End of life care: Delivery of adult services for people in the last year of life
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7	**Action on Hearing Loss**	**General**	**General**	Action on Hearing Loss is the charity formerly known as RNID. Our vision is of a world where deafness, hearing loss and tinnitus do not limit or label people and where people value and look after their hearing. We help people confronting deafness, tinnitus and hearing loss to live the life they choose. We enable them to take control of their lives and remove the barriers in their way. We give people support and care; develop technology and treatments and campaign for equality. Our response will focus on key issues that relate to people with hearing loss. Throughout this response we use the term 'people with hearing loss' to refer to people with all levels of hearing loss, including people who are profoundly deaf and who may use British Sign Language as their main language. We are happy for the details of this response to be made public. **General comments** Action on Hearing Loss welcomes the creation of a NICE service delivery guideline on improving supportive and palliative care for adults, and the expansion of the guideline for adults with cancer to adults with a wider range of life-limiting conditions. Hearing loss is a long term condition which affects more than eleven million people in the UK, about 1 in 6 of the population. The prevalence of hearing loss increases with age. Over 71.1% of over 70 year olds have some form of hearing loss. With the ageing population, the number of people with hearing loss is set to grow in the years to come. By 2035, there will be approximately 15.6 million people with hearing loss in UK - that's a fifth of the population. Hearing loss reduces someone's ability to communicate, which, particularly if left unaddressed, can lead to social isolation, difficulties accessing services and difficulties preventing and managing other physical and mental health conditions[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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Thank you for your feedback related to communicating with people with hearing loss who may need palliative care. Information provision and face to face communication, is covered in the NICE Patient experience guideline which includes recommendations on how to establish the best ways of communicating with all patients. It makes explicit reference to people with hearing loss. More details can be found at the following link: https://www.nice.org.uk/guidance/cg138v Additionally, NICE is currently in the process of developing guidance on hearing loss. Details related to this project can be found at: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0833.

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[1] Action on Hearing Loss (2015) Hearing Matters, available at: www.actiononhearingloss.org.uk/hearingmatters

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				The age-related incidence of hearing loss and the need for supportive and palliative care for progressive illnesses means that there will be many people who have a hearing loss and need supportive or palliative care. In order for holistic support needs to be met it is essential that the communication requirements of those receiving care and their family/ carers are always identified, recorded and shared with any professionals involved in working with an individual, and also that the impacts of unaddressed hearing loss are understood and considered seriously by staff delivering supportive and palliative care. This will ensure that staff and clinicians can communicate with people, people can contribute to the planning and delivery of their care as much as possible and that quality of life isn't impaired by not having hearing support needs addressed. We know that often people with a hearing loss don't have access to the communication support they need in healthcare situations, for example more than a quarter of people (28%) have said they haven't understood a diagnosis, and one in five (19%) have been unsure about their medication after an appointment[2]. For British Sign Language users this is worse. Our research shows that even when people ask for a BSL interpreter at appointments, around two-thirds (68%) don't currently get	

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[2] Ringham (2013) Access all areas: A report into the experiences of people with hearing loss when accessing healthcare. Action on Hearing Loss (available at http://www.actiononhearingloss.org.uk/accessallareas.aspx)

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				one; and almost half of those who do find the quality of interpretation isn't good enough[3]. The Accessible Information Standard, produced by NHS England, becomes mandatory for all NHS and adult social care providers from 31st	
8	**Action on Hearing Loss**			July 2016 and states that providers must have robust processes in place for identifying, recording and meeting the communication needs of people with hearing loss.[4] The standard will ensure people with hearing and other sensory losses understand the information they are given and are able to participate fully in decisions about their care. Providers and health and social care professionals must commit to implement its requirements swiftly and fully. Hearing loss impacts on social wellbeing, psychological and emotional wellbeing[5] and cognitive functioning (particularly increasing the risk of	

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[3] Action on Hearing Loss (2012) Our Health in Your Hands (Available at: http://www.actiononhearingloss.org.uk/get-involved/campaign/equal-treatment/the-problem/survey-of-bsl-users.aspx); Sign Health (2014) Sick of it; how the health service is failing deaf people

[4] NHS England Accessible Information Standard (2015). Available at: https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/#standard

[5] Herbst et al (1990) Implications of hearing impairment for elderly people in London and in Wales. Acta Oto-laryngologica. 476: 209-214; Du Feu and Fergusson (2003) Sensory impairment and mental health. Advances in psychiatric treatment. 9: 95-103; Monzani et al (2008) Psychological profile and social behaviour of working adults with mild or moderate hearing loss. Acta Otorhinolaryngologica Italica. 28(2): 61-6; Barlow et al (2007) Living with late deafness: insight from between worlds. International Journal of Audiology. 46(8):442-8; Hétu et al (1993). The impact of acquired hearing loss on intimate relationships: Implications for rehabilitation. Audiology 32(3): 363–81; Gopinath et al (2012) Hearing-impaired adults are at increased risk of experiencing emotional distress and social engagement restrictions five years later. Age and Ageing 41(5): 618–623; Echalier (2010) In it together – the impact of hearing loss on personal relationships. Available at: www.hearingloss.org.uk/~/media/Documents/Policy%20research%20and%20influencing/Research/Previous%20research%20reports/2010/In%20it%20together/In%20it%20Together.ashx National Council on the Aging. (2000) The consequences of untreated hearing loss in older persons. Head & Neck Nursing. 18(1): 12-6; Fellinger et al (2007) Mental distress and quality of life in the hard of hearing. Acta Psychiatrica Scandinavica 115: 243–245; Arlinger (2003) Negative consequences of uncorrected hearing loss – a review. International Journal of Audiology 42(2): 17-20; Monzani et al (2008) Psychological profile and social

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				developing dementia)[6], which are key holistic needs identified in the scope for this guideline, and untreated hearing loss also impacts the development and management of other conditions[7]. It is very important, therefore, that the hearing support needs of those who are also requiring supportive and palliative care are taken into account in order for the best outcomes to be achieved. Action on Hearing Loss has produced a toolkit for caring for older people with hearing loss (http://www.actiononhearingloss.org.uk/nursingtoolkit), which outlines simple steps hospital and wider staff can take to improve the care of older people with hearing loss, such as: training for staff on hearing aid maintenance and understanding hearing loss; communication and hearing aid maintenance equipment, hearing aid storage boxes and hearing screening devices being kept on wards/ in care settings; and putting a protocol in place to ensure steps are taken to address hearing loss and refer patients to appropriate services and	

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behaviour of working adults with mild or moderate hearing loss. Acta Otorhinolaryngologica Italica. 28(2): 61-6; Saito et al (2010) Hearing handicap predicts the development of depressive symptoms after three years in older community-dwelling Japanese. Journal of the American Geriatrics Society 58(1): 93-7

[6] Lin et al. (2011) Hearing loss and incident dementia. Archives of Neurology 68(2): 214-220; Lin et al (2013) Hearing loss and cognitive decline in older adults. Internal Medicine 173(4): 293-299; Lindenberger and Baltes (1994) Sensory functioning and intelligence in old age: a strong connection. Psychology and Aging. 9: 339-355; Lindenberger and Baltes (1997) Intellectual functioning in old and very old age: cross-sectional results from the Berlin aging study. Psychology and Aging. 12: 410-432; Uhlmann et al (1989) Relationship of hearing impairment to dementia and cognitive dysfunction in older adults. Journal of the American Medical Association 261: 1916-1919; Gurgel et al (2014) Relationship of hearing loss and dementia: A prospective, population-based study. Otology & Neurotology 35(5): 775-81; Cacciatore et al (1999) Quality of life determinants and hearing function in an elderly population: Osservatorio Geriatrico Campano Study Group. Gerontology 45: 323-323; Gurgel et al (2014) Relationship of hearing loss and dementia: A prospective, population-based study. Otology & Neurotology 35(5): 775-81; Albers et al (2015) At the interface of sensory and motor dysfunctions and Alzheimer's disease. Alzeimer's and Demebtia Journal, 11 (1), 70-98

