to Mental Health Services programme. Guidance related to condition specific psychological needs can be found on the NICE website at: http://www.nice.org.uk/Guidance.
396	**London Cancer**	General	General	Communication is a cornerstone to good supportive care. The loss of ACST from peer review measures has meant that there is a serious lack of guidance about how services should be taking an evidence based approach to improving the communication skills of staff. We recommend ensuring that communication remain within the guidance.	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. Additionally, communication is covered in

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					the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
397	**London Cancer**	General	General	Recommend, under equality considerations, mention of individuals with pre-existing mental health issues BME/seldom heard from populations. Evidence shows that all of these populations have poorer access to services (including supportive care) and poorer outcomes, so it seems remiss to have minimised this.	Thank you for your comment. 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.
398	**London Cancer**	General	General	Recommend that the scope questions include a question to assist the guidance to address the continuum that is supportive care; ranging from information, educational workshops, therapeutic interventions all of which make up and are needed to provide excellent "supportive care". A question about "what constitutes complex supportive care needs would be beneficial as this would encompass vulnerable adults, complex cognitive and psychological presentations, risk management and safety.	Thank you for your comment, which is noted.
399	**London Cancer**	3 (table)	1-5 (in table)	This definition of supportive care is different from the definition used in the original guidance. This definition has more of a palliative care focus. More clarity is needed here. We suggest making distinction between general and specialist supportive care as the palliative care section has	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

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				retained. A definition of 'specialist supportive care' should specify psychologists and other psychologically trained practitioners (in line with the existing Guideline's delineation of Level 3 and Level 4 psychological care). The same comments to apply to rehabilitation therapists (delineating generalists from level 3 to 4 specialists)	guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.
400	**London Cancer**	3	48	Does 'before diagnosis' include people who are considering or have had genetic testing? In the 2004 manual it states that supportive care "…is given equalpriority alongside diagnosis and treatment" however this is not stated in the current draft. This, or an equivalent, statement needs to be included in the definition of supportive care so that the draft is aligned with the principle of Parity of Esteem (https://www.england.nhs.uk/mentalhealth/parity/).	Thank you for your comment. The guideline will focus on service delivery within the last 12 months of life for all conditions, whether or not they are considering or have had genetic testing.
401	**London Cancer**	3	52	Reference in the definition of 'supportive care' refers to 'cure or continuing illnesses. It remains unclear where individuals who may have been 'cured' or being viewed under the 'survivorship' tag fit, and how far these guidelines stretch. Will the guidelines begin to be more explicit on who might fit under this umbrella? Would an individual who has been in remission for 3 years be entitled to the same care? Would an individual who suffered from a childhood illness (e.g. cancer) who is now being monitored under an adult 'late effects' service be entitled to the same care? The language here will need to be clear, as they also seem to be 'adults (over 18)	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. 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

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				with life-limiting conditions'.	now being used within a revised scope.
402	**London Cancer**	4 6	65 135-141	As HNA [distress thermometer] is now standard practice within oncology / haematology settings, it may be worth considering using this as the standard assessment tool to ensure continuity for both healthcare professionals and patients as they will be familiar with the language and assessment tool. It can be shared between acute and palliative care teams more easily.	Thank you for your comment, which will be given consideration by the committee.
403	**London Cancer**	4	73-74	Psychology is the "scientific study of people, the mind and behaviour" (http://www.bps.org.uk). Therefore, recommend that these two lines be rewritten as: "psychological (including emotional, cognitive and behavioural) wellbeing".	Thank you for your comment. This section has been redrafted**.**
404	**London Cancer**	4	75	The inclusion of sexual functioning and wellbeing is very much welcomed as it is generally absent from NICE guidelines.	Thank you for your comment.
405	**London Cancer**	4 + 5	77 + 107	Will 'Service Organisation for Supportive Care' continue to use the Levels 1-4 model outlined in the existing guidance? Will this section retain paragraph D4 (pp. 84, in the manual version of the current guidelines) given that Education and Training will not be included? (line 107)	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.
406	**London Cancer**	5	93	Request that 4 levels of psychological input be preserved, and particularly the capacity at level 4 to offer a range of	Thank you for your comment. Following consideration of all stakeholder comments

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				psychological therapies by one practitioner (i.e. clinical psychology).	the guideline will focus on service delivery within the last 12 months of life for all conditions.
407	**London Cancer**	5	94	Recommend rewording to signposting and sharing information.... to promote and protect high quality holistic care.	Thank you for your comment. This section has been redrafted.
408	**London Cancer**	5	96	Request that 4 levels of rehabilitation input be preserved. This will require more investment in rehabilitation services but should also link to the work being taken forward in secondary care and primary care focusing on rehabilitation and wellbeing following cancer diagnosis & treatment	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.
409	**London Cancer**	5	105-107	Concerns with education and training not being covered- without education and training the assessments done risk being poorer. Advanced communication and level 2 training underpin holistic needs assessing. In addition, there are significant education and training issues in the supportive care workforce which link directly to how services are delivered. For example, we know there is a shortfall of specialist Allied Health Professionals.	Thank you for your comment. .
410	**London Cancer**	5	106	Clarity is needed here whether by 'clinical' or 'medical' care being referenced as (e.g.) physiotherapy could be considered clinical care.	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 section of the scope has

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					been redrafted to take into account various stakeholder comments.
411	**London Cancer**	5 5	109 109-115	It would be helpful to understand rationale for removing the 6 domains being omitted. All the domains are important to the provision of quality healthcare and they all seem critical areas under the 'supportive care' umbrella. Cancer services continue to struggle to ascribe the necessary importance to issues such as the provision of key information at stages of treatment, appropriate levels of user involvement to shape services, necessary resource to cover social support needs and appropriate use of face-to-face communication for delivering significant information. With regards to complementary therapies in particular, these are often requested by patients and some organisations provide them. It is crucial that whatever evidence is available re: efficacy / impact on patient experience, is properly summarised with related guidance offered. If complementary therapies is going to be removed, will separate guidelines be provided to address this?	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place. 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

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					committee sees a gap in evidence, further research will be recommended. User involvement in planning, delivering and evaluating services, face to face communication and the provision of information have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v. .
412	**London Cancer**	5	110 -111	The section on 'Research in supportive and palliative care: current evidence and recommendations for direction and design of future research' should be included so that readers have a clear understanding of the evidence base for psychological and rehabilitation therapies.	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. 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.

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413	**London Cancer**	5	112	Removal of user involvement: we have significant concerns regarding this. It will be vital to fully engage service users in the implementation of the guidance and at key points in the process. The section on 'User involvement in planning, delivering and evaluating services' should be retained so this document is in line with the principle of 'co-production' (Health and Social Care Act, 2012; Transforming participation in health and care – the NHS belongs to us all, 2013).	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. Additionally, 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.
414	**London Cancer**	5	113	The section on 'Face-to-face communication' should be retained or updated as without it there is a risk that commissioners will choose to purchase telephone computerised- and telephone-based psychological therapies. Relational care has been demonstrated to be important in patient experience (e.g. geriatric services where patients say good service and yet outcomes poor) and is the basis for good treatment choices and decisions, patient adherence , shorter bed stay, and reduced complaints and staff burn out. Based on the evidence for benefits of good and supported face to face communication, it should remain in scoping to shape and inform discussion for final guidance.	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. Additionally, 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.

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415	**London Cancer**	6	124	We agree that addressing the economic aspects is vital in this guidance but it is important to acknowledge that for many of the supportive care services e.g. cancer rehabilitation, there is a lack of good quality data on the economic benefits. This requires addressing.	Thank you for your comment. We are familiar with the limitations of the evidence.
416	**London Cancer**	6	134	HNA- focus is on 'which tool'. Real issue is – what happens afterwards to patient? Recommend including the question "what is the assessment for, rather than which tool" And "how do we know that HNA has achieved its goal, if stated?"	Thank you for your comment, which is noted.
417	**London Cancer**	7	150	Recommend a range of models being advocated so that services can, where necessary, adapt service provision in a way that fits with local needs.	Thank you for your comment,, which is noted.

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418	**London Cancer**	7	154	Supportive services should be available in a range of settings so that services users can access them in both geographically and timely ways, as highlighted in the 'Psychological support for people living with cancer – Commissioning guidance for cancer care in London.'	Thank you for your comment, which is noted.
419	**London Cancer**	7	161	Recommend removing the inclusion of specialist palliative care as this is picked up in 3.7. Instead could frame question along lines "what triggers specialist palliative care involvement" This addresses the need for clear and good communication between supportive care and palliative care.	Thank you for your comment. The draft questions in the revised scope have been revised to include the following: 'What types of end of life care services, incuding specialist services, should be available and what is the minimum level needed to delivery unplanned 24/7 care?' These questions will be refined when drafting the full review protocol in conjunction with the guideline committee.
420	**London Cancer**	8 8	183 183	The psychological evidence base should be included in the sources of evidence when looking at the Main Outcomes. Considering the 'main outcomes', we would hope that these would be specifically considered from an equality perspective as well, spelling out the differences that already exist for those populations identified in the 'equality considerations' but also providing guidance on specific outcomes where the differences may be more pronounced. The emphasis in the 'equality considerations' section	Thank you for your comment. These are the main outcomes. When the full review protocols are developed additional outcomes may also be included. The equalities will be considered when reporting outcomes and may be sub grouped in order for the guideline committee to make separate recommendations for different populations,

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

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				appears to have been on 'opportunities to access services' (lines 39-40) but the inequalities go much further than that in services.	if appropriate.
421	**London Cancer**	8	193	Under this section should also include - Treatment adherence - Reduced time to treatment i.e. breach - Reduced complaints	Thank you for your comment. These are the main outcomes. When the full review protocols are developed additional outcomes may also be included.
422	**London Cancer**	9	196	There is no mention of the 'Depression in adults with chronic physical health problem: recognition and management' (2009) NICE guideline CG91. Is this an oversight or an intentional attempt at distinguishing between 'life-limiting' and 'chronic' illness.	Thank you for your comment. The scoping template only lists related NICE guidance currently in development; the guidelines listed are those that have a clear link to end of life care.
423	**London Cancer**	9 13/14	218-287 300-316	This is excellent that the recognition that supportive care starts from diagnosis, this work needs to be across the complete pathway for the disease, including primary, secondary and tertiary care. There will need to be an increase in primary care to manage 24/7 service	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. Consequently, the context section has been amended to reflect the changes to the final scope.
424	**London Cancer**	14	340	Please review 'Psychological support for people living with cancer – Commissioning guidance for cancer care in	Thank you for your comment and for providing this reference.

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				London.'	

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425	**London Cancer**				
306	**Multiple System Atrophy Trust**	2	41-44	We think this list should also include people with communication difficulties as this group experience specific issues in making their needs known.	Thank you for your comment. 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.
307	**Multiple System Atrophy Trust**	5	93	We are pleased that the guidance will update psychological support services. Between 40-80% of people with MSA will experience depression and anxiety and this services are patchy and hard to access. This needs to be reflected in supportive and palliative care.	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. Further, guidance related to the provision of psychological services are the remit of the National Clinical Centre for Mental Health, which is tasked by NHS England and NICE to develop products to support the Achieving Better Access to Mental Health Services programme. Guidance related to condition specific psychological needs can be found on the NICE website at:

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					http://www.nice.org.uk/Guidance.
308	**Multiple System Atrophy Trust**	5	109-115	We cannot understand why these elements will be removed. Complementary therapies, user involvement, face-to-face communication and information are all really important.	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place. Holistic needs assessments: Thank you for your comment. This guideline covers service delivery for the dying adult in the last year of life. Holistic needs assessments will not be specifically addressed by any review question, but

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					may be considered as part of service delivery models, in accordance with available evidence. User involvement in planning, delivering and evaluating services, Face to face communication and information provision have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.
309	**Multiple System Atrophy Trust**	8	186-7	What will these outcomes actually consist of? Without user involvement will these be what academics think rather than what people themselves see as important.	The scope includes the main outcomes for the guideline. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee.
310	**Multiple System Atrophy Trust**	13	306-308	These sentences clearly allude to people who are currently underserved with current services, yet these are not reflected in sentences 41-44. This does not seem to make sense unless they are catered for somewhere else in the scope which doesn't seem to be the case?	Thank you for your comment. The identification of groups of patients who may currently be underserved is simply an indication that services overall need to be improved, and does not mean that those groups will be considered individually.
368	National	3	47	Table of definitions: we note that this definition of palliative	Thank you for your comment.