[7] DCAL and Action on Hearing Loss (2013) Joining Up: Why people with hearing loss or deafness would benefit from an integrated response to long-term conditions (Available at: http://www.actiononhearingloss.org.uk/joiningup.aspx)

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				support. We also know that many people have unidentified hearing loss; people wait on average 10 years to seek help for their hearing loss and research also suggests that GPs currently aren't referring 45% of those reporting hearing loss to hearing services[8]. Where it is appropriate, professionals administering supportive or palliative care must ensure that those who could benefit from hearing aids are referred to audiology and provided with hearing aids and appropriate ongoing support, to limit damage to health and wellbeing that unaddressed hearing loss can cause. Supportive and palliative care must take into account the communication and cultural needs of people whose first language is sign language. Based on the 2011 census, we estimate that there are at least 24,000 people across the UK who use a sign language as their main language – although this is likely to be an underestimate[9]. Many of these people will identify as belonging to the Deaf community, and it is very important that their communication and cultural needs are taken into account. There is a lack of specialist support available for people who are deaf or have a hearing loss and have additional needs. It is important that communication support is integrated into all care and support being provided, for example an Age UK End of Life evidence review	

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[8] Davis et al (2007) Acceptability, benefit and costs of early screening for hearing disability: a study of potential screening tests and models. Health Technology Assessment, 2 (42).
[9] Action on Hearing Loss (2015) Hearing Matters, available at: www.actiononhearingloss.org.uk/hearingmatters

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				highlighted the "gaps in specialist services for older people with mental health problems and sensory impairments"[10] as a key policy issue around palliative and end of life services. In general, the guideline should make reference to: • The requirements of the Accessible Information Standard and other best practice guidance on meeting the communication and information needs of people with hearing loss[11].	
9	**Action on Hearing Loss**			• The importance of recognising the impact of unaddressed hearing loss and meeting the hearing needs of people planning or receiving supportive and palliative care, to ensure holistic needs are met and the best possible outcomes are achieved. • The importance of meeting the communication and cultural needs of those who are profoundly deaf, for whom sign language is their first language, or those who are deaf or have a hearing loss and additional needs.	.

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[10] Age UK (2013) End of Life Evidence Review (Available at: http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Age%20UK%20End%20of%20Life%20Evidence%20Review%202013.pdf?dtrk=true)

[11] NHS England Accessible Information Standard (2015). Available at: https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/#standard; Action on Hearing Loss (2015) Caring for older people with hearing loss: a toolkit for change (Available at: http://www.actiononhearingloss.org.uk/nursingtoolkit); Action on Hearing Loss guidance on communication support and access to services (Available at: http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/policy/policy-statements/access-to-services.aspx)

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10	**Action on Hearing Loss**	2	41-44	Considering the age-related overlap between people with a hearing loss and people needing supportive or palliative care, the guideline should include looking at inequalities in access for people with hearing or sensory loss, and this should be included in this list. We know that people with hearing loss often encounter difficulties accessing other health services. Action on Hearing Loss research found that nearly three quarters (72%) of people with a hearing loss phoned their GP surgery themselves to book an appointment, but just under half (44%) wanted to book in this way, and just under half (46%) of people visited their GP surgery in person to make an appointment but a much smaller proportion (9%) wanted to. This research also revealed that people with a hearing loss encounter difficulties accessing appropriate communication support during GP consultations. For example, more than a quarter of people (28%) have said they haven't understood a diagnosis, and one in five (19%) have been unsure about their medication after an appointment[12]. For British Sign Language users this is worse. Our research shows that even when people ask for a BSL interpreter at appointments, around two-thirds (68%) don't currently get one; and almost half of those who do find the quality of interpretation isn't good enough[13].	

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[12] Ringham (2013) Access all areas: A report into the experiences of people with hearing loss when accessing healthcare. Action on Hearing Loss (available at http://www.actiononhearingloss.org.uk/accessallareas.aspx)

[13] Action on Hearing Loss (2012) Our Health in Your Hands (Available at: http://www.actiononhearingloss.org.uk/get-involved/campaign/equal-treatment/the-problem/survey-of-bsl-users.aspx); Sign Health (2014) Sick of it; how the health service is failing deaf people

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11	**Action on Hearing Loss**	4	65-76	- It is very important that appropriate communication support is provided for people undertaking a holistic needs assessment or discussing their care, in order for the results of assessments and discussions to meet needs as well as possible. We know that often the communication needs of people with hearing loss aren't met in healthcare settings[14], and think this point should be included in this section of the guideline, with the requirements of the Accessible Information Standard[15] and best practice referenced, in particular best practice around how to communicate well with people with a hearing or sensory loss, how to set up an environment that facilitates good communication, the need for staff to carry out any training required to support this, and how best to identify, record, flag, share and meet communication needs. Action on Hearing Loss has produced a nursing toolkit on caring for older people with hearing loss, and has guidance on accessing communication support and accessing services[16]. - There is evidence showing that unaddressed hearing loss leads to worsened	.

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[14] Ringham (2013) Access all areas: A report into the experiences of people with hearing loss when accessing healthcare. Action on Hearing Loss (available at http://www.actiononhearingloss.org.uk/accessallareas.aspx); Action on Hearing Loss (2012) Our Health in Your Hands (Available at: http://www.actiononhearingloss.org.uk/get-involved/campaign/equal-treatment/the-problem/survey-of-bsl-users.aspx); Sign Health (2014) Sick of it; how the health service is failing deaf people

[15] NHS England Accessible Information Standard (2015). Available at: https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/#standard

[16] Action on Hearing Loss (2015) Caring for older people with hearing loss: a toolkit for change (Available at: http://www.actiononhearingloss.org.uk/nursingtoolkit); Action on Hearing Loss guidance on communication support and access to services (Available at: http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/policy/policy-statements/access-to-services.aspx)

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				health outcomes overall and increased mortality[17]. The impact of hearing loss on several aspects of the holistic needs assessment listed, and the need to identify and manage hearing loss, should also be acknowledged in this section of the guideline, in particular: • social wellbeing • psychological and emotional wellbeing • cognitive functioning There is evidence to show that social isolation is a significant risk for people with a hearing loss[18], which impacts psychological and emotional wellbeing, in particular increasing the risk of depression. Older people with hearing loss are more than twice as likely to	

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[17] Appollonio et al (1996) Effects of sensory aids on the quality of life and mortality of elderly people: A multivariate analysis. Age and Ageing 25: 89-96; Karpa et al (2010) Associations between hearing impairment and mortality risk in older persons: the Blue Mountains Hearing Study. Annals of Epidemiology 20(6): 452-9; Yamada et al (2011) Impact of hearing difficulty on dependence in activities of daily living (ADL) and mortality: A 3-year cohort study of community-dwelling Japanese older adults. Archives of Gerontology and Geriatrics 52(3): 245–249

[18] Herbst et al (1990) Implications of hearing impairment for elderly people in London and in Wales. Acta Oto-laryngologica. 476: 209-214; Du Feu and Fergusson (2003) Sensory impairment and mental health. Advances in psychiatric treatment. 9: 95-103; Monzani et al (2008) Psychological profile and social behaviour of working adults with mild or moderate hearing loss. Acta Otorhinolaryngologica Italica. 28(2): 61-6; Barlow et al (2007) Living with late deafness: insight from between worlds. International Journal of Audiology. 46(8):442-8; Hétu et al (1993). The impact of acquired hearing loss on intimate relationships: Implications for rehabilitation. Audiology 32(3): 363–81; Gopinath et al (2012) Hearing-impaired adults are at increased risk of experiencing emotional distress and social engagement restrictions five years later. Age and Ageing 41(5): 618–623; Echalier (2010) In it together – the impact of hearing loss on personal relationships. Available at: www.hearingloss.org.uk/~/media/Documents/Policy%20research%20and%20influencing/Research/Previous%20research%20reports/2010/In%20it%20together/In%20it%20Together.ashx National Council on the Aging. (2000) The consequences of untreated hearing loss in older persons. Head & Neck Nursing. 18(1): 12-6; Fellinger et al (2007) Mental distress and quality of life in the hard of hearing. Acta Psychiatrica Scandinavica 115: 243–245; Arlinger (2003) Negative consequences of uncorrected hearing loss – a review. International Journal of Audiology 42(2): 17-20; Monzani et al (2008) Psychological profile and social behaviour of working adults with mild or moderate hearing loss. Acta Otorhinolaryngologica Italica. 28(2): 61-6;

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				develop depression as their peers without hearing loss, and the risk increases threefold with moderate hearing loss[19]. There is also a growing body of evidence that has identified a strong association between all levels of hearing loss and decreased cognitive functioning and dementia[20]. - There should also be reference in the guideline to the needs of those who are profoundly Deaf. Many people who use British Sign Language as their first language will identify as belonging to the Deaf community, and it is very important that their communication and cultural needs are recognised.	
12	**Action on Hearing Loss**	5	92	The updated "Co-ordination of care" section should reference the Accessible Information Standard, and the requirement for health and social care professionals to ensure that "the communication needs of patients, service users, carers and parents, will be identified, recorded, flagged, shared and met"[21].	

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[19] Saito et al (2010) Hearing handicap predicts the development of depressive symptoms after three years in older community-dwelling Japanese. Journal of the American Geriatrics Society 58(1): 93-7

[20] Lin et al. (2011) Hearing loss and incident dementia. Archives of Neurology 68(2): 214-220; Lin et al (2013) Hearing loss and cognitive decline in older adults. Internal Medicine 173(4): 293-299; Lindenberger and Baltes (1994) Sensory functioning and intelligence in old age: a strong connection. Psychology and Aging. 9: 339-355; Lindenberger and Baltes (1997) Intellectual functioning in old and very old age: cross-sectional results from the Berlin aging study. Psychology and Aging. 12: 410-432; Uhlmann et al (1989) Relationship of hearing impairment to dementia and cognitive dysfunction in older adults. Journal of the American Medical Association 261: 1916-1919; Gurgel et al (2014) Relationship of hearing loss and dementia: A prospective, population-based study. Otology & Neurotology 35(5): 775-81; Cacciatore et al (1999) Quality of life determinants and hearing function in an elderly population: Osservatorio Geriatrico Campano Study Group. Gerontology 45: 323-323; Gurgel et al (2014) Relationship of hearing loss and dementia: A prospective, population-based study. Otology & Neurotology 35(5): 775-81; Albers et al (2015) At the interface of sensory and motor dysfunctions and Alzheimer's disease. Alzeimer's and Demebtia Journal, 11 (1), 70-98

[21] NHS England Accessible Information Standard (2015). Available at: https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/#standard

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				It is also important to identify hearing loss, ensure it is managed, and coordinate care, as there is evidence of communication difficulties caused by unaddressed hearing loss and / or dementia leading to a lack of diagnosis, misdiagnosis and/or mismanagement of either or both conditions[22], and we know that hearing loss is linked to increased health care use and burden of disease among older adults[23] and carries an increased risk of conditions commonly requiring supportive or palliative care, including cardiovascular disease[24], diabetes[25] and stroke[26].	
13	**Action on Hearing Loss**	5	102	When "The role of the holistic needs assessment" is defined in this guideline, it should include the importance of discussing communication support needs for people with hearing loss, due to the impact not meeting these needs can have on quality of life and the outcomes of other support, and due to the likelihood of those undertaking a holistic needs assessment having some form of age-related or other hearing loss.	

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[22] Bauer K. et al., A claims data-based comparison of comorbidity in individuals with and without dementia. BMC Geriatrics, 2014. 14(10); Behrman S. et al., Considering the senses in the diagnosis and management of dementia. Maturitas, 2014.

[23] Genther et al (2013) Association of hearing loss with hospitalization and burden of disease in older adults. Journal of the American Medical Association 309(22): 2322

[24] McKee et al (2011) Perceptions of cardiovascular health in an underserved community of deaf adults using American Sign Language. Disability and Health 4(3): 192-197; Margellos-Anast et al (2006) Cardiovascular disease knowledge among culturally Deaf patients in Chicago. Preventive Medicine 42(3): 235-9; Joining Up: Why people with hearing loss or deafness would benefit from an integrated response to long-term conditions. (Available at: http://www.actiononhearingloss.org.uk/joiningup.aspx)

[25] Kakarlapudi et al (2003) The effect of diabetes on sensorineural hearing loss. Otology and Neurotology 24(3): 382-386; Mitchell et al (2009) Relationship of Type 2 diabetes to the prevalence, incidence and progression of age-related hearing loss. Diabetic Medicine 26(5): 483-8; Chasens et al (2010) Reducing a barrier to diabetes education: identifying hearing loss in patients with diabetes. Diabetes Education 36(6): 956-64

[26] Formby et al (1987) Hearing loss among stroke patients. Ear and Hearing 8(6): 326-32; Gopinath et al (2009) Association between age-related hearing loss and stroke in an older population. Stroke 40(4): 1496–1498

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14	**Action on Hearing Loss**	5	104	We agree that "Sharing information between multiprofessional teams" is an important section to include in the update of this guideline, and suggest that this section also mentions the requirements of the Accessible Information Standard, particularly the need to record and share communication needs.[27] The identification of any unmet communication needs should also be shared between multiprofessional teams, and people with a hearing loss should be referred, where appropriate, to audiology to get their hearing checked and receive hearing aids and other support.	
15	**Action on Hearing Loss**	5	107	Although "Education and training" is not going to be covered in this guideline, we feel it is important there is enough emphasis placed on ensuring staff are trained and aware of how to meet the communication needs of with people with hearing loss and other communication difficulties, both in terms of how to communicate and how to set up an environment in which good communication is possible, as is required by the Accessible Information Standard[28]. The guideline should also signpost to best practice guidance in this area, for example, Action on Hearing Loss's nursing toolkit on caring for older	.

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[27] NHS England Accessible Information Standard (2015). Available at: https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/#standard
[28] NHS England Accessible Information Standard (2015). Available at: https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/#standard

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				people with hearing loss, and guidance on accessing communication support and accessing services[29]. We feel these points are particularly important as the area of the current guideline on face-to-face communication section (line 113) is due to be removed.	
16	**Action on Hearing Loss**	5	113	We disagree that the "Face-to-face communication" section of the guideline should be removed. Communication is a key component of supportive and palliative care, and also an area where guidance on best practice is helpful for health and social care professionals. A Healthcare Commission complaints review, independently reviewing over 10,000 complaints to the NHS between August 2006 and July 2007, found that "Communication/ information provided to patients" was the second biggest issue raised. The report highlighted that "poor support for basic comfort, family and patient privacy, and spiritual, cultural and psychological needs were all common issues in complaints about palliative care. Our advisers felt that a basic lack of communication led to many of these problems."[30]	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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[29] Action on Hearing Loss (2015) Caring for older people with hearing loss: a toolkit for change (Available at: http://www.actiononhearingloss.org.uk/nursingtoolkit); Action on Hearing Loss guidance on communication support and access to services (Available at: http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/policy/policy-statements/access-to-services.aspx)

[30] Healthcare Commission (2008) Spotlight on complaints: A report on second-stage complaints about the NHS in England (Available at: http://webarchive.nationalarchives.gov.uk/20090104012205/http:/healthcarecommission.org.uk/_db/_documents/5632_HC_V18a.pdf)