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	Bereavement Alliance			care is focused more narrowly on the patient than in the 2004 guidance, which stated *'Palliative care aims to….offer a support system to help patients to live as actively as possible until death and to help the family to cope during the patient's illness and in their own bereavement'*. We would like to see this reinserted: possibly replacing 'the family' with 'the family and carers' or 'carers and those important to the person'. We are aware that whatever definition of palliative care is included in the guidance is very likely to be cited and used in documents by other organisations, and that this will not always be accompanied by the definition of supportive care. We think it is very important to include carers and people important to the person in the definition of palliative care. To omit this would signal a retreat from the WHO definition of palliative care. This adjustment would also provide a rationale for including the identification and referral of people at risk of complex bereavement (line 88) under palliative rather than supportive care.	The terminology and definitions 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. Recommendations on bereavement can be found in the 2004 guideline.
369	National Bereavement Alliance	5	98	We welcome the intended update on services for families and carers, including bereavement care.	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.

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					Recommendations on bereavement can be found in the 2004 guideline, and will not be updated.
370	National Bereavement Alliance	4-5	77-90	The guidance mentions 'identification and referral of people at risk of complex bereavement' (line 88) but it does not mention covering how these needs would be met, nor how bereavement support could be provided more generally, including to those not at risk of complex bereavement. These elements should be included. The 2004 guidance included a 3-component model of bereavement support, which has formed the basis for • extensive empirical research into bereavement support needs in Australia (eg Rumbold and Aoun, 2015) • models of bereavement needs, support and training requirements including the Irish Child Bereavement Pyramid • work underway in the National Bereavement Alliance to bring the components up to date with more recent research into the impact of bereavement and the efficacy of support. A narrow focus on the component concerned with complex	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. Recommendations on bereavement can be found in the 2004 guideline, and will not be updated. The draft questions have been revised to reflect these changes and will be refined when drafting the full review protocol in conjunction with the guideline committee.

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				bereavement would weaken the case for lower-level, preventative support which undoubtedly reduces the need for more intensive interventions. We recommend that this 3-component model is considered for adaptation and inclusion in the new guidance, as it provides a helpful framework for understanding responsibilities for commissioners and providers, and how these align with community and societal responsibilities.	
371	National Bereavement Alliance	6	139	1.3 We would suggest relaxing this to 'What are the best tools…' as there may more than one. A 'hub and spokes' approach to assessment may be more appropriate.	Thank you for your comment.
372	National Bereavement Alliance	6	141	We would suggest including a question specifically related to bereavement (and not rolling bereavement into supportive care), ie *1.4: What are the best tools to identify bereavement support needs before and after the death in carers and those (including children and young people) who are important to people with life-limiting conditions?*	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. The draft questions have been revised to reflect these changes. Recommendations on bereavement can be found in the 2004 guideline, and will not be updated.
373	National Bereavement	6	148	1.7 should also include identification of these people: eg	Thank you for your comment. Following consideration of all stakeholder comments

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	Alliance			*'How should carers and those (including children and young people) important to people with life-limiting conditions be identified? When and how often should their supportive care needs be reviewed?'*	the guideline will focus on service delivery within the last 12 months of life for all conditions. The draft questions have been revised to reflect these changes. The revised scope will also adopt a wider focus on service models that provide support for the carers or those important to the people accessing end of life services.
374	National Bereavement Alliance	6	148	In parallel to our comment 5, we would suggest including a further question *1.8 When and how often should their bereavement care needs be reviewed?*	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. The draft questions have been revised to reflect these changes. Recommendations on bereavement can be found in the 2004 guideline, and will not be updated.
375	National Bereavement	General		There is a gap between holistic needs assessment and service organisation, which is about the actual care provided.	Thank you for your comment. Following consideration of all stakeholder comments

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	Alliance			We note that 'clinical aspects of care' and 'education and training' are specifically excluded from this guideline. For the patient themselves, it may be felt that this is covered by other guidelines such as *Care of the Dying Adult*, *Older People with Social Care Needs and multiple Long-term conditions.* However, for pre- and post-bereavement care, no such complementary guidelines exist, and therefore we would like to see clinical aspects of bereavement care included in this guideline. These could be based on the 2014 *Bereavement Care Service Standards* produced by Cruse Bereavement Care and the Bereavement Services Association.	the guideline will focus on service delivery within the last 12 months of life for all conditions. Recommendations on bereavement can be found in the 2004 guideline, and will not be updated. The more detailed, review questions will be refined when drafting the protocols with the assistance of the guideline committee.
376	National Bereavement Alliance	General (inc EIA)		We support the point made by the Childhood Bereavement Network in their response: Children are affected when their parent or carer (or someone else important) has palliative care needs. This group has specific support needs before and after their parent's death, yet are often overlooked in policy and practice issues. We believe the EIA (and the scope) should make specific reference to this group, in line with the 2004 guidance p24: '*The Guidance concentrates on services for adults, but the needs of children who may be affected by an adult carer or relative with cancer are acknowledged'*.	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. Additionally, those aged under 18 are outside the scope of this guideline. There is current NICE guidance in development on End of life care for infants, children and young people.

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					We will not be able to review the evidence or make specific recommendations for the needs of the children or young people you describe but we will bring your comments to the committee for their consideration in interpreting relevant service delivery evidence.
315	**National Counselling Society**	**General**	General	As an Accredited Register holder for counselling the Society views it important that counselling and associated modalities are still included within palliative care	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4.
316	**National Hypnotherapy Society**	**General**	General	As an Accredited Register holder for hypnotherapy the Society views it as important that hypnotherapy, where evidence based, is still included within palliative care and that hypnotherapy is not seen as a complementary therapy but rather as a psychological therapy.	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. Recommendations from

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					CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
92	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. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. After consideration we have included this topic area in order to conduct a full evidence review and make any specific recommendations related to end of life care service delivery, taking into consideration the quality standards.

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93	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 guidance.	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. 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). The scope has however been revised to include adaptations to adults' services for young adults thought to be entering the last year of life.
352	**Nottingham University Hospitals NHS Trust**	General	General	This guideline provides is an opportunity is to clearly define what the core business of specialist palliative care services should be given the current resources and differentiate this from what sits within the realms of supportive care which is the responsibility of the generalists and specific specialists	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.
353	**Nottingham University**	5	109	Will complementary therapies be the subject of a separate NICE guidance, if not we question why it is not included	Thank you for your comment. Following consideration of all stakeholder comments

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	Hospitals NHS Trust				the guideline will focus on service delivery within the last 12 months of life for all conditions. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
1	**OneReality**	4	65	Great to see the inclusion of holistic assessment	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. Consequently, holistic needs assessments will not be specifically addressed by any review question, but may be considered as part of service delivery models, in

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End of life care: Delivery of adult services for people in the last year of life

Consultation on draft scope
Stakeholder comments table 1

31/12/15 to 29/01/16

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ID	Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					accordance with available evidence.
2	**OneReality**	5	109	Why is the section on complementary therapy being removed? It seems contradictory that the assessment should include holistic aspects yet the means of satisfy the more holistic needs (complementary therapy) are now no longer covered!!	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
3	**OneReality**	3		Definition of Palliative Care: "integrate the psychological and spiritual aspects" Excellent.	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.

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					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.
4	**OneReality**	3		Specialist palliative care: if you include medical specialists in this list, you should also include spiritual specialists, those specialising in integrating the physical and spiritual such as holistic, complementary or integrated health experts.	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. 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.
5	**OneReality**	8	189	Why 'health related' Quality of Life? Why not just 'Quality of Life'? Their health is fading, so all the more reason to focus on other factors!	Thank you for your comment. These are the main outcomes. When the full review protocols are developed additional outcomes may also be included after

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					discussion with the Guideline Committee.
6	**OneReality**	11	Overview diagram	As life is ebbing away, the 'spiritual wellbeing' becomes far more than another factor to consider, it become the PRIMARY level at which to focus and at which palliative care needs to work.	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. Consequently, a new overview diagram will be developed in line with the content and rational of the revised scope.
7	**OneReality**	12	255	"High-quality, timely and compassionate" Excellent	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. Consequently, the context section of the scoping document has been amended to reflect these changes.
8	**OneReality**	12	260-269	Definition of supportive care is good and welcomed	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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					conditions. Consequently, in line with the content and rational of the revised scope, the definition for supportive care is no longer required as the guideline will focus on the delivery of services for adults in the last year of life.
9	**OneReality**	General		Extending the scope to all life-limiting conditions is welcome. It also emphasises that issues are more about personal needs beyond (deeper than) the purely medical	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. The revised scope will still focus on all progressive life-limiting conditions.
10	**OneReality**	14	325-330	Why focus on 'oncology and haemato-oncology'? Integration needs to be with spiritual mentoring, 'quality of life' specialists and whichever cares/therapist the patient calls for – e.g. holistic/complementary therapists such as Reflexology, Massage, reiki, etc. (all of which are widely acknowledged as being particular relevant to those who are dying)	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency

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					between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place. The content of the context section of the scope has been amended to reflect these changes.
11	**OneReality**	14	331-338	Excellent. To satisfy holistic needs, holist/complementary services WILL need to be procured!	Thank you for your comment.
12	**OneReality**	15	343-347	Holistic/complementary provision is often a very cost-effective approach.	Thank you for your comment.
128	**Parkinson's UK**	1	11-12	We agree that the scope for the supportive and palliative care guidelines should be widened to include adults with life-limiting conditions, including those with Parkinson's.	Thank you for your comment.
129	**Parkinson's UK**	4	71-76	We agree that an assessment should be holistic taking into account every need a person has; whether that is physical or social. We believe these assessments should be carried out by assessors with expertise in supportive and palliative care, and also condition-specific specialists when dealing with people who have Parkinson's.	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.

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					This guideline does not focus on condition specific clinical details, 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.
130	**Parkinson's UK**	5	104	Parkinson's UK is pleased that details on sharing information between multi-disciplinary teams (MDTs) will be included in the updated guideline. People with Parkinson's are often treated by a range of professionals during their diagnosis, ongoing treatment, and palliative care journey. If teams do not coordinate, the care for the person with Parkinson's could vary greatly in quality. People with Parkinson's will be treated by separate specialists, for example Occupational Therapist, Speech Therapist, or mental health practitioner. It's vital these professionals share information about the individual, to ensure they provide a coordinated care journey, especially if they have other health conditions.	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. The revised scope will include planning and coordinating services, including sharing information between multi-professional teams.
131	**Parkinson's UK**	5	107	We are concerned that information about education and training will not be covered by this guidance. It is essential that staff across health and social care are given appropriate training in order to provide effective assessments of people with life limiting conditions. For many people who work in health and social care, assessing the need for supportive or palliative care may only be a small part of their normal	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. It is beyond NICE's remit to provide

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				workload, so they may not know how to address specific issues relating to these needs. They might also not be aware of all the expert services available for people with Parkinson's to access. It's essential to educate and up-skill generalist health and social care staff so they better understand supportive and palliative care issues for people with Parkinson's. With this knowledge they will be better able to support individuals with life limiting conditions and those close to them.	guidance on education and training provision and content. This function is fulfilled by Health Education England for NHS staff and by Skills for Care for those providing social care. Employing organisations also maintain a responsibility for the continuing development of their staff in this regard.
132	**Parkinson's UK**	5	112	We are extremely concerned by the suggestion to remove the section on 'user involvement' from the new guidelines. It is essential that both patients and carers who rely on support and palliative care services have a way to contribute to the development and evaluation of these 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. Additionally, 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.
133	**Parkinson's UK**	5	113	We do not think guidance on face to face communication should be removed from the guidelines. Communicating complex and sometimes sensitive news and information should be done face-to-face where possible, to make 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

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				environment as supportive as it can be for the patient, family and carers. Face to face communication should be actively encouraged as the top choice for communicating around these difficult issues.	conditions. Additionally, 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.
134	**Parkinson's UK**	5	115	People with Parkinson's, their families and carers should be able to access high quality information easily. Without this information their navigation of the health and care system will not be as streamlined as it could otherwise be. Often people navigate the system in times of immense distress, so it is essential that the system is streamlined to make this process as easy as possible. We therefore believe that the current section in the guidelines on 'Information' is useful to include and do not agree that it should be removed.	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. Additionally, recommendations related to information provision can be found in the NICE patient experience guideline. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v.
135	**Parkinson's UK**	5	117	As this guidance is widening the scope to include people with life limiting conditions, not exclusive to cancer, we believe it would be beneficial to have condition specific holistic needs assessments. Parkinson's is a complicated, progressive, neurological condition which will often require an assessor with specialist knowledge to understand which	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.