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				The face-to-face section in the current NICE guidance for adults with cancer[31] ensures health and social care professionals are equipped with the skills needed to communicate information in a timely and appropriate way, and that good systems are in place that enable patients and their families/ carers are able to have open discussions and make the fully-informed choices. It also contains important references to the need to have appropriate communication support in place for people with a sensory loss.	
17	**Action on Hearing Loss**	7	152-153	In answering the question "What is the best way to share information between multiprofessional teams to ensure continuity of supportive care services?", the need to pass on communication support requirements of people using services and their families/ carers should be included, as the Accessible Information Standard requires[32].	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.
18	**Action on Hearing Loss**	12	268-269	We welcome the reference to "Supportive care not being related to the patient's condition or prognosis, rather to the needs of the person and those important to them". Given this reference, we urge there to be importance placed on meeting the communication needs of people and promoting the diagnosis and	Thank you for your comment. This guideline will not focus on condition specific clinical details. Further guidelines specific to a range of life-limiting illnesses and

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[31] NICE guidance for improving supportive and palliative care for adults with cancer (2004) (Available at: https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-773375005)

[32] NHS England Accessible Information Standard (2015). Available at: https://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/#standard

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				management of periphery conditions that are having an added adverse effect on quality of life for people receiving supportive and palliative care. This is particularly important as there is a continual increase of people living with comorbidities who will have a wide range of health and holistic needs[33].	conditions are also available on the NICE website: http://www.nice.org.uk/Guidance. The management of multimorbidities is dealt with by a separate guideline currently in development. Details can be found at: https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0704
305	**Association of Palliative Care Social Workers**	5	114	We are concerned that it is proposed to remove the **social support services** from the guidance. In the existing NICE guidance, *Improving Supportive and Palliative Care for adults with Cancer* Chapter 6 is a comprehensive guide which sets out in the objectives to ensure that: • Social care needs of individual patients and carer are addressed • Patients and carers experience a coherent and integrated system of social support, matched to their personal circumstances, to ease the social consequences of living	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. .

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[33] DCAL and Action on Hearing Loss (2013) Joining Up: Why people with hearing loss or deafness would benefit from an integrated response to long-term conditions (Available at: http://www.actiononhearingloss.org.uk/joiningup.aspx)

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				with cancer • Practical and financial support is available to patients and carers where and when needed and in a way that is acceptable to them. We are concerned that the removal of this section shows a fundamental lack of recognition that people's social, as well as their psychological and spiritual needs are integral to the provision of adequate palliative and supportive services. We are worried that palliative care in the NHS is seems to becoming increasingly 'clinical' and based on an exclusively medical model. The impact of this is compounded by the fact that, especially under current funding pressures local authority adult social care services are not consistently able to meet the care and support needs of people who are approaching the end of their lives. It is becoming increasingly hard for many people who are approaching the end of their lives to access suitable housing and adequate personal and nursing care. Social work support and advocacy is thus an important element of supportive and palliative care, Social workers have an essential role to play in enabling as many people as possible to continue to be cared for in their community, preventing avoidable hospital admissions and enabling individuals to achieve their preferred place of care and death.	

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306	**Association of Palliative Care Social Workers**	5	93	The guidance needs to recognise the level of expertise that social workers bring to supportive and palliative care. For example, In the existing guidance social workers are deemed to be capable of only level 1 interventions unless they complete *Advanced Communication Skills Training,* which is actually much more limited than the skills that social workers are required to develop through their initial qualifying training. Palliative care social workers also undertake more specialist professional development in the areas of counselling and therapeutic skills.	Thank you for your comment **The guideline will consider the organisation and composition of multi-professional teams and the coordination of services rather than the role of individuals within a service.**
307	**Association of Palliative Care Social Workers**	2	33	The equality statement should include reference to the need to provide supportive and palliative care to people in **prisons.**	Thank you for your comment. All settings in which National Health services are commissioned and funded are within the remit of NICE guidance and this includes Prisons.
74	**Association of Respiratory Nurse Specialists**		48 (Table)	Palliative care is not just end of life, using this description does not support current evidence for early intervention	Thank you for your 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 We have changed the title of the guideline to . End of life care: Service delivery for adults in the last year of life The terminology to be used in this guideline will be agreed with the guideline committee to

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					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.
75	**Association of Respiratory Nurse Specialists**		General	The differentiation of supportive and palliative is a difficult one. They are the same in many ways and an attempt to separate them may lead to further silo thinking and planning. If we further separate specialist palliative care it becomes even more complex with a risk of division.	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.
76	**Association of Respiratory Nurse Specialists**		77-	In the same sentiment, to plan these services separately may further silo our thinking.	Thank you for your comment The guideline will consider planning, coordinating and integrating the deliver of services.
77	**Association of Respiratory Nurse Specialists**		107	The future of supportive and palliative care as we know from all key documents is reliant on consistent, funded and outcome focused education. We would be concerned if this is not included within the scope. Particularly the evidence base for effective delivery of education.	.
78	**Association of Respiratory Nurse**		134-148	We advocate the need for effective tools. We would also suggest the 'how' is included in the scope. As we know from LCP, the tool may be effective but it is how it is communicated and delivered	As mentioned above the guideline has now refocused on service delivery within the last 12 months of life.

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	Specialists			that ensures positive outcomes. We would like to see the review of person- centred assessment included in this area	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.
79	**Association of Respiratory Nurse Specialists**		149-182	Looking separately at service provision for palliative and supportive care again may be confusing and complex. Services are intertwined with no real role boundaries and when these boundaries do exist they cause problems. Service development should include the nature of relationships required to support people of all conditions and circumstance. For example someone with COPD would not need a separate supportive care and palliative care service but would need a model which had demonstrated effectiveness of how respiratory/primary care and palliative care teams work together at all stages.	Thank you for your comment. The guideline will consider the planning, coordination and integration of services.
80	**Association of Respiratory Nurse Specialists**		183	Are preferred place of care and death service led or patient led outcomes? Although we know people 'usually' wish to die at home, we now know this is not the case for all and actually their priorities are different; to not have pain or other symptoms, to be with people they love, to feel secure, to have care when they need it. Patients wishes change by the minute and the hour dependent on circumstance and this is not reflective in this measurement. Again with a patient with COPD their primary focus would not necessarily be where they died but that they were not breathless,	Thank you for your comment. These are the main outcomes. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee.

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				had timely care and psychological support. Most die in hospital and for a significant proportion this may be the right thing. Should our outcomes therefore be focused on ensuring patient stated outcomes are achieved above all. The concern for those of us working with preferred place of care as our outcome measurement is that is service focused and does not indicate quality.	
81	**Association of Respiratory Nurse Specialists**		270-280	Palliative care in practice is often not used until the last weeks and months of life. This is however not how it should be, particularly for non-cancer conditions which will often have usual care continued until the end of their lives and require palliative care support sporadically dependent on need. If we continue to define palliative care as "end of life" it will reinforce these barriers which currently exist to provision of care to those with non-cancer conditions. Our definition of palliative care should be needs focused and not time focused to ensure these barriers and inequalities are addressed and there are some excellent working models of this in respiratory care which could be shared.	Thank you for your 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 have changed the title of the guideline to . End of life care: Service delivery for adults in the last year of life 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.
82	**Association of Respiratory Nurse**		general	We would have liked to see models for advance care planning included	**Thank you for your comment** The revised scope will look at the best models to support advance care planning in the last year of life.