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				services could help, and how the condition will change over time.	The guideline does not focus on condition specific clinical details. 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.
136	**Parkinson's UK**	6	142	Parkinson's is a progressive condition. With this in mind, it can be distressing for all concerned when people with Parkinson's and their carers are assessed numerous times, despite their needs remaining the same. However, as Parkinson's is progressive it might be appropriate to re-assess if a person's needs significantly increase. This review could be initiated by the person with Parkinson's or their carers (as long as they are informed they can request this when circumstances change). Alternatively the MDT working with the person with Parkinson's should get in touch at regular intervals to ensure the patient and carers have everything they need to manage the condition. We would therefore recommend that the scope explain that those with long term, progressive conditions, do not need to be assessed at regular intervals. We also believe the guidance should recommend that professionals who form part of the person's MDT team should make contact regularly to check all necessary support is in place..	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. The scope will not focus on condition specific clinical details. 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 Additionally, any recommendations will be informed by the evidence identified for each review.

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137	**Parkinson's UK**	7	150	We believe people in need of supportive care services should be assessed using an integrated model. Integrated care puts the patient at the centre of the process, It demands that all the professionals and services providing health and care for the patient communicate and coordinate with each other. It is essential that their assessment, and the support allocated afterwards, is based on the individual needs of the person with Parkinson's, but also the preferences of them, their family and carers. The system needs to recognise the potential for specialist supportive services which will benefit patients from the time of diagnosis. It will also need to factor in the fluctuating nature of need for people with life limiting conditions. It is crucial carers of the person with Parkinson's are involved in planning care in partnership with the MDT. Carers play a vital role providing care for their family member or loved one; often providing the majority of personal care. They are an important source of continuity, as well as a resource with knowledge of the person's needs, wishes, values and preferences. We would therefore recommend that the scope state that integrated models of care should be used to plan supportive care 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. The revised scope will cover service delivery models for end of life care including those covering both acute community and third sector settings.
138	**Parkinson's UK**	7	151	Parkinson's UK strongly believes that supportive care	Thank you for your comment. Following

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				services should be coordinated by a person's MDT. It is essential that all teams involved in meeting the person's care needs work together to achieve the best outcome. This requires monitoring, and recognition, of unmet supportive care needs, identification of triggers for specialist referrals, and close working between neurological and specialist services. Advanced care planning is essential for effective supportive care services for people with Parkinson's owing to the high risk of developing Parkinson's dementia. Up to eight out of 10 people who have Parkinson's for more than 10 years develop dementia. (Perez et al, Risk of dementia in an elderly population of Parkinson's disease patients: A 15-year population-based study, 2012). We would therefore recommend the scope stipulate that care should be coordinated by a person's MDT.	consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. Any recommendations will be informed by the evidence identified for each review.
139	**Parkinson's UK**	7	154	Supportive care services should be delivered wherever is most appropriate for the patient, their loved ones, and the condition(s) they have. We acknowledge it is important to assess the practicalities concerning which location should be used to deliver supportive care service; it may be that a mixture of settings (community, home, acute hospitals) are needed. These options should be discussed with the professional team, the person with Parkinson's and their loved one.	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. The revised scope will cover service delivery models for end of life care, including those covering both acute community and third sector settings.

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				We would recommend the setting for supportive care services is covered in the scope with particular reference to initiating discussions with the patient, family, carers and professionals to find out their preference.	
140	**Parkinson's UK**	7	165	Parkinson's UK advocate for an integrated, rather than prognostic, approach to identifying and managing palliative care services for people with and affected by Parkinson's. We also believe that carers should play an active role in planning both the care for individuals and the development of palliative services. We would therefore recommend that the scope state that integrated models of care should be used to plan palliative care 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. The revised scope will cover service organisation for care in the last year of life and this will address planning and coordinating services and service delivery models for end of life care, including those covering both acute community and third sector settings. This will address types of services, who delivers the services and how, multidisciplinary team composition, timing, review and location of services and 24/7 access.
141	**Parkinson's UK**	7	166	Parkinson's UK strongly believes that integrated care should be delivered by a person's MDT as a matter of course throughout a person's care journey. It is essential as part of this model for a person's family, loved-ones and carers to be	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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				effectively involved. They should be enabled to maintain their relationships, and also provide comfort, support and any elements of practical care they are able to perform. We would therefore recommend the scope stipulate that care should be coordinated by a person's MDT.	conditions. The revised scope will cover service organisation for care in the last year of life and this will address planning and coordinating services, including sharing information between multiprofessional teams.
142	**Parkinson's UK**	7	169 - 170	Many people with Parkinson's receive much of their palliative care in generalist settings such as hospitals and care homes, where staff typically have very limited knowledge about the complexities of managing advanced Parkinson's. They may not have had training in palliative and end of life care, are often under considerable time pressure, and workplace culture may not acknowledge the importance of dealing with dying. Though people with Parkinson's often tell us they would prefer to die at home, studies suggest that they are most likely to die in hospital (*Walker, Palliative care and end-of-life planning in Parkinson's disease, 2013).* Analysis of English mortality data has shown that of more than 49,000 people who died with Parkinson's mentioned on their death certificate, only 9% died in their own home (http://www.endoflifecare-intelligence.org.uk/resources/tools	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. The revised guideline will look at service delivery models for end of life care, including those covering both acute community and third sector settings. This will address location of services, for example place of care. Additionally, we recognize that some services in this setting are provided by the charitable sector and these providers may find the recommendations of relevance to

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				- click on Deaths from Neurodegenerative Diseases in England, 2002 to 2008). We believe conversations need to take place at the start of the palliative care journey to between health and social care professionals and the person with Parkinson's and their carers, to discuss what options they would prefer. While we support the right of a person to die at home if they wish, we emphasise that this must be backed up by sufficient investment in community services. It must also be acknowledged that many people with Parkinson's develop dementia; up to eight out of 10 people who have Parkinson's for more than 10 years develop dementia. (Perez et al, Risk of dementia in an elderly population of Parkinson's disease patients: A 15-year population-based study, 2012). This results in a loss of capacity to communicate palliative wishes. We would therefore recommend the guidance state that a conversation should take place between the patient, carers, family about where palliative care is to be delivered. Then professionals should try to make this happen where possible.	their services however, Non NHS or care funded settings are beyond the remit of NICE in relation to guidance provision. It is also beyond NICE's remit to provide guidance on education and training provision and content. This function is fulfilled by Health Education England for NHS staff and by Skills for Care for those providing social care. Employing organisations also maintain a responsibility for the continuing development of their staff in this regard. Areas from the published guideline that will be removed.
143	**Parkinson's UK**	7	171	As Parkinson's is a complex condition, it is important that services are commissioned and managed in a multidisciplinary way, so that knowledge from the domains of neurology and palliative care, as well as speech 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

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				language therapy (swallowing) and all the other necessary therapy areas, can be brought together to provide holistic support across all settings. There is a need for appropriate staffing (staff ratios and skill mix), effective clinical leadership, information gathering (GP registries) and information sharing protocols and systems. Those who provide care for people with Parkinson's, and wish to get involved in palliative care services, should be enabled to do this. They will require support to fulfil this role which could be provided through peer support and training, including how to recognise and cope with the final phase of the condition and access adequate respite care. We would therefore recommend the guidance state that a conversation should take place between the patient, carers, family about who should provide palliative care. It should also be stated that carers, or family members who wish to take on this role, should be enabled to do this where possible.	conditions. The revised guideline will not focus on condition specific clinical details. 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. The revised scope will adopt a wider focus on service models that provide support for the carers or those important to the people accessing end of life services.
283	**Princess Alice Hospice**	5	93	We support the update to psychological support services and will remain engaged with the process and comment at the next stage	Thank you for your comment.
284	**Princess Alice Hospice**	5	94	We support the update to spiritual support services and will remain engaged in the process and comment at the next	Thank you for your comment.

ID	Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				stage	
285	**Princess Alice Hospice**	5	96	We support the update to rehabilitation services and will remain engaged in the process and comment at the next stage	Thank you for your comment.
286	**Princess Alice Hospice**	5	97	We support the update to specialist palliative care services and will remain engaged in the process and comment at the next stage	Thank you for your comment
287	**Princess Alice Hospice**	5	98	We support the update to services for families and carers, including bereavement care, and will remain engaged in the process and comment at the next stage	Thank you for your comment. Recommendations on bereavement can be found in the 2004 guideline, and will not be updated.
288	**Princess Alice Hospice**	5	109	The draft scope proposes that complementary therapies are removed from the guidance and we would challenge this move. Complementary therapies are used widely to support our patients and their carers and we believe that the body of evidence is growing to support its use. Further evidence for the benefit of complementary therapies has been supplied by the Complementary and Natural Healthcare Council.	**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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline.** Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place. We will ensure consistency between the

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					new recommendations in End of life care: service delivery and any such recommendations from CSG4.
289	**Princess Alice Hospice**	5	110	We challenge the rationale in removing research from the guidance as there is a developing national agenda to encourage hospices to become more research active and evidence based. We feel this would be a retrograde step and impact on this strategy.	Thank you for your comment. 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.
290	**Princess Alice Hospice**	5	112	We challenge the rational to remove user involvement in planning, delivering and evaluating services as they are experts by experience and hugely valuable to the planning of appropriate and effective 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. User involvement in planning, delivering and evaluating services, face to face communication and the provision of information have been covered in the NICE Patient experience guideline, more details can be found at the following link:

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					https://www.nice.org.uk/guidance/cg138v.
219	**Public Health Agency**	1	12	Suggest consider including frailty in scope of guidance	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. The guideline will not focus on individual clinical conditions. 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.
220	**Public Health Agency**			Suggest to scope should be palliative and end of life care for adults of all conditions (cancer and non- cancer). Challenging to develop service delivery guidelines if including supportive care as per definition on page 3.	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. 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

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					services' and 'care at the end of life' are now being used within a revised scope.
221	**Public Health Agency**	1	19	Suggest the scope should include independent sector and community/ voluntary sectors.	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 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.
222	**Public Health Agency**	2	28	Suggest including the words '*Generalist'* and *Specialist* Palliative care services	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

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					services' and 'care at the end of life' are now being used within a revised scope.
223	**Public Health Agency**	2	38-40	Suggest inclusion of other groups such as prisons, travellers and neurological conditions.	Thank you for your comment. 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.
224	**Public Health Agency**	3	48	Term '**supportive care'** – This definition has not been embraced in N.Ireland . Suggest removal of the reference to 'cure' It appears to contradict the scope outlined on line 11. 'Adults with life-limiting conditions'.	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.
225	**Public Health Agency**	3	48	Term '**palliative care'** – suggest change in line with the World Health Organisation definition. Palliative care can be for weeks, months or years. End of life care is seen as an element of 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

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					the guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.
226	**Public Health Agency**	3	48	Term '**non specialist'** – suggest using the term 'generalist' as per line 20 on page 1. Keep continuity of wording throughout the document.	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.
227	**Public Health Agency**	3	53	Suggest referring to specialist and generalist palliative care services.	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
228	**Public Health Agency**	General	General	Suggest term' palliative and end of life care' used to reflect current culture and practice . Suggest removal of term Supportive care –	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline

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					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.
229	**Public Health Agency**	4	60	Suggest further clarity on settings not included.	Thank you for your comment. The only settings now explicitly excluded are non NHS funded settings, which are beyond the remit of NICE.
230	**Public Health Agency**	4	76	Suggest consideration given to including 'Quality of life and planning for the future'	Thank you for your comment
231	**Public Health Agency**	4	80	Suggest more detail to include Primary Care , Independent sector, community and voluntary sector.	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. The revised scope will cover service delivery models for end of life care, including those covering both acute community and third sector settings, which will address location of services, for example place of care.

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232	**Public Health Agency**	4	81	Suggest further clarity on specialist services – is this non pall care specialist 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. 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, that the meaning of terms uses is explicit, and that vague terminology is avoided.
233	**Public Health Agency**	4	84	Suggest including specialist palliative care	Thank you for your comment.
234	**Public Health Agency**	4	87	Suggest scope should be '24/7 provision of care and access to palliative care services. Not specialist services but specialist advice	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. The revised scope covers service delivery models for end of life care and will address out of hours, weekend and 24/7 availability of services, including access to advice.
235	**Public Health**	5	99	Suggest adding section of role of the palliative care key	Thank you for your comment.

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	Agency			worker included in this update.	NICE guidelines make recommendations on treatment and processes of care and will not specify the roles of different healthcare professionals. The committee anticipates that this will be Trust and service setting lead.
236	**Public Health Agency**		106	Strongly suggest clinical aspects be covered	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. 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.

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237	**Public Health Agency**	5	107	Strongly suggest 'education and training should be covered	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. Additionally, it is beyond NICE's remit to provide guidance on education and training provision and content. This function is fulfilled by Health Education England for NHS staff and by Skills for Care for those providing social care. Employing organisations also maintain a responsibility for the continuing development of their staff in this regard.
238	**Public Health Agency**			Clarity why complementary therapy is suggested to be removed.	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency

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					between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
239	**Public Health Agency**	5	112	Strongly suggest User involvement should NOT be removed but revised	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. 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.
240	**Public Health Agency**	5	113	Strongly suggest face to face communication should NOT be removed but revised	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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					conditions. 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.
241	**Public Health Agency**		114	Strong suggest social support services are NOT removed but revised	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. Guidelines related to the provision of social support are the remit of the Social Care Institute of Excellence. More details on this agency and its published work can be found at: http://www.scie.org.uk/.
242	**Public Health Agency**	5	115	Strongly suggest Information – this should NOT be removed but revised	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.

ID	Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					Recommendations related to information provision can be found in the NICE patient experience guideline. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v.
243	**Public Health Agency**	6	137-138	'…holistic needs for palliative care …' would suggest including the words 'palliative and end of life care'	Thank you for your comment. 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.
244	**Public Health Agency**	7	154-155	Suggest further clarity on this statement	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. Consequently, the draft questions listed on the revised scope have been amended to reflect these changes.

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245	**Public Health Agency**	7	161	Suggest it is confusing using 'supportive services' and 'specialist palliative care' the same sentence.	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. 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.
246	**Public Health Agency**	7	164	Suggest change in terminology. There are specialist palliative care services , however generalist palliative care can be provided within a heath care model but not necessary a service per se . I.e. GP , District nursing role, Core AHP services.	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.
247	**Public Health**	7	169-170	Suggest need to include reference to care homes	Thank you for your comment. Following

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	Agency				consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. Consequently, the draft questions listed on the revised scope have been amended to reflect these changes.
248	**Public Health Agency**	7	171	Suggest scope to include service specifications / standards	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. It is not within NICE's remit to develop service specifications. Standards are developed through a different process.
249	**Public Health Agency**	7	176	Suggest replacing non-specialist palliative care with generalist 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, that the meaning of terms uses is explicit, and that vague terminology is avoided.
250	**Public Health**	14	331-333	Very strongly support for this statement.	Thank you for your comment.

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	Agency				
251	**Public Health Agency**	General	General	The proposed guideline development has been very strongly welcomed by a range of health professionals working across different care settings. However we would suggest the scope should be palliative (generalist and specialist) and end of life care for adults with cancer and non -cancer conditions, unlikely to be cured.	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.
252	**Public Health Agency**	General	General	The document does not appear to comment on tools/strategies for the identification of 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.
15	**Pumping Marvellous Foundation**	General	General	Although it is to be welcomed that the scope guidance has now widen its remit, the scope fails to mention the published guidance that will be referred to e.g. Chronic Heart Failure Clinical Guideline, which would provide evidence of the poor prognosis of heart failure, which has mortality rates worse than most forms of 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. Consequently, the guideline does not focus on any condition specific clinical details. For all life limiting conditions, please see the following link on the NICE website: http://www.nice.org.uk/guidance/published

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					?type=guidelines.
16	**Pumping Marvellous Foundation**	General	General	Applications for members for the recruitment fail to mention any Cooptees, it is to be hoped that this will include a heart failure specialist, preferably a heart failure specialist nurse who are often has the day to day management of patients who are end stage heart failure/end of life.	Thank you for your comment. Whether or not anyone will be coopted onto the Guideline Committee, and if so, who, will be agreed at a later date with the help of full Committee members.
73	**Royal College of Physicians of Edinburgh**	General	General	Specific mention is made in several places of patients with dementia. This is welcome. However, the overwhelming issue facing healthcare professionals relates to patients who have both physical and cognitive frailty and those who have extreme physical frailty with multiple chronic conditions. Such patients are not necessarily old. There is no specific mention of this very large patient group in the document - which we would suggest is an omission.	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 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.
74	**Royal College of Physicians of Edinburgh**	2	41-42	Patients with cognitive impairment and frailty are rightly mentioned here. Another vulnerable group are patients with extreme physical frailty, especially those who are housebound and have no family members or advocates.	Thank you for your comment. 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

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					services at the end of life.
75	**Royal College of Physicians of Edinburgh**	3		We suggest taking out the phrase "towards the end of life" from the definition of palliative care as this is unnecessary and may be misconstrued.	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. 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.
76	**Royal College of Physicians of Edinburgh**	4	64	A key area that should be covered is identification of patients for palliative care. This should take place prior to a holistic needs assessment as suggested in Scotland and in the Gold Standards Framework guidance, where 1) identification, 2) assessment and 3) planning are the three main steps in delivering palliative care. We recommend that identification is highlighted so that it is seen as an important prerequisite step. The tools suggested, for instance the Sheffield Spark Profile,	Thank you for your comment. The guideline's scope will cover patient care in their last year of life after they have received a diagnosis of a progressive life-limiting condition.

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				do not identify people, they assess needs. These are helpful when the person has already been identified for palliative care. There are a number of tools specifically for identification and these are listed in a systematic review – Maas EA, Murray SA, Engels Y & Campbell C. *What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice*. BMJ Supportive and Palliative Care, 2013;3:444-451.	
77	**Royal College of Physicians of Edinburgh**	4	79	Service delivery models should specifically include innovative services such as hospital at home which span the boundaries of acute and community settings.	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. The revised scope will cover service delivery models for end of life care, including those covering acute, community (including home) and third sector settings. The evidence identified will inform any recommendations made.
78	**Royal College of Physicians of Edinburgh**	5	88	Identification and referral is appropriate at this point, but this would be a particular stage in identification, for specialist palliative care support or other specialist input, e.g	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery

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				bereavement care.	within the last 12 months of life for all conditions. Recommendations on bereavement can be found in the 2004 guideline, and will not be updated. The more detailed, review questions will be refined when drafting the protocols with the assistance of the guideline committee.
79	**Royal College of Physicians of Edinburgh**	5	91	It would be helpful to also include identification of patients for a palliative care approach.	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. The revised scope will cover patient care in their last year of life after they have received a diagnosis for a progressive life-limiting condition. The revised scope includes a question on identification of those likely to be in the last year of life.
80	**Royal College of Physicians of Edinburgh**	5	117	We suggest including condition-specific identification tools for advanced illness.	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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					conditions. The revised scope does not focus on condition specific clinical details. For all life limiting conditions, please see the NICE website for further details: http://www.nice.org.uk/Guidance.
81	**Royal College of Physicians of Edinburgh**	6	131	We suggest 1.5.1 should be identification for supportive and palliative care; then 1.5.2 would be holistic needs assessment,1.5.3 would be service organisation for supportive care and 1.5.4 should be service organisation for palliative care.	Thank you for your comment.
82	**Royal College of Physicians of Edinburgh**	6	135-137	It should be borne in mind that any tool must consider the frail patient – or the alternative approach would be to recognise the need for more than one tool to reflect this patient group.	Thank you for your comment.
83	**Royal College of Physicians of Edinburgh**	6	142-148	Guidance on when and how often supportive/palliative needs should be reviewed is patient-dependent and it is difficult to be prescriptive as this is individual to each patient.	Thank you for your comment.
84	**Royal College of**	8		This should include outcomes with a public health	Thank you for your comment. The scope

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	Physicians of Edinburgh			perspective, such as the percentage of people who die having been identified for supportive or palliative care.	lists the main outcomes. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee. Public health guidelines can be found on the NICE website at the following link: https://www.nice.org.uk/guidance/published?type=ph
85	**Royal College of Physicians of Edinburgh**	11		We suggest the top box would include adults identified as in need of supportive and palliative care, their carers and those important to 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. Consequently, a new overview diagram will be developed in line with the content and rational of the revised scope.
86	**Royal College of Physicians of Edinburgh**	12	256-259	"There is a need to identify & standardise the supportive and palliative care that is needed for people…". We suggest it is important to ensure there is personalised care as far as possible.	Thank you for your comment.
87	**Royal College of**	13-14	309-316	Many of the examples used sound more appropriate for	Thank you for your comment.

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	Physicians of Edinburgh			chronic pain services than palliative care.	
253	**Royal Marsden NHS FT**	3	47	Definitions are not clear. There is clear overlap between supportive and palliative care. Could be simpler Caution in suggesting that palliative care is limited to end of life care as for those of us in the hospital this would not be the case	Thank you for your comment. 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.
254	**Royal Marsden NHS FT**	4	66-68	With reference to Holistic Needs assessment IPOS and/or the OACC suite of measures are established tools that are being used by an increasing number of palliative 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. 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.
255	**Royal Marsden**	5	107 and 110	As this is guidance to inform service delivery we would	Thank you for your comment.

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	NHS FT			expect some description towards education and training and research and how this should be incorporated	It is beyond NICE's remit to provide guidance on education and training provision and content. This function is fulfilled by Health Education England for NHS staff and by Skills for Care for those providing social care. Employing organisations also maintain a responsibility for the continuing development of their staff in this regard. Research recommendations will be made following the standard NICE methodology.
256	**Royal Marsden NHS FT**	5	108-115	Rationale for why these services have been removed was unclear	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. Further, 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.

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					User involvement in planning, delivering and evaluating services, face to face communication and the provision of information have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v. Social support services: Guidelines related to the provision of social support are the remit of the Social Care Institute of Excellence. More details on this agency and its published work can be found at: http://www.scie.org.uk/.
257	**Royal Marsden NHS FT**	7	169	Difficult to determine what is intimated in the statement where should palliative care services be delivered, should this not be to deliver in all areas?	Thank you for your comment. Additionally, the scope includes draft questions. The more detailed, review questions will be refined when drafting the protocols with the assistance of the guideline committee.
94	**Severn Hospice**	5	109	Severn Hospice wish to register opposition to the removal of complementary therapies in Supportive and Palliative Care.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery

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				Data shows that therapies are well used in hospice and palliative care. In the UK, within the National Health Service, reflexology was found to be available for people with cancer in 62% of units (Egan B, Gage H, Hood J, Poole K, McDowell C, Maguire G et al. Availability of complementary and alternative medicine for people with cancer in the British National Health Service: results of a national survey. *Complementary Therapies in Clinical Practice 2012; 18(2):75-80)*. Within Severn Hospice our complementary therapy service provides a valuable addition to the wider package of integrated patient care. Working as part of the multi-disciplinary team our therapists add to a holistic package of care for patients. Complementary Therapies provide patients with relief from symptoms such as pain, nausea, insomnia and anxiety as well as providing a sense of pleasure, comfort and wellbeing. Providing a therapy also helps us to provide spiritual care for patients, often opening channels of communication which can be challenging for our medical team. Complementary therapies are well loved by patients and extremely well respected by our medical team. It is an expanding and developing team not only within the hospice but also within the community and local acute hospital.	within the last 12 months of life for all conditions. Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				"Reflexology put me in a place I have never been before … completely blank of worries and anxieties, dispelled at kind hands" *"The aromastick I was given for nausea was absolutely great – it really helped"* *"I have found huge emotional support through being able to talk and relax during a treatment"* *"My anxiety was giving me headaches. 3 weeks on, after these wonderful treatments, these symptoms have disappeared – an enormous relief. I felt down and anxious … I now feel ready to face the world again"* We feel that removal of guidelines for complementary therapies particularly without rationale would be a retrograde step. In the same way that medical interventions need guidelines, so do complementary therapies in order to ensure safe and effective delivery. Therapies are seen as an important and valued service for patients. The presence of NICE guidelines are therefore of utmost importance.	
20	**Shooting star chase hospice**	General	General	Transition not acknowledge – while not unique they present often with a life limiting illness that family may know more about than medical staff, where capacity has never been in place. They may be new to adult law, adult medical care.	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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				Consequently staff may need different preparation, training. The end point may be the same but it is folly to think the starting point is the same.	conditions. 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). The scope has however been revised to include adaptations to adults' services for young adults thought to be entering the last year of life. Further, it is beyond NICE's remit to provide guidance on education and training provision and content. This function is fulfilled by Health Education England for NHS staff and by Skills for Care for those providing social care. Employing organisations also maintain a responsibility for the continuing development of their staff in this regard.
21	**Shooting star chase hospice**	General	General	Young siblings in family may still be known to children's hospice, consider referral or joint work if it makes sense	Thank you for your comment. Following consideration of all stakeholder comments

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					the guideline will focus on service delivery within the last 12 months of life for all conditions. 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). The scope has however been revised to include adaptations to adults' services for young adults thought to be entering the last year of life.
96	South Tyneside NHS Foundation Trust				
97	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 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 will include consideration as to who should be delivering end of life care.