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	Specialists				
83	**Association of Respiratory Nurse Specialists**		general	People with respiratory disease have a greater burden of symptoms than those with lung cancer and yet continue to receive disproportionate levels of palliative care support. We welcome this review and its inclusion of non- cancer conditions. We hope that this focus will help us to ensure a greater equity of service provision with models of care and service delivery to support this.	Thank you for your comment.
474	**Breast Cancer Care**	2	45	Breast Cancer Care welcomes the definitions but would value additional clarity over the use of these. For example, it can be difficult to see where palliative care starts and supportive care ends. Therefore, is it more appropriate to (at the least) highlight and clarify that supportive care and palliative care can- and do- run alongside each other? Supportive care services don't necessarily stop when a person is transferred to palliative care (for the patient or for the carer/ family members). (And the same could also be said of the interface between palliative and end of life 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. We have changed the title of the guideline to . End of life care: Service delivery for adults in the last year of life 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.
475	**Breast Cancer Care**	4	65	Too often, we know that the needs of the whole person are not addressed and instead that there is a tendency to focus on clinical outcomes. Inclusion of the holistic needs assessment is in	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within

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				line with new recommendations in *Achieving World Class Cancer Outcomes: A strategy for England, 2015-2020* to put patient experience on a par with clinical outcomes and patient safety. In addition, the *NICE guidance for Advanced Breast Cancer* currently states that there should be a holistic assessment of a patient's needs at diagnosis, during and after treatment, at relapse and when death is approaching. This assessment should cover physical as well as psychosocial and spiritual needs. Breast Cancer Care therefore welcomes the holistic needs assessment as a key area that will be covered in the consultation on improving palliative and supportive care in adults.	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.
476	**Breast Cancer Care**	5	109	Breast Cancer Care questions why complementary therapy services are to be removed from the guideline. While there are questions around the value of such treatments and their impact on clinical outcomes, there is some research in this area that shows the value of such therapy for cancer patients. For example, acupuncture has been studied in patients with cancer to reduce chemotherapy and radiotherapy induced nausea and vomiting, for pain control, to reduce vasomotor symptoms in women receiving antioestrogen treatment for breast cancer, to diminish cancer related fatigue etc. [*Garcia MK, McQuade J, Haddad R et al. Systematic review of acupuncture in cancer care: a synthesis of the evidence. J Clin Oncology 2013*] Several randomized, controlled trials have demonstrated the usefulness of hypnotherapy in palliative cancer care, with efficacy in	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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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				controlling pain and nausea/vomiting in various settings. [*Redd WH, Montgomery GH, DuHamel KN. Beahvioral intervention for cancer treatment side effects. J Natl Cancer Inst 2001*] In addition to the research, complementary therapies are important to patients. Patients with secondary breast cancer tell us that therapies like acupuncture, massage, reiki etc, help reduce pain, manage anxiety and stress- all too common 'side effects' of living with an incurable disease. For many, complementary therapies are an additional strategy in managing side effects of treatment and symptoms of the disease, helping individuals to manage and cope. As emphasis is being placed on patients' holistic needs with inclusion of such an assessment in the scope, it is important to consider how complementary therapies will be used to meet the wide range of patients' needs. Breast Cancer Care would therefore welcome the inclusion of these points somewhere within the scope (perhaps in the section on the holistic needs assessment), due to the importance placed on complementary therapies by many patients living with incurable breast cancer and other conditions.	
477	**Breast Cancer Care**	5	112	Breast Cancer Care does not agree that the section on user involvement in planning, delivering and evaluating services should be removed from the guideline, especially as increased	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within

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				emphasis has been placed on user involvement in a number of policy areas over recent years. The NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* highlights how "involving service users in the evaluation of services is fundamental to ensuring patient-centred provision" NHS England's *Five Year Forward View* has a section on empowering patients especially "…increasing the direct control patients have over the care that is provided to them" (p13) while *Achieving World Class Cancer Outcomes: A strategy for England, 2015-2020* refers to "cancer patients being better informed, and more involved and empowered in decisions around their care" (p6) Additionally, the *NHS Constitution* sets out patients' rights in detail: "You have the right to be involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services." It is difficult therefore to justify the removal of this section and how this policy direction would be achieved without enabling	the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. As you mention, recommendations related to user involvement in planning, delivering and evaluating services can be found in the NICE patient experience guideline. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v. However, the guideline does not focus on condition specific clinical details for all life limiting conditions. Please see the NICE website for access to all guidance at the following link: http://www.nice.org.uk/Guidance.

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				patients to be involved in the planning, delivering and evaluation of services. We would therefore welcome such mechanisms remaining in place in the updated guidance. Breast Cancer Care wishes to understand the rationale as to why this area is not being covered in the new guideline. If the reason for the removal of this section is because user involvement has been addressed in another guideline, we would urge caution. We would argue that, for example, the guideline (CG138 Patient experience in adult NHS services: improving the experience of care for people using adult NHS services) does include some information along these lines but is too generic and does not address in enough detail the particular inadequacies of care in supportive and palliative care. In addition, healthcare professionals working in supportive and palliative care may not always have time to refer to a plethora of documentation on this topic (or any other topic that has been removed). Having information in one place on palliative and supportive care is important for the purposes of ease and time, and for the reasons listed above.	
478	**Breast Cancer Care**	5	113	Breast Cancer Care does not agree that the section on face to face communication should be removed from the guideline. We know that for many secondary breast cancer patients their care pathways are unstructured and ill defined and that coordination of care is poor. This is especially apparent when compared with the coordination, information and support those diagnosed with early	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service

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				stage disease receive. Many do not have access to a clinical nurse specialist- and this lack of face to face communication- together with the lack of information- makes living with secondary disease problematic. *"I received really good care from a secondary breast cancer nurse. Having a secondary breast care nurse meant I could ask countless questions…She's my link between the consultants and me. So she makes a massive difference" Frances, woman with secondary breast cancer* Breast Cancer Care is concerned that removing face to face communication from the guideline will put in place additional barriers for patients. The ability for patients to be involved with decision making and planning of their care is truly difficult if face to face communications are lacking. Work undertaken by Breast Cancer Care's Secondary Breast Cancer Taskforce in 2006-2008 highlighted that there is still a reticence among some healthcare professionals to speak about distressing topics, such as palliative care, end of life and death. In addition, in 2014 Breast Cancer Care found that 41% of people with secondary breast cancer had never been offered a referral to a palliative care team and a further 25% had never had a discussion about palliative care with their oncologist or nurse. [*Breast Cancer Care, 2014, 'Share your Experiences' survey with 204 secondary breast cancer patients between 19/08/2014 to 22/09/2014*]. We must therefore not add	delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. As you mention, recommendations related to information provision and user involvement in planning, delivering and evaluating services can be found in the NICE patient experience guideline. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v. However, the guideline does not focus on condition specific clinical details for all life limiting conditions. Please see the NICE website for access to all guidance at the following link: http://www.nice.org.uk/Guidance.

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				to this by removing important guidance on face to face communication. The Secondary Breast Cancer Taskforce also highlighted how, at the point of a secondary diagnosis, patients need a clear and honest explanation of their situation. It recognised that in the weeks and months following, it was essential for professionals to discuss the uncertainty and lack of conclusive facts surrounding the patient's diagnosis. It is impossible to see how this can be achieved without good and timely face to face communication. We wish to understand the rationale as to why this area is not being covered in the new guideline. If the reason for the removal of this section is because user involvement has been addressed in another guideline, we would urge caution. We would argue that, for example, the guideline (CG138 Patient experience in adult NHS services: improving the experience of care for people using adult NHS services) does include some information along these lines but is too generic and does not address in enough detail the particular inadequacies of care in supportive and palliative care. In addition, healthcare professionals working in supportive and palliative care may not always have time to refer to a plethora of documentation on this topic (or any other topic that has been removed). Having information in one place on palliative and supportive care is important for the purposes of ease and time, and for the reasons listed above.	
479	**Breast Cancer Care**	5	114	Breast Cancer Care does not agree that the section on social support services should be removed from the guideline.	Thank you for your comment. Following consideration of all stakeholder comments the

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				People with secondary breast cancer are increasingly living longer and outside of the healthcare setting; there is a role that social support services should, and does, play in enabling them to do so. In addition, social wellbeing (often supported by social support services) is a key area addressed in the holistic needs assessment. It is difficult to see how the holistic needs of a patient would therefore be met, without inclusion of the role that social support services plays in providing good supportive and palliative care. The removal of this section is therefore surprising and concerning. Breast Cancer Care wishes to understand the rationale as to why this area is not being covered in the new guideline. If the reason for the removal of this section is because user involvement has been addressed in another guideline, we would urge caution. We would argue that, for example, the guideline (CG138 Patient experience in adult NHS services: improving the experience of care for people using adult NHS services) does include some information along these lines but is too generic and does not address in enough detail the particular inadequacies of care in supportive and palliative care. In addition, healthcare professionals working in supportive and palliative care may not always have time to refer to a plethora of documentation on this topic (or any other topic that has been removed). Having information in one place on palliative and supportive care is	guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. .

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				important for the purposes of ease and time, and for the reasons listed above. However, if the decision is made to remove social support services as a standalone section, Breast Cancer Care would urge that social support services are integrated into the whole of the document. This approach would fit with the wider integration approach for health and social care.	
480	**Breast Cancer Care**	5	115	Breast Cancer Care does not agree that the section on information should be removed from the guideline. Breast Cancer Care believes that information should be retained in the scope. Women with metastatic breast cancer have a high need for information in understanding their medical condition, treatment options and how to anticipate and address physical symptoms and that they have a strong reliance on their oncologists for information. *Reed E., Simmonds P, Haviland J, Corner J: Quality of life and experience of care in metastatic breast cancer: a cross sectional survey. J. Pain Symptom Manage. 43(4) 747-758 (2012)* As secondary breast cancer becomes more complex and moves towards the supportive and palliative care stages, the provision of information becomes ever more important. However, there is much research in this field which highlights the	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. As you mention, recommendations related to information provision and user involvement in planning, delivering and evaluating services can be found in the NICE patient experience guideline. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v. However, the guideline does not focus on

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				lack of information patients feel they receive when, and after, they receive a secondary breast cancer diagnosis. In 2006-2008, Breast Cancer Care led a taskforce on the needs of patients with secondary breast cancer. The taskforce identified a number of gaps in provision for this patient group, especially in accurate and appropriate information. It made a number of recommendations which focused on meeting those gaps through the timely and regular provision of information from diagnosis onwards and at key stages. [LINK] NICE's own guidance *Improving Supportive and Palliative Care for Adults with Cancer* refers to inadequacies in care being frequently reported, including poor face to face communication and lack of information (P106). These gaps in information provision still exist today and it is for these reasons that we do not feel that the scope of the consultation should remove the information section from the guidelines. Breast Cancer Care does not understand the rationale used when considering the removal of the 'information' section from the published guideline. If the reason for the removal of this section is because user involvement has been addressed in another guideline, we would urge caution. We would argue that, for example, the guideline (CG138 Patient experience in adult	condition specific clinical details for all life limiting conditions. Please see the NICE website for access to all guidance at the following link: http://www.nice.org.uk/Guidance.

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				NHS services: improving the experience of care for people using adult NHS services) does include some information along these lines but is too generic and does not address in enough detail the particular inadequacies of care in supportive and palliative care. In addition, healthcare professionals working in supportive and palliative care may not always have time to refer to a plethora of documentation on this topic (or any other topic that has been removed). Having information in one place on palliative and supportive care is important for the purposes of ease and time, and for the reasons listed above.	
481	**Breast Cancer Care**	6	135/137/139	Breast Cancer Care welcomes the reference on using established tools. However, in reference to the NHS Five Year Forward View, it's important to recognise that "England is too diverse for a 'one size fits all' care model to apply everywhere. But nor is the answer simply to let 'a thousand flowers bloom'." There is no one Holistic Needs Assessment that can meet all patients' needs, especially when considering demographics AND conditions in tandem (e.g. younger women under 45, with incurable breast cancer vs older women with early stage disease). Instead, there are a few tools that are helpful to use- some of which are listed in the consultation scope. It is important that 1) tools are used which have been evaluated and validated, 2) tools are tailored and appropriate to the group, disease and stage and 3) providers are given the resources,	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessment will not be specifically addressed by any review question, but will be considered as part of service delivery models, in accordance with available evidence.

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				support and training to implement holistic needs assessments effectively. Finally, we would welcome reference within the holistic needs assessment to financial wellbeing.	
482	**Breast Cancer Care**	6	142/144/146	Breast Cancer care believes that people's needs (and their carers and families) (in both supportive and palliative care) should be reviewed at diagnosis and at key stages such as a change in condition or treatment options. Additionally, they should also be reviewed at any stage as required by the patient or carer/family. Breast Cancer Care's standards on secondary breast cancer outlines that patients should: receive timely information on the benefits of local palliative and supportive care services for them (and those closest to them). Patients should be referred for specialist input as soon as they need it for symptom control and have access to advice and treatment out of normal working hours. Ideally an initial conversation on what palliative and supportive care services provide should happen at, or soon after, the point of diagnosis so that the patient is fully informed. This would help break down the barriers around the meaning of palliative care (in a 2014 Breast Cancer Care survey of over 200 women living with secondary breast cancer, 70% first thought palliative care was	Thank you for your comment.

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				only to be used at the very end of life).	
483	**Breast Cancer Care**	7	154/169	Breast Cancer Care believes that there is no one place where supportive care services and palliative care services should be delivered. This is why involving service users in the planning and design of services is vital (and why it shouldn't be removed from the scope of this document) because ultimately these decisions should be made by determining what patients need locally.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. User involvement in planning, delivering 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.
484	**Breast Cancer Care**	7	159/174	Breast Cancer Care believes that services should be provided at or soon after the point of diagnosis and according to patient need. Certainly with regards to palliative care, patients tell us about the value of these services and how they wish they had been able to access them sooner.	Thank you for your comment One of the key areas of the scope is service delivery models for end of life care, covering the timing and review of service provision in both acute community and third sector settings.

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				"When I was first diagnosed I had never heard of palliative care. I had no idea what it meant. Certainly I was very afraid of the hospice. Literally, physically afraid. I wanted to avoid it. I had absolutely no idea they weren't for the very end of life. But they were able to alleviate some of the most troubling and distressing symptoms I was suffering from. In my opinion women, or men, with secondary breast cancer should be informed that the hospice has the facilities to make their lives much easier very early on in the diagnosis." Eleanor, woman with secondary breast cancer There should also be scope to address digital options in meeting patient needs in this area; physical 'bricks and mortar' type services may not always be necessary. Instead options like Skype and digital apps may be more suitable and cost effective.	
485	**Breast Cancer Care**	General	General	The scope is very focused on service delivery; while there is inclusion of a holistic needs assessment (which we welcome) there is no reference at any point in the scope to the patient's quality of life. Quality of life should be included (at the least) alongside the holistic needs assessment. We would debate that it is almost impossible to see how you could have one without the other. For many people with secondary breast cancer, support that enables a patient to have a good quality of life is crucial. It affects almost every bit of intervention, treatment and care and arguably it is maintaining and/or improving the patient's quality of life that is the sole purpose of palliative and 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					Additionally, health-related quality of life has been included on the list of main outcomes that will be considered when searching for and assessing the evidence.
472	British Heart Foundation	1	11	We welcome the decision to extend this guideline to cover beyond adults with cancer to the population of adults with life-limiting conditions. The BHF estimates that heart failure, which is often the final outcome of a variety of cardiac diseases, currently affects over half a million people in the UK[34]. Despite therapeutic advances, heart failure is a progressive clinical syndrome. Although heart failure survival rates are worse than for some cancers, unlike cancer patients, very few people with heart failure receive specialist end of life care. The 2013/14 National Heart Failure Audit shows that only 4% of heart failure	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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[34] British Heart Foundation – Heart Statistics 2015
https://www.bhf.org.uk/research/heart-statistics