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98	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.
99	South Tyneside NHS Foundation Trust	4	82	positive to identify this group	Thank you for your comment.
100	South Tyneside NHS Foundation Trust	4	65	it would be helpful to include some outcome measurement as part of the assessment process	Outcomes are listed later in the scope, please see section 1.6.
101	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	Thank you for your comment.
102	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.
103	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.
104	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. . Consequently, holistic needs assessments

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					will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
105	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. The scope lists the main outcomes for the guideline . When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee. Any strata or subgroups will be considered within evidence review protocols and agreed after discussion with the guideline committee.
106	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. 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. Information sharing across multidisciplinary teams and services is one of the key questions included in the

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					revised scope. Any recommendation will be informed by available evidence. EPACCS may therefore be considered as part of service delivery models in this area, in accordance with available evidence. NICE's remit is to provide advice to the NHS, and so covers NHS funded care. It is beyond the remit to comment on other sources of funding.
107	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.
108	South Tyneside NHS Foundation Trust	7	169-170	Mention hospices specifically.	Thank you for your comment. The revised guideline will cover service delivery models for end of life care, including those covering both acute community and third sector settings, so long as they are funded (at least in part) by

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					the NHS.
109	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. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. 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).
110	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 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, that the meaning of terms uses is explicit, and that vague terminology is avoided.
36	**St Michaels**	5	109	Complementary Therapies to be removed, causing concern	**Thank you for your comment.**

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	Hospice (North Hampshire)]			within the organisation as feedback from service users shows this is a very valued and successful part of the service. Would like to understand the reasons for removing this group	Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
88	**St Wilfrids Hospice**	5	109	The draft is currently looking at removing Complementary therapies from the guidelines. As a unit providing holistic care to all our patients, their families and carers, and bereaved relatives we feel this would be a backward step in not offering Complementary therapies the recognition and validation they deserve. In order to provide a safe delivery of these therapies it is imperative they are included in nationally recognised guidelines. As a professional therapist I maintain high standards of conduct and adhere to guidelines that are recommended in our unit, by removing them it could open the door to the dumbing down of our high standards which we have fought so hard to maintain.	**Thank you for your comment.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
95	**St.Helena's Hospice**	General	General	The North East Essex Locality End of Life Project Group agrees that the scope of the guidance should be widened from just cancer to include other long term conditions. We see this as a key priority in the provision of palliative care in	Thank you for your comment. Transition from paediatric to adult services will no longer be addressed in the

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				the next few years. We also welcome the inclusion of provision of palliative care for those transitioning from children's to adult services. Locally we have seen the benefits of 24/7 service for coordinating care and we agree that addressing inequality of provision of such services should be a priority.	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).
354	**Stroke Association**	general	general	Stroke is the fourth largest cause of death in the UK.[1] One in eight of those who have a stroke die within 28 days, but little is known about the palliative needs of stroke patients.[2] According to the most recent Royal College of Physicians' Sentinel Stroke National Audit Programme (SSNAP) statistics around 5% of patients who have a stroke experience a stroke of such severity that a decision is made to palliate within 72 hours. Around 11% of patients are put on an end of life pathway after 72 hours.[3] Those who have suffered an acute stroke (and their family and friends) can have huge care needs to enable them 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. Condition specific issues are not being considered, and nor will any specific recommendations be made that are condition specific.

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[1] https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2016_110116_0.pdf
[2] http://ageing.oxfordjournals.org/content/39/5/554.full?sid=a0c58dbb-9b41-459d-8ed0-af978885791a
[3] https://www.strokeaudit.org/Documents/Results/National/AprJun2015/AprJun2015-PublicReport.aspx

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				cope with the complex decision making involved in managing the impact of what has happened to them.[4] There is currently a lack of research and understanding surrounding the most appropriate palliative care interventions for acute stroke.[5] The SSNAP data suggest that palliative care needs to improve for those who have had a stroke. The majority of patients prefer to die at home, but in reality, this only happens in a minority of cases. Research suggests that most patients dying from stroke are not referred to specialist palliative care services, and can have unmet palliative care needs.[6] Although condition-specific pathways have been listed as outside the scope of this review, Baroness Neuberger's recent review of the Liverpool Care Pathway has recommended the use of condition specific pathways at the end of life where they are required. [7] The combination of symptoms stroke patients can have towards the end of life are very specific to stroke, such as muscle contractures,	

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[4] http://stroke.ahajournals.org/content/early/2014/03/27/STR.0000000000000015
[5] https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-full-report.pdf
[6] http://spcare.bmj.com/content/2/Suppl_1/A14.1
[7] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

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				neuropathic pain, paralysis and cognitive impairment. Therefore we would question why there is not more consideration of condition-specific needs when developing end of life care pathways. It should also be considered that stroke is different from many other conditions in that palliative care may be necessary at a very early stage due to the sudden onset of stroke. Of course, better communication between clinicians and family and friends is also very important for improving end of life care, particularly around uncertainty.	
355	**Stroke Association**	2	37	We would like to see socio-economic inequality being included in the range of inequalities that the guideline will look at. People from the most economically deprived areas of the UK are around twice as likely to have a stroke than those from the least deprived areas, meaning more people are likely to be reliant on social care services. People from the most economically deprived areas are also three times more likely to die from a stroke than those from the least deprived areas and this is therefore a key inequality which needs to be addressed.[8]	Thank you for your comment. 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.

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[8] https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf

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356	**Stroke Association**	4	81	We are pleased that the scope will examine access to specialist services and access to round-the-clock care. There are particular challenges in offering palliative care to those who have had a stroke, and therefore, in some contexts, specialist support may be appropriate. It can be difficult for clinicians to know when to initiate palliative care for stroke patients, as the trajectory of a patient who has had a stroke is not easily calculable.[9] Patients who have a diagnosis of stroke are most likely to make the transition to palliative care than patients with other common life limiting conditions. The odds of a transition to palliative care are multiplied by an estimated 5.1 for patients with a cancer, by 8.0 for stroke diagnosis, and by 2.6 for a dementia diagnosis. However, patients with a cancer diagnosis are more likely to receive specialist palliative care than stroke patients, making the case for condition-specific pathways even stronger.[10] Research has shown that healthcare professionals are only like to consider specialist palliative care for stroke patients if	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. The revised scope will cover the planning, coordination and out of hours, weekend and 24/7 availability of services.

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[9] http://www.gla.ac.uk/media/media_181950_en.pdf
[10] http://www.journalslibrary.nihr.ac.uk/__data/assets/pdf_file/0011/94277/FullReport-hsdr01110.pdf

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				they have complex physical or psychological symptoms, discharge needs, family needing psychological support, cancer, they have been known to specialist services, or for help with ethical conditions. The role of specialist services is not clear to staff, and specialist services are still linked with cancer. This needs to change, and improved education and better links between stroke and specialist palliative teams could improve end of life care for those that have experienced acute stroke.[11]	
357	**Stroke Association**	5	93	We are pleased that psychological factors are being taken into account, as they form an invaluable part of the palliative care pathway, particularly for those that have been affected by stroke and their family and carers. Stroke survivors commonly experience depression and/or anxiety following their stroke. In response to a survey for our 'Feeling Overwhelmed' report, a third reported that they experienced post-stroke depression and 20% experienced emotionalism in the first 6 months after stroke.[12] One in four stroke patients report concerns about death and dying, 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. Guidance related to the provision of psychological services are the remit of the National Clinical Centre for Mental Health, which is tasked by NHS England and NICE to develop products to support the Achieving Better Access to Mental Health

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[11] http://spcare.bmj.com/content/2/Suppl_1/A14.1

[12] https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2016_110116_0.pdf

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				in addition, 66% have concerns about dependence and disability.[13]	Services programme. Guidance related to condition specific psychological needs can be found on the NICE website at: http://www.nice.org.uk/Guidance.
358	**Stroke Association**	5	96	The Stroke Association welcomes the fact that rehabilitation services in palliative and supportive care are being considered as part of this review. Stroke has a greater disability impact on an individual than any other chronic disease, and over half of all stroke survivors are left with a disability.[14] The role of rehabilitation is critical for improving outcomes for stroke survivors, and relieving the long-term symptoms associated with stroke. Rehabilitation is crucial to survivors' quality of life and a key example of this is swallow support which ensures that a stroke survivor does not choke on food and/or develop pneumonia. It also helps people taste some food for pleasure without swallowing. This, from a quality of life perspective, is important because easy to swallow foods are often tasteless and bland. Supportive care is also important to prevent painful	Thank you for your comment. .

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[13] http://www.eapcnet.eu/LinkClick.aspx?fileticket=-608F2HB3-I%3D&tabid=625

[14] https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2016_110116_0.pdf

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				complications relating to being bed-bound such as venous thromboembolism. Stroke survivors can often be left with speech and throat problems, difficulty swallowing, and may depend on others for help with activities. They may develop musculoskeletal and neuropathic conditions which impair their physical functioning.	
359	**Stroke Association**	5	98	We are pleased that there will be a review of services for families and carers. Family, friends and carers can often find it difficult to understand the impact that a stroke has had on an individual, and may need to make difficult decisions about end-of-life care or ongoing supportive care. One in five stroke survivors is cared for by family or friends. According to our research, 64% of carers find that the emotional impact of stroke is the hardest thing to cope with, 79% experience anxiety, and 84% experience some frustration.[15] According to a recent report, professionals describe two	Thank you for your comment.

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[15] https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2016_110116_0.pdf

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				distinct end-of-life trajectories following acute stroke – either sudden death, or prolonged dying. It has been found that relatives are uncomfortable with prolonged dying, and are unprepared for this outcome. However, relatives feel most discomfort when either excluded from decision making, or feeling overly responsible for making decisions. Better communication between clinicians and family and friends is very important for improving end of life care, particularly around uncertainty.[16] NHS Quality Improvement Scotland has produced a best practice statement for end of life care for acute stroke. They point out that, because of the rapid onset of acute stroke, patients and carers require support in coping with the pace of events, and making decisions.[17]	
360	**Stroke Association**	5	107	The National Stroke Clinical Guideline recommends that stroke teams should have a good understanding of the principles and practices of care at the end of life, recognise individuals who are dying and may benefit from palliative care, and facilitate access to expert and co-ordinated	Thank you for your comment.

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[16] https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2015/triggers-for-palliative-care-full-report.pdf
[17] http://www.gla.ac.uk/media/media_181950_en.pdf

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				palliative care services. The guidance suggests that personnel in stroke teams should increase their expertise in end-of-life palliative care, and accept that this is part of the work of a comprehensive stroke service.[18] Therefore, we are concerned that education and training have been excluded from the scope of the review, and feel this may be a lost opportunity to improve palliative care delivery, and the understanding of the needs of patients with specific conditions. By excluding education and training from the scope of the review, we lose both the potential for staff to become better informed about the specific palliative need of stroke patients, and for staff on stroke wards to fully understand the nature of palliative care. Therefore we are disappointed that education and training has been left out of the scope of this review, and strongly urge NICE to include it in the full consultation. .	
361	**Stroke Association**	8	189	We welcome the inclusion of health-related quality of life as one of the main outcomes to be considered when searching for and considering the evidence. In any after-stroke care and support, there should be an emphasis not just on the	Thank you for your comment.