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				patients who were admitted to hospital were referred to palliative care services[35], although some heart failure specialist nurses also have palliative care training.	
473	British Heart Foundation	4	79	We are pleased to see that both acute and community settings will be covered in the service delivery model as we know on average, a GP will look after 30 patients with heart failure annually[36].	Thank you for your comment.
491	**British Infection Association**			The BIA are content with this draft scope as written and have no suggestions for additions or amendments.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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[35] National Heart Failure Audit 2013/2014 www.ucl.ac.uk/nicor/audits/heartfailure/documents/annualreports/hfannual13-14-updated.pdf

[36] National Institute for Health and Care Excellence (2010) chronic heart failure: Management of chronic heart failure in adults in primary and secondary care. NICE clinical guideline 108. www.nice.org/guidance/cg108

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466	**British Lymphology Society**	General		The draft scope does not mention the recognition or treatment of lymphoedema / chronic oedema. We feel that this should be included because this condition is recognised in many long term conditions and can worsen as patients near the end of life. Lymphoedema may be only one of many complex problems presenting with advanced disease, and requires management alongside the other conditions. Lymphoedema has a detrimental effect on quality of life and is associated with skin infections such as cellulitis. There is evidence that early recognition and intervention can improve outcomes, this includes patient and staff education and awareness. Patients who present with advanced disease may not always want or tolerate the full recommended therapy and, as a consequence, the assessment, intervention and overall management will be modified according to each patient's preference and needs. Patients also require an interdisciplinary approach; therapists need to understand and incorporate principles of palliative care in order to facilitate interdisciplinary communication and provide optimum care, including psychological support (BLS, 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The guideline does not focus on the clinical management of people in the last year of life. The NICE guideline on Care of dying adults in the last days of life was published in 2015 and addresses the clinical aspects of care of dying adults – details on this guideline can be found at: https://www.nice.org.uk/guidance/ng31. Additionally, 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 edited scope includes service delivery models for end of life care among its key topic areas and this includes multidisciplinary team

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					composition and planning and coordinating services which covers sharing information between multiprofessional teams.
6	**British Renal Society**	general	general	The draft scope excludes discussion about specific medical conditions. However, in many, and for patients on dialysis or considering dialysis, in particular, a key part of supportive care is discussion with patient and close persons about starting or withholding dialysis (and opting for conservative care) or discontinuing/withdrawal of dialysis when quality of life no longer acceptable to patient. There is ample evidence that rates of withholding and withdrawal vary amongst centres – and both would therefore benefit from integration into guideline. This could be generic for other long-term conditions dependent on interventional medical management (eg CPAP for COPD)	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The guideline will not focus on condition specific clinical details. For all life limiting conditions, please see the NICE website. http://www.nice.org.uk/Guidance, which includes guidance related to renal disease..
486	**Cancer Counselling London**		109/1	The removal of complementary therapies from the scope – already widely used in palliative care and shown to be effective in reducing anxiety and pain is a grave mistake. The term is often used to cover therapeutic support (counselling/psychotherapy) as well as body therapies, all contributing to wellbeing even in very	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new

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				ill patients. Cancer Counselling London works with cancer patients and their families at all stages of the disease, and on the basis of 20 years' prior experience with CancerBacup and then The Cancer Counselling Trust, we know through our work and feedback from clients the value of complementary support . The transition from active treatment to palliative care is emotionally as well as medically challenging and personalized support in conjunction with specialist medical care, both through talking therapy and hands on body therapies, by reducing anxiety, significantly helps with coping with pain and adjusting and accepting the terminal diagnosis. To underestimate the worth of the items listed by removing them from the guideline does immense disservice to people at the most challenging time of their life.	recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place. .
487	**Cancer Counselling London**		110/2	The removal of research into supportive and palliative care. An essential part of the development of best practice.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, the standards for drafting and

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					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.
488	**Cancer Counselling London**		112/3	The removal of user involvement – surely also an essential factor.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, 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.
48	**Cancer**			The removal of social support services – again essential.	Thank you for your comment. Following

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9	**Counselling London**				consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, guidelines related to the provision of social support are the remit of the Social Care Institute of Excellence. More details on this agency and it's its published work can be found at: http://www.scie.org.uk/.
490	**Cancer Counselling London**		115/6	The removal of information. How can the document claim transparency if this is removed?janej	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					Additionally, 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.
384	**College of Occupational Therapists**	2	41, 42, 43	People with dementia, cognitive impairment and learning disabilities are all listed separately but overlap. Suggest saying: people with cognitive impairment including dementia and learning disabilities.	Thank you for your comment. The current NHS definition states that dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities. It is a type of cognitive Impairment. We would prefer to be inclusive and include cognitive impairment, dementia and learning disability. 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.
385	**College of Occupational Therapists**	2	44	Any particular reason this group of people have been listed specifically? Equal opportunities could include many more e.g. people in prison, travellers etc.	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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386	**College of Occupational Therapists**	3	48	Tables of terms and definitions: how helpful are the timeframes and can the document new guidance also seek to address the need to ensure users have the same understanding of language as professionals – once it's agreed.	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. In addition the key recommendations in the guideline will be summarised in Information for the public which will be available alongside the published guideline on the NICE website.
387	**College of Occupational Therapists**	3	48	Table of definitions – there are implications of these as they stand on many current job titles. Many titles are 'specialists palliative... ' at present; however given these definitions many are likely to be providing supportive care – and is this a specialist area or not? Do we need to consider specialist supportive and palliative care?	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.
388	**College of Occupational Therapists**	3	48	Specialist palliative care definition – agree that it is provided by expert MDT, who are trained and keep knowledge updated. But not convinced it's only to 'manage persisting and complex problems'. Where does this leave the work of the SPC team to utlise their SPC knowledge and skill to carryout short term interventions – such as advanced care planning, or breathlessness? Why would we wait until its persisting to address	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

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				this – surely that is not in the users best interest? Also this part of the definition has enabled many SPC service to reject referrals because they are not complex or 'specialist' enough. There can be a risk of the patient being expected to be a specialist! When a professional is considered 'specialist' there is usually an element of the diagnosis in other specialisms – this is broader for palliative care making it more complicated. However we suggest that it is also about the *extended skill set*, from core practice that the professionals have. In palliative care this seems to be about holistic management of symptoms such as pain, breathlessness, fatigue, and impacts of symptoms that generalists rarely have skills to manage such as body image and sexual dysfunction and advance care planning discussions.	now being used within a revised scope.
389	**College of Occupational Therapists**	3	56	This section does not cover or mention the under 18 dependants of the person with a life limiting condition – and this is an important group. Fully understand that the clinical input is directed at adults 18 and over but if the rhetoric is to support carers and/or those important to people accessing supportive and palliative care there must be provision of a children and young people's pre-bereavement service.	Thank you for your comment. As you note those aged under 18 are outside the scope of this guideline. However, the revised scope now includes consideration of the needs of young carers of people at the end of life. In addition there is current NICE guidance in development on **End of life care for infants, children and young people**, that also includes sibling bereavement. Recommendations on bereavement can be found in the 2004 guideline.
390	**College of**	3	59	Be good to clarify that it includes services that are part funded. What about private sector? Are the patients still covered because	Thank you for your comment. We recognize that some services in this setting are provided

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	Occupational Therapists			they have a GP and so will ultimately be NHS?	by the private sector and these providers may find the recommendations of relevance to their services however, non NHS care funded settings are beyond the remit of NICE in relation to guidance provision.
391	**College of Occupational Therapists**	4	75	Like that this has been made explicit as often lost and wonder if body image should also be more explicit.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessment is no longer a priority area for the guideline and will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence. Service delivery models that deal with body

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					image, may be reviewed if published evidence is identified that meets our review protocols.
392	**College of Occupational Therapists**	4	86	The document talks about care and delivery models for palliative and end of life care together, but supportive care is spate (72) – whereas the definition separates these with timeframes. Service delivery recommendations for palliative and end of life care that is timeframe specific could be very different from each other so may be worth separating.	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.
393	**College of Occupational Therapists**	5	96	Rehabilitation services – if the plan is to continue with specialist and generalist supportive and palliative care it would be useful to define constitutes as specialist and generalist for AHPs and other rehabilitative professionals (Social Workers) or suggest professions define this.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, rehabilitation will not be specifically addressed by any review question, but may be considered as part of service delivery models,

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					in accordance with available evidence.
394	**College of Occupational Therapists**	5	96	Rehabilitation should not be a separate entity, but rather embedded throughout and part of the ethos of palliative care. Hospice UK has published a document about the rehabilitative palliative care approach to synergise these approaches going forwards.	Rehabilitation will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
395	**College of Occupational Therapists**	5	98	Be good to explore evidence and make recommendations about use of group work – with patients, carers and bereaved and also as per point 6: the support of children and young people of patients needs to also be considered.	Thank you for your comment. The Guideline development group will develop review questions based on the scope and make recommendations where evidence is available to guide practice. Recommendations on bereavement can be found in the 2004 guideline.
396	**College of Occupational Therapists**	5	109	Extremely concerned with the suggested removal of Complementary Therapy from the guidance – why would we not maintain this integration into the holistic care and support of people affected by life limiting illness? It's a step backwards.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within

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					CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
397	**College of Occupational Therapists**	5	114	Very concerned that social support will be removed from the guidance – again it seems to be moving back to a segregated and fragmented system that does not have the person at the centre.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
398	**College of Occupational**	5	110-115	All to be removed from guidance – is this because separate guidance exists – in which case that is not such an issue so long	. Thank you for your comment. Following consideration of all stakeholder comments the

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	Therapists			as clear reference is made to it or because it's not felt pertinent – in which case that is a concern.	guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. User Involvement in planning, delivering and evaluating services, face to face communication and information provision have all been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v. .
399	**College of Occupational Therapists**	7	152-153	Urge you to reference multiagency and third sector – not just multi-professional teams.	Thank you for your comment. One of the key areas the revised scope has highlighted for inclusion is service delivery models for end of life care, including those covering both acute community and third sector settings). We would include members of other agencies as

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					professional team members and do not feel any amendment is necessary.
400	**College of Occupational Therapists**	7	169-170	Be good to explore method of intervention alongside this e.g. one to one or in a group setting – which will in turn influence location to some extent as group work requires a communal setting other than own home.	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. One of the key areas highlighted in the revised scope is service delivery models for end of life care, and this includes location of services, for example place of care, covering both acute community and third sector settings.
459	**Compassion in Dying**		general	Compassion in Dying welcomes the development of this clinical guideline. We are a national charity working to inform and empower people to exercise their rights and choices around end-of-life care. We do this by: • providing information and support over our freephone Information Line; • supplying free Advance Decision to Refuse Treatment (ADRT) forms and publications which inform people how they can plan ahead for the end of their life; • raising awareness and delivering one-to-one support to older	Thank you for your comment and participation in the consultation process.

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				people through our outreach service, My Life, My Decision; • running information sessions and training for professionals, community groups and volunteers on a range of end-of-life topics, including accredited Continuing Professional Development (CPD) modules; • conducting and reviewing research into end-of-life issues to inform policy makers and promote patient-centred care.	
460	**Compassion in Dying**		general	We broadly welcome the guideline scope, however there needs to be explicit reference to advance care planning. This should cover looking at awareness raising of our current end-of-life rights and choices and an examination of effective support for care professionals who work with patients with life-limiting conditions to discuss and record their end-of-life treatment and care preferences. The 2015 NICE Care Of The Dying Adult covered communicating and decision making *during the last few days of life*. It is crucial that the Improving Supportive & Palliative Care guidance addresses decision making and the effective communication of preferences in those who have a life-limiting condition, but which (as set out in the draft guideline scope) *"is not related to the patient's condition or prognosis, rather to the needs of the person and those important to them"* i.e. it isn't limited to a particular time-frame.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. One of the key questions covered in the revised scope is: What are the best models to support advance care planning in the last year of life? This will be looked at within the larger issue of service organisation for end of life care services.

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				There is some evidence that advance care planning improves experience at the end of life. In a poll of 3,000 people conducted in 2015 by YouGov, 2,000 were able to think back to the last close relative or friend who died from a short or long-term illness (i.e. those who should have had planned care). 52% of those whose end-of-life wishes had been formally recorded were reported as dying in a good way, whereas, for those whose wishes weren't recorded, only 37% died in a good way. In other words, those who had their wishes formally recorded were 41% more likely to die well. Similarly, when end-of-life wishes were not recorded people were 53% more likely to receive treatment that they did not want. Putting patients at the heart of planning will mean they get the death they want and should ensure that care professionals aren't left having to make difficult decisions based on their own clinical judgement and the views of relatives. As evidenced by our Information Line and My Life, My Decision service, supporting patients to think about and record their preferences can be challenging and time consuming. Even when an individual wants to plan ahead, care professionals need the skills and time to navigate family relationships and concerns, alongside supporting the recording of patient preferences which involve, for example, encouraging the individual to think about quality of life and what matters to them and translating these into the kinds of treatment preferences that a care professional can act on. Our My life, My Decision service goes some way to	

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				address these needs. The guideline scope needs to address i) Awareness raising of end-of-life rights and choices of public and professionals ii) Care professionals' understanding of these rights and choices and the range of tools associated with them iii) Support for care professionals to work with patients to enable them to plan ahead	
461	**Compassion in Dying**		152-3	2.3. What is the best way to share information between multi-professional teams to ensure continuity of supportive care services? This element of the guideline scope is crucial. Research shows that there is a lack of a systematic approach to the recording of discussions with patients or carers about end-of-life issues, and that care professionals often carry information about patients 'in their heads' rather than relying on recorded notes to support the transfer of information between staff across organisational boundaries.* National initiatives to electronically record and share preferences (EPaCCS) are specifically for end-of-life patients, but there is	Thank you for your comment and participation in the consultation process. Thank you for your comment. Information sharing across multidisciplinary teams and services is one of the key questions included in the scope. Any recommendation will be informed by available published evidence from service delivery models. EPACCS may therefore be eventually considered as part of service delivery models in this area of enquiry, in accordance with available evidence.

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				little in place to ensure that the preferences of those not in receipt of specialist care or those not identified as palliative are recorded and can be accessed by appropriate care professionals. A detailed examination of what is and isn't working around sharing information between care professionals and care settings is much needed in order to say with confidence what best practice should be. *Cox K et al (2011) Is it recorded in the notes: Documentation of end-of-life care and preferred place to die discussions in the final weeks of life BMC Palliative Care 10(18) doi:10.1186/1472-684X-10-18, and Munday D, Petrova M, Dale J (2009) Exploring preferences for place of death with terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England British Medical Journal 339:b2391, and Paget A, Wood C (2013) Ways and Means Demos/Sue Ryder	
462	**Compassion in Dying**		109/191	Preferred and actual place of care/death As stated in the draft scope, two key outcomes that will be considered when searching for and assessing the evidence are *preferred and actual place of care and death*. Whilst we acknowledge the importance of these to dying patients, we believe that the scope should consider whether other treatment and care preferences – such as those recorded in an Advance Statement or Advance Decision - have been recorded appropriately and acted