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[18] https://www.rcplondon.ac.uk/guidelines-policy/stroke-guidelines

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				maintenance of wellbeing and quality of life but improvement in wellbeing and quality of life. With the appropriate support and rehabilitation, stroke survivors' wellbeing and quality of life can improve significantly in the months and years following their stroke.	
153	**Sue Ryder**	3	52	Sue Ryder welcome NICE updating the supportive and palliative care guideline for adults with cancer (2004), by widening the scope of the consultation to include the supportive and palliative care needs of all regardless of condition.	Thank you for your comment.
154	**Sue Ryder**	5	100	Sue Ryder welcomes the inclusion of transitional care for young adults being moved from children's services to adult services being included in the draft scope. Transfers of care for children	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). The scope has however been revised to include adaptations to adults' services for young adults thought to be entering the last year of life.
155	**Sue Ryder**	5	102	Sue Ryder welcomes that the importance of a holistic needs assessment has been recognised and is being included in	Thank you for your comment.

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				the scope of the report.	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.
156	**Sue Ryder**	5	104	Sue Ryder welcomes that the guideline including information regarding	Thank you for your comment.
157	**Sue Ryder**	5	106	Sue Ryder feels that the guideline should cover clinical aspects of care.	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. 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.

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					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.
158	**Sue Ryder**	5	112	Sue Ryder is concerned that NICE plan to remove user involvement in planning, delivering, and evaluating services from the scope of the draft guideline. We are concerned about the effect that this will have on patient reported outcomes and person centred care if this is removed from the guideline, and would like to see this retained.	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.
159	**Sue Ryder**	5	109	We feel the draft scope's removal of complimentary therapies from is a premature move. Sue Ryder has anecdotal evidence of the effectiveness of complimentary therapies for patients receiving our care and the positive effect on their quality of life. Not much research has been undertaken into the benefits of complimentary therapies, we would like to see further research before they are removed from the guideline altogether.	**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. **Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered**

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					in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
160	**Sue Ryder**	5	110	The Draft scope currently removes research in supportive and palliative care. We would like further clarification from NICE as to why research is being removed from the scope of the guideline. Organisations look to NICE to provide robust evidence base, and highlight any gaps in research so removing this would be a key loss. The Care of the Dying Person Guideline made 4 recommendations for further research 1. Recognising dying 2. Agitation and delirium. 3. Noisy respiratory secretions, 4. Anticipatory prescribing. This was a clear mandate for research into end of life issues, and removing it would be completely at odds with the Care of the Dying Adult guideline. Financial concerns cannot be used as an excuse for this, as an earlier commitment was made in previous guidelines.	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. 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.
198	**The Bach Centre**	5	109	We feel it is an extremely retrograde move to remove references to complementary therapies from the NICE guidelines on supportive and palliative care. It seems especially wrong as the Guideline Scope talks specifically and repeatedly about the need for a holistic approach. The Bach Centre has on its register of Bach practitioners	**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.** Recommendations from *CSG4: Improving supportive and palliative care for adults*

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				many people who offer support and palliative care. Many volunteer at hospices and give their time for free. The support our practitioners offer is not a physical treatment. Instead it involves talking with people, focusing on emotional and spiritual health, and providing to patients and their families simple tools that they can use to manage their feelings for themselves. Many patients and their families find complementary therapies useful. Others may have heard about one technique or another but will want advice. On line 331-332 the Guideline Scope speaks of the need for "clear guidance... on providing more equitable and consistent supportive and palliative care". Removing the guidance on complementary therapies will we feel lead to the opposite situation. In the absence of any guidance, individual carers will have to fall back on what they know (or don't know) about particular therapies, leading to an inconsistency in approach that will lead to some individuals not getting help that might have benefited them. Helping people with palliative and supportive care, as NICE acknowledges, often means helping people achieve a measure of emotional and spiritual well-being. The role of complementary techniques in this area should therefore be recognised by NICE, as it is in the existing guidance.	*with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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147	**The Brain Tumour Charity**	4	65-76	We are pleased that the use of holistic needs assessment has been included within service delivery of supportive and palliative care. For brain tumours, holistic needs assessments can play a valuable role in helping to identify the neurorehabilitation and support needs of patients following treatment and are awaiting discharge from hospital into the community. The role of neurorehabilitation in delivering functional improvement after treatment and improving quality of life has been set out in the previous NICE guideline on Improving Supportive and Palliative Care for Adults with Cancer (2004) and Improving Outcomes for People with Brain and Other CNS Tumours (2006). However, in practice, we know that there is variation in access to neurorehabilitation services across the UK. Our report, Losing Myself: The Reality of Life with a Brain Tumour, showed that there were variations between high and low grade brain tumour patients in access to physiotherapists and psychologists.	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. 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.
148	**The Brain Tumour Charity**	4	87	We are pleased to see the inclusion of this area within the scope of the guideline. Supportive and palliative care could be improved for people with a terminal diagnosis of a brain tumour by the expansion of access to specialist 24/7 advice	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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				and support services. In particular, we think Clinical Commissioning Groups (CCGs) can play a more prominent role in prioritising access to 24/7 coordinated support services. A Sue Ryder campaign, *Dying Doesn't Work 9-5*, found that only 8% of CCGs commission the level of support that dying people, their carers and their loved ones need and deserve. To improve the situation, we believe that CCGs in England should specifically commission services that will provide 24/7 coordination and particularly for those receiving palliative care or dying at home.	conditions. The revised scope will cover service delivery models for end of life care and this will address out of hours, weekend and 24/7 availability of services.
149	**The Brain Tumour Charity**	5	89-90, 100	We strongly support the inclusion of transitional care for young adults within the draft scope of the guideline. It is critical that teenagers and young adults between the ages of 13 and 24 are treated in an age-appropriate environment with suitable key workers and support. The NICE guideline *Improving Outcomes in Children and Young People with Cancer* from 2005 highlighted gaps in a number of aspects of supportive care for teenagers and young adults, such as occupational therapy, psychology, psychiatry and social worker support.	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. 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). The scope

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				To this end, we are pleased that the draft scope document that this guidance will be updated as a result of the NICE guideline on supportive and palliative care. We recommend the Teenage Cancer Trust's document, *Blueprint of Care,* as a reference point for informing measures on transitional care for young adults.	has however been revised to include adaptations to adults' services for young adults thought to be entering the last year of life.
150	**The Brain Tumour Charity**	5	112	We are concerned that user involvement has been removed from the scope of the updated guideline. Both NHS England's Patient and Public Participation Policy, and the Five Year Forward View have emphasised the importance of involving patients directly in decisions about health and social care services. In the context of support and palliative care, we believe that user involvement in planning, delivering and evaluating services can help to embed choice at the end of life. With brain tumour patients who have received a terminal diagnosis, having conversations around end-of-life care planning at an early stage, it is more likely that a person with a terminal diagnosis will have the choice and control to exercise important decisions such as the place of their death.	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. 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.
151	**The Brain Tumour Charity**	5	115	We are disappointed with the exclusion of information from the service delivery measures for supportive care.	Thank you for your comment. Following consideration of all stakeholder comments

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				The previous guideline in 2004 emphasised the value of information to patients at this stage of the care pathway, noting, *"Patients and carers cannot express preferences about their care or make choices on whether to be involved in decision-making unless they are given appropriate information."* Whilst NICE's guideline, *Patient Experience in Adults NHS Services,* does reference the importance of access to information to promote active participation in care, we believe that there is a need to embed this within the new guideline on supportive and palliative care. Our report, *Losing Myself: The Reality of Life with a Brain Tumour*, provided evidence that people affected by a brain tumour are not being provided with information about supportive and palliative care services that are available. Only 29% of those personally affected said that they had received appropriate information about end of life care, and 49% said that they had not. Similarly, a fifth (21%) of patients in the study had been given a terminal diagnosis, but 55% said that they not been given end of life care options.	the guideline will focus on service delivery within the last 12 months of life for all conditions. As you state in your comment, recommendations related to information provision can be found in the NICE patient experience guideline. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v. It is NICE's policy to refer to other guidance where recommendations exist that support the guideline being developed. This ensures that development work is not repeated and improves clarity as it helps to avoid the existence of contradictory recommendations.

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				These figures reflected the isolation that patients felt at this stage of the care pathway, suggesting problems both the provision of too little information and insensitivity where information was provided. Given that many charities deliver services directly, they are well placed to produce information resources that contain robust evidence and are tailored to the needs of patients. In particular, we recommend the use of information resources from charities on supportive and palliative care which are certified by the Information Standard. The Information Standard was devised by the Department of Health provide assurance to patients about the quality of information available. Additionally, while the scope of the guideline is being widened beyond cancer, we feel that information resources have strong importance in informing the treatment and care choices of disease areas like Dementia, Rheumatoid Arthritis or Parkinson's disease.	
435	**The British Dietetic Association**	5	96	The previous 'Improving supportive and palliative care for adults with cancer' guidance highlighted the input of dietitians within the configuration of services. Dietetic input, including nutritional screening should be included under	Thank you for your comment. Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will

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				rehabilitation within the new guidance.	focus on service delivery within the last 12 months of life for all conditions. Clinical treatment is out of remit, but nutrition support services may be considered as part of a service delivery model, in accordance to any eventual evidence, for example composition of the multidisciplinary team.
436	**The British Dietetic Association**	7	156	Dietitians should be recognised as member of the multidisciplinary team within supportive and palliative care settings	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. Clinical treatment is out of remit, but nutrition support services may be considered as part of a service delivery model, in accordance to any eventual evidence, for example composition of the multidisciplinary team.
437	**The British Dietetic Association**		general	Will access to services provided by allied health professionals be included in the guidance?	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery

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					within the last 12 months of life for all conditions. The revised scope will cover, planning and coordinating services, Including access to services provided by allied health professionals.
282	**The Confederation of Registered Essence Practitioners (COREP)**	5	109	The Confederation of Registered Essence Practitioners (COREP) is the UK lead body for people who work with essence therapy. Essence therapy is a gentle and safe approach to well-being that particularly focuses on emotional and spiritual health. It is often used by people in the final stages of their lives, since it does not interfere with other more direct and physically-focused forms of treatment such as chemotherapy and surgery. Many COREP members offer essence therapy to people who are in palliative and supportive care. They also help their families and carers. It is a fact that people often look for help from complementary practitioners, and we believe that medical staff need to know how to respond when asked for advice. NICE correctly, therefore, included a short section on complementary therapies in its guidelines. We are surprised and alarmed that this advice is to be removed.	**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.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				There is evidence that essence therapy can have a positive effect on people receiving palliative care. For example, Action Cancer in Northern Ireland and the Bristol Cancer Clinic have both reported beneficial outcomes. In addition, by providing a listening ear and a way for people to manage their emotions for themselves, essence therapy can be a positive aid to maintaining a sense of well-being even in the final stages of life. COREP believes that NICE should continue to offer sensible guidance in this area.	
311	**The Erasmus Foundation**	5	109	In response to learning about your plans under the restructuring of NICE guidelines suggesting that under section **'108 Areas from the published guideline that will be removed; 109 Complementary therapy services'**, we are concerned to learn about this proposal. Are you saying that spiritual healing has no value for those who are suffering during the last days of their life on Earth? Our practise of spiritual healing at the Erasmus Foundation healing clinic, always offers healing free of charge without exception, and never promises to cure anyone of any illness, but at least provides some comfort and assists in the quality of life a person may endure at the termination of their 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.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				Please confirm exactly how you are proposing to proceed with your new guidelines because we are very concerned about your evaluation of a voluntary service which is there to provide help and support for anyone in need.	
111	**The Haven**	5	109	Previous NICE guidance on complementary therapies facilitated decisions about their use, without making direct recommendations. This included enabling healthcare workers and patients to obtain reliable information, thus empowering them to make decisions for themselves, assisting commissioners in determining what complementary therapy services they may want to fund, and giving advice to providers on the measures they should take to ensure patients can access complementary therapies safely. If NICE were to withdraw complementary therapy guidance, the question would be "where should patients, carers and health care professionals go to obtain such information?" People with cancer are using these services anyway and it is preferable to have some guidance in this area than to have none at all. Our Haven figures tell us that this is around 20% of the people diagnosed with breast cancer in the local areas in which we operate. If the guidance is removed then it could be misconstrued that providing complementary therapies was of no value in providing support for cancer survivors. This is clearly not what the patient reported outcomes from	**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.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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				our service evaluations and research have shown us over the last 10 years (see below). The Haven is a national breast cancer support charity which has been offering supportive care and complementary therapies for people at all stages of breast cancer since February 2000. Now operating from four centres across England (London, Herefordshire, Yorkshire, Wessex), we have offered in-depth, personalised programmes of emotional, practical support and complementary therapies to over 13,500 people affected by breast cancer, and provided over 180,000 appointments. In November 2015 the government gave us £2.65m to continue to expand our much needed services; in 2016 we will be offering additional breast cancer support services in Worcestershire (in the NHS breast unit of the hospital) and Solihull (Birmingham). We collaborate closely with the NHS in providing care for their cancer patients, informing their GPs and hospital consultants at the beginning and end of their Haven programmes. We also conduct and publish research and evaluation of our services. In a 2015 online survey (N=980) of Haven service users, the key reasons they gave for seeking our help were emotional support (77%) and the physical side effects of cancer treatments (67%). In addition, individual complementary therapies were the services that users most wanted if new services were made available locally: London 87.5%,	

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				Hereford 78.8% and Leeds 79.7%. This is further evidence of the extent of the demand for complementary therapies to help meet the support needs of people living with breast cancer.	
112	**The Haven**	5	109	The Haven has created a model of collaboration between the NHS and the charitable sector which has been providing an integrated programme of supportive and complementary care for people affected by breast cancer that is the envy of the world. We regularly have people visiting us from both within the UK and from other countries to learn more about how we make this model so effective. Health care professionals, breast cancer patients and their families/friends tell us that they would, without exception, like this model of support services available to them. We have a healthcare professionally led model of service delivery with therapists who are trained and experienced and who we continue to support in their professional development around breast cancer care. More details of The Haven and its services and evaluations can be found on our website www.thehaven.org.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.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
113	**The Haven**	8	186	Our Haven in-house expertise in research and evaluation enables us to ensure that we are capturing patient experience and satisfaction, regularly receiving patient-reported outcomes as well as carrying out more rigorous research as funding allows. At The Haven we 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.**

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				conducted and published 10 research studies and evaluations of our supportive and complementary therapy services, the findings of which have demonstrated the positive impact they have had on the quality of life of service users as they go through their breast cancer experience. For example, the largest of our randomised controlled trials (N=229) showed statistically significant benefits of mindfulness-based stress reduction compared to controls in mood state, quality of life and wellbeing (Hoffman C.J. et al, Journal of Clinical Oncology (JCO) 2012; 30: 1335-1342). Another large randomised controlled study (N=302) in which we collaborated showed significant benefits from acupuncture for fatigue in breast cancer compared to controls (Molassiotis A. et al, JCO 2012; 30: 4470-4476). This demonstrates the high quality research being carried out in complementary therapies in cancer and published in the highest quality cancer journals (JCO's impact factor is 18.4); however, more research of this calibre is needed.	Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
114	**The Haven**	8	186	Further evaluation of complementary therapies performed at The Haven included the use of the Measure Yourself Concerns and Wellbeing (MYCaW) questionnaire. This was used to evaluate the concerns and wellbeing of service users of the Haven support services nationally (Harrington JE et al. Complementary Therapies in Clinical Practice 2012; 18: 182-189): The 2911 concerns presented by 1524 users across London,	Thank you for bringing this to our attention.

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				Hereford and Yorkshire Havens were: • 48% psychological and emotional • 34% physical side effects of treatment • 17% related to wellbeing The Haven therapies most commonly used to help with these concerns were acupuncture, nutritional therapy, aromatherapy massage, shiatsu, counselling and reflexology. Statistically significant improvements were found in main concerns and wellbeing identified by the users after the Haven Programme: • Concern 1 (n=402) $p < 0.0001$ • Concern 2 (n=372) $p < 0.0001$ • Wellbeing (n=402) $p < 0.0001$ After the Haven Programme, 91% of reported scores (n= 328) rated the concern as being a little better, much better or gone. These findings show that women with breast cancer find the Haven programme effective for addressing their key concerns and improving their wellbeing.	
115	**The Haven**	8	186	Feedback on complementary therapy use was also obtained from service users (N=341) in the London, Hereford and Yorkshire Havens following a course of an individual complementary therapy. Once again physical and	Thank you for bringing this to our attention.

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				psychological issues were rated most highly by our service users. Of the physical issues, the most frequently listed were hot flushes/sweats and nutritional needs. Of the psychological/ emotional issues, the most frequently listed was fear and anxiety. Also, over three quarters of the Visitors wanted help with general wellbeing. Therapies used to address these concerns were in descending order: nutrition; acupuncture; counselling; shiatsu; massage/ aromatherapy; reflexology. The number of Visitors reporting on the helpfulness of their course of therapy was: • 99% found it helpful • 88% found it very helpful • 87% found it essential for their recovery from breast cancer	
116	**The Haven**	8	194-195	We recognise the existing problem of lack of evidence in evaluating cost effectiveness in supportive and palliative care in general. Of particular interest to The Haven for our next large randomised controlled trial (in collaboration with our local NHS and academic partner) is to rigorously perform a cost benefit analysis of the services provided by us, a large proportion of which is complementary therapies, to determine whether this can save money for the NHS in their care of people living with breast cancer.	Thank you for your comment.

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117	**The Haven**	8	186	Research and service evaluations publications from The Haven. Haven research staff (past and present in bold): **Baker, B.S, Hoffman C.J.** Emotional Freedom Techniques (EFT) to reduce the side effects associated with tamoxifen and aromatase inhibitor use in women with breast cancer: A service evaluation. European Journal of Integrative Medicine 2015; 7: 136-142. Eyles, C., Leydon G., **Hoffman C**., Copson E, Prescott P., Chorozoglou M., Lewith G. Mindfulness for the self-management of fatigue, anxiety and depression in women with metastatic breast cancer: a mixed method feasibility study. Integrative Cancer Therapies 2015; 14: 42-56. **Baker, B.S., Harrington, J.E., Hoffman, C.J.** A service evaluation of The Haven at Home as a support programme for breast cancer survivors. European Journal of Integrative Medicine 2013; 5: 153-164. **Hoffman, Caroline J**., Ersser, Steven J., Hopkinson, Jane B., Nicholls, Peter G., **Harrington, Julia E**., Thomas, Peter W. Effectiveness of mindfulness-based stress reduction in mood, breast- and endocrine-related quality-of-life and wellbeing in stages 0 to III breast cancer: a randomized, controlled trial. Journal of Clinical Oncology 2012; 30(12): 1335-1342. **Harrington, J.E, Baker, B.S., Hoffman, C.J.** Effect of an integrated support programme on the concerns and well-	Thank you for bringing these to our attention.

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				being of women with breast cancer: a national service evaluation Complementary Therapies in Clinical Practice 2012; 18): 10-15. **Baker, B.S., Harrington J.E.,** Choi B.-S., Kropf P., Muller I., **Hoffman C.J**. A randomised controlled pilot feasibility study of the physical and psychological effects of an integrated support programme in breast cancer. Complementary Therapies in Clinical Practice 2012; 18: 182-189. **Hoffman, Caroline J**., Ersser, Steven J., Hopkinson, Jane B. Mindfulness-Based Stress Reduction in breast cancer: a qualitative analysis. Complementary Therapies in Clinical Practice 2012; 18: 221-226. Seers, H.E., Gale, N., Paterson, C., Cooke, H.J., Tuffrey, V., **Polley, M.J**. Individualised and complex experiences of integrative cancer support care: combining qualitative and quantitative data. Supportive Care in Cancer 2009; 17(9): 1159-1167. (In collaboration with Penny Brohn Cancer Care). **Polley, M.J**., Seers, H.E., Cooke, H.J., **Hoffman, C**., Paterson, C. How to summarise and report written qualitative data from patients: a method for use in cancer support care. Supportive Care in Cancer 2007; 15(8): 963-971. (In collaboration with Penny Brohn Cancer Care). **Jeffs, E**. Treating breast cancer related lymphoedema at the London Haven: A clinical audit. European Journal of	

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				Oncology Nursing 2006; 10: 71 -79.	
22	**The James Whale Fund for Kidney Cancer**	general	general	I agree that supportive and palliative care guidelines are just as relevant for 'conditions other than cancer' and the guidelines should reflect this.	Thank you for your comment.
23	**The James Whale Fund for Kidney Cancer**	5	109	I am pleased that the term complementary therapies is being replaced with a section talking about holistic needs. The term 'Complementary therapies' separates the therapy techniques from what should be a fully integrated way of thinking about treatment and medicine.	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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the published guideline. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4.
24	**The James Whale Fund for Kidney Cancer**	5	general	I'm curious to know more about why the research section is to be removed. On one hand 'is supportive and palliative care the right place to be conducting research'? but on the other hand isn't it a step backwards to be not evaluating 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

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				techniques and moving forward with best practice. It depends what type of research is normally conducted in the area of supportive and palliative care and whether this section is being replaced elsewhere?	conditions. 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.
25	**The James Whale Fund for Kidney Cancer**	general	general	I think that the place where the supportive and palliative care takes place is of importance. Every effort should be made to get people out of hospital and into their own home if this is what they and their family wish. I think this is important on a personal comfort level and on and economic level. General practitioners should be supported with this. In my experience far too many people with palliative care needs are put into elderly 'rehabilitation wards' in smaller hospitals, because there is nowhere else available to them. These wards are not equip to deal with palliative care needs and are covered by already overstretched GP's and underqualified nurses who do their best. These elderly patients are then sent in the last hours of their life on a long ambulance journey to a larger central hospital. Wouldn't it be more ethical for the real needs of these patients to be evaluated (rather than to have 'rehab wards' for people who have nowhere else to go) 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. There is no specific question around the cost effectiveness of place of care however we have prioritised place of care and place of death as outcomes for review questions and this will be considered during review of the evidence.

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				for there to be more palliative care available in the community and for it to be properly funded (not just to rely on over stretched GP's who may or may not have specialist training in palliative care)?	
181	**The Leeds Teaching Hospitals NHS Trust**	General	General	Lack of clarity around definitions given for supportive care, palliative care, and specialist palliative care, and the relationship between 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. 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.
182	**The Leeds Teaching Hospitals NHS Trust**	12	277-8	Is there any objective evidence to support the statement: 'In practice palliative care is restricted to the last months and weeks of life' ? Does this refer to, 'palliative care' or 'Specialist Palliative Care?	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. The context section of the scoping

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					document has been amended to reflect these changes.
183	**The Leeds Teaching Hospitals NHS Trust**	12	254-5	End of life care is conflated with the Liverpool Care Pathway and therefore last hours/days of life - elsewhere in the document palliative care is defined as being towards the end of life - this suggests that palliative care is synonymous with the dying phase, which is not the view of many palliative care practitioners	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. 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, that the meaning of terms uses is explicit, and that vague terminology is avoided.
184	**The Leeds Teaching Hospitals NHS Trust**	5	109-115	No reason has been given for the areas to be removed from the published guideline, most notably complementary therapy services. Given the intrinsic role of all 6 excluded areas in the delivery of palliative care this is open to wide interpretation.	**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. Recommendations from CSG4: Improving supportive and palliative care for adults with cancer which are not updated will remain within the**

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

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					published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place. We will ensure consistency between the new recommendations in End of life care: service delivery and any such recommendations from CSG4. 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, face to face communication and the provision of information have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.

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					Guidelines related to the provision of social support are the remit of the Social Care Institute of Excellence. More details on this agency and its published work can be found at: http://www.scie.org.uk/.
185	**The Leeds Teaching Hospitals NHS Trust**	General	General	The recognition that the palliative care needs of differing groups of people are likely to require differing service models is not apparent - eg those of the community with dementia versus those undergoing bone marrow transplant as an extreme example. For 470,000 people, one size will definitely not fit all. Too much reliance on historical data on inpatient hospice usage will give a very distorted picture of palliative care provision - this was evident in the Marie Curie/Alzheimer's Society report on palliative care and dementia (Dec 2014) where inpatient hospice data was used to evidence a lack of provision - when ideally palliative care for people with dementia should be within their own environment (NICE p13 303-4). There is the risk that inappropriate models of care will be imposed on groups of people in the name of best practice guidelines - when they have not been evaluated for this population	Thank you for your comment. We note your observations that differing groups may have different needs, but it would be beyond the capacity of the process to consider all of those different needs. The scope will therefore be generic in outlook.
186	**The Leeds Teaching Hospitals NHS Trust**	13	310-316	Chronic pain services are not stated as being within the scope of the guidelines, and yet reference is made to conditions managed by chronic pain 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

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					conditions. Chronic pain services are not specifically mentioned, however may be specified in the evidence review protocols and in evidence identified. We do not wish to pre-judge the evidence, but will base recommendations on available published information on a wide range of services.
187	**The Leeds Teaching Hospitals NHS Trust**	General	General	An increasing issue in the frontline delivery of palliative care is managing expectations - given the demographic and financial challenges facing the NHS, and the workforce challenges in primary care, this needs to be addressed within the report	Thank you for your comment.
188	**The Leeds Teaching Hospitals NHS Trust**	14	337	What is the purpose of the inverted commas around 'specialist'?	Thank you for your comment. This has been amended.
19	The Sam Buxton Sunflower Healing Trust	5	109	The draft intends to exclude Complementary Therapy Services. As a provider of funds to the NHS to provide complementary therapy I believe that not to include complementary would be a contradiction to your definition of supportive care on page 3.	**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.** Recommendations from *CSG4: Improving*

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				There is a wealth of patient experience describing how Complementary Therapy supports and enhances conventional care along with a growing body of research to support the patient's qualitive evidence.	*supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
161	**The Society and College of Radiographers**	5	107	The Society and College of Radiographers wish to raise a concern that education and training require consideration for inclusion in the future guidance. If this were to be included it would help to provide structure, support and leverage with implementation for service managers. The radiographic professions are involved in a variety of aspects of the required care which is at the core of service quality and 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. .
162	**The Society and College of Radiographers**	5	General point for lines 109-115	It is possible that the 6 areas that are to be removed may contribute to devaluing the importance of these core principles in service delivery for supportive and palliative care. It is challenging to envisage how supportive and palliative care can be provided without these integral areas and the Society and College of Radiographers would consider it appropriate for them to be included in this guidance document.	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. The standards for drafting and including research recommendations established by

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					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, face to face communication and the provision of information have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v. Guidelines related to the provision of social support are the remit of the Social Care Institute of Excellence. More details on this agency and its published work can be found at: http://www.scie.org.uk/.
163	**The Society and College of Radiographers**	5	109	In addition to comment 2 it is important to recognise as specialist healthcare professionals that some Radiographers train and have expertise in complimentary therapies.	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.

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					Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
164	**The Society and College of Radiographers**	5	112	The Society and College of Radiographers consider this of key importance in order to ensure future patient centric services and alignment with government policy.	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.
165	**The Society and College of Radiographers**	5	38-44	While it is clear that special consideration for the dementia, cognitive impairment, learning disabilities and homeless people is key to reduce healthcare inequalities there is significant evidence to indicate that also people from lower socio economic classes do not access services to the same degree. It is challenging to delineate what constitutes equal opportunities in terms of levels of engagement by healthcare	Thank you for your comment. 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.

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				professionals in primary and secondary care.	
89	The Society of Homeopaths	general	general	This commentary is a response to the proposed removal of complementary therapy services (CAM) in the new NICE guideline on supportive and palliative care, from the perspective of one CAM therapy – Homeopathy. Treatment by homeopaths is being effectively employed in hospices, NHS settings and privately. Patients select this treatment method and patient rated improvements in wellbeing and clinical symptoms are measured in studies. We argue that treatment by homeopaths can provide a patient centred, cost effective option in end of life and palliative care which addresses the five priorities for care outlined by the Department of Health in their recent Inquiry, and which it is important to include in any new NICE guidelines.	**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.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
90	The Society of Homeopaths	general	general	CAM treatments are non-specific. From the scoping workshop it appears that NICE guideline writers struggle to incorporate CAM within existing frameworks. Similarly, CAM struggles to provide evidence suitable for NICE guidelines. In the long term I suggest that a separate CAM framework is called for to assess provision within the NHS for these safe, cost- effective options. Assessment might prioritise safety, side effects, patient satisfaction and cost.	**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.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will

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					remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
91	The Society of Homeopaths	2	38	"Equality". If CAM therapies are excluded from the draft guideline, they will only be accessible to those paying for them, reducing patient choice. Provision of homeopathy within the NHS offers cost effective patient choice and higher quality of life care at this vulnerable juncture, valuing patient's wishes, addressing their discomforts and providing them with autonomy as they approach end 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.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
27	**The University of Essex**	3	47	**Action:** In the definition of 'supportive care' change: 'cure or continuing treatment or death and bereavement' to: 'cure, continuing treatment, death or bereavement'.	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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				Rationale: The current wording suggests a contrast between 'cure or continuing treatment' on the one hand and 'death or bereavement' on the other. This is confusing because it involves an implicit shift of perspective, from that of the patient to that of those close to the patient. Our suggestion covers the areas that supportive care must cover without involving this shift in perspective.	conditions. 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. Recommendations on bereavement can be found in the 2004 guideline.
28	**The University of Essex**	3	47	**Action:** In the definition of 'supportive care' add '**remission'** after 'continuing treatment'. If our previous suggestion is taken up, the modified passage would read: 'cure, continuing illness, **remission,** death or bereavement'. If it isn't, then the passage would read: 'cure, continuing treatment **or remission**, or death and bereavement' **Rationale:** In the current wording of the definition, there is no allowance for care for those who are neither 'cured' nor being treated for their illness but who still require care, such as cancer patients in remission. Our suggestion picks up on lines 278-280, which explicitly mention the 'care of long term cancer survivors' as being within the remit of supportive	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. 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. Recommendations on bereavement can

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				care.	be found in the 2004 guideline.
29	**The University of Essex**	3	47	**Action**: In the definition of palliative care, replace 'live as **actively** as possible' with 'live as **well** as possible'. **Rationale:** Surely the most important thing is that patients at the end of their lives should live as well as possible, and there is no reason to presuppose that an 'active lifestyle' will deliver this result for all. For example, some patients may take great comfort just from not being in pain and from being able to spend quiet time in the company of those whom they love. Others may like to meditate or reflect on the meaning of their lives so as to find peace. Urging such patients to be 'more active' could actually get in the way of their being able to live well. Our suggestion focuses on the most important aspect (living well) and leaves space for less active ways of living well towards the end 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. The context section of the scoping document has been amended to reflect these changes.
30	**The University of Essex**	12	272	**Action:** Replace 'actively' with 'well'. **Rationale:** Same as comment #3	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. The context section of the scoping document has been amended to reflect these changes.

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297	**Transforming Cancer Services Team**	general	general	We are delighted to see aspects of Supportive and Palliative Care being reviewed and feel this is very timely in light of the recent publication of 'Achieving world class outcomes: a strategy for England'. We are concerned that this publication does not seem to be referenced in the draft scope of the document and advise that the proposed Guidance must align with the Cancer Strategy for England . Although the previous Improving Supportive and Palliative Care document was implemented through the cancer networks, for many in the system it felt like a 'stand-alone' document and perhaps was not optimally implemented for that reason. If the proposed guidance is going to achieve maximum impact it must be seen to fully align with current policy and strategy.	Thank you for your comment. NICE does not refer to other non-NICE publications in its guidance.
298	**Transforming Cancer Services Team**	general	general	The previous NICE Guidance addressed only cancer and we welcome the change in focus to include all life-limiting illness and a focus on inequalities. However, we feel it is not clear to what extent the proposed Guidance will address the supportive care elements associated with living with and beyond cancer. For example, will it address the supportive care needs of patients who no longer have a cancer diagnosis but who are living with the consequences of treatment? Many of these patients will require extensive support such as specialist rehabilitation and psychological support. If the proposed Guidance will not address these aspects of supportive care then where will they be covered? We would be concerned if they were omitted.	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. The revised scope is dealing with the last year of life and survivors are out of remit. However we will cover coordination of services that may cover this issue.

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299	**Transforming Cancer Services Team**	3 (table)	1-5 (in table)	This definition of supportive care is different from the definition used in the original guidance. This definition has more of a palliative care focus. Hence our general comment above. More clarity is needed here.	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. 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.
300	**Transforming Cancer Services Team**	5	106	Clarity is needed here whether by 'clinical' you mean 'medical' care as physiotherapy could be considered clinical care.	Thank you for your comment.
301	**Transforming Cancer Services Team**	5	110	There are still significant gaps in the literature in this field and it is essential that specialist therapists who are working in rehabilitation and operating at level 4 (as per original guidance) are research active. Having this aspect covered within the new Guidance would help develop the workforce and encourage research within these clinical teams. If this is omitted from the new guidance then will it be covered elsewhere?	Thank you for your comment. 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.

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302	**Transforming Cancer Services Team**	5	107	There are significant education and training issues in the supportive care workforce which link directly to how services are delivered. For example, we know there is a shortfall of specialist Allied Health Professionals in London (http://www.londoncanceralliance.nhs.uk/media/88180/ahp-mapping-and-workforce-requirement-report-2014.pdf) meaning education and training of the non specialist workforce is vital in improving supportive and palliative care. Where will this be addressed?	Thank you for your comment. .
303	**Transforming Cancer Services Team**	5	112	Removal of user involvement: we do have some concerns about the removal of this aspect. It will be vital to fully engage service users in the implementation of the guidance and at key points in the process.	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.
304	**Transforming Cancer Services Team**	5	113-115	We have concerns about the removal of these aspects as they appear fundamental to improving the care of people living with and beyond cancer as demonstrated in the Cancer Strategy, National Cancer Patient Experience survey, Long-term Conditions programmes etc.	Thank you for your comment. 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

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					committee sees a gap in evidence, further research will be recommended. User Involvement in planning, delivering and evaluating services, face to face communication and the provision of information have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v Thank you for participating in the consultation process.
305	**Transforming Cancer Services Team**	6	124	We agree that addressing the economic aspects is vital in this guidance but it is important to acknowledge that for many of the supportive care services e.g cancer rehabilitation, there is a lack of good quality data on the economic benefits. The Improving Rehabilitation Services Programme at NHS England has been doing some work on the economic benefits of rehabilitation and it will be important to liaise with them on this work.	Thank you for your comment. Thank you for highlighting the work of NHS England.
312	**UK Reiki Federation**	5	109	Complementary therapies should be accessible to all and our experience of giving Reiki, in a palliative care situation, has been well received and much appreciated. Individuals have positively chosen to receive Reiki as they have felt it	**Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the**

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				helps them to deal better with their illness and pain management. Examples of how therapies have been successfully used can be viewed at http://www.cancertherapies.org.uk/nhsprojects	**last 12 months of life for all conditions.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
313	**UK Reiki Federation**	5	110	Complementary Therapies are given by hundreds of volunteers and some paid staff in a range of complementary therapy practices. There is an emerging, though as yet small, body of evidence regarding how these practices support patients, their carer's and bereaved families to cope with the myriad stresses and strains an illness such as cancer or other end of life illness places 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** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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314	**UK Reiki Federation**	9	214-226	Complementary therapies should be accessible to all and our experience of giving Reiki, in a range of care situations, has been well received and much appreciated. Individuals have positively chosen to receive Reiki as they have felt it helps them to deal better with their illness and pain management.	**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.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
362	**University College London Hospitals NHS Foundation Trust**	'general'	'general'	The direction of travel in the scope is good in that it will cover all diagnostic groups and there is more detail on the supportive care aspects than previous guidance. It is also heartening to see a greater focus on HNA and how it could be used both more widely and more often. Some areas are missing which we would expect to be reflected in some way: • Research. • Workforce both planning and development.	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. 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.

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				• Communications skills as a key component of all clinical care. • Education or some indication of the different level of clinical practice/ expertise.	With reference to future research, 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. With reference to workforce planning, the revised scope includes draft questions on the planning and coordination of services, and service delivery models for end of life care. Face to face communication and information sharing are covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v. Thank you for your contribution to the consultation process.

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363	**University College London Hospitals NHS Foundation Trust**	6	134	HNA focus is on 'which tool'. The key clinical issue is what happens afterwards to patient? Clinical observation is that it is becoming an end in itself and not being used clinically. (I.e. could ask the question: what is the assessment for, rather than which tool. And- how do we know that HNA has achieved its goal ?)	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. 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. 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.
364	**University**	'general'	'general'	We are keen that the four levels of psychological input be	Thank you for your comment.

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	College London Hospitals NHS Foundation Trust			preserved and particularly the capacity at level 4 to offer a range of psychological therapies by one practitioner (i.e. clin psychology).	
13	**Velindre NHS Trust**	148-154	General complementary therapies section	To remove complementary therapies completely from the guidelines would be a huge detriment to the provision of complementary therapies within the healthcare setting. Currently provision of complementary therapies within the NHS is provided with guidance from NICE and this ensures a level of safety, professionalism and consistency across the public sector. It gives both stakeholders, NHS trusts and its partner organisations and service users confidence that the therapies and services being provided are governed, safe and regulated.	**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.** Recommendations from *CSG4: Improving supportive and palliative care for adults with cancer* which are not updated will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.

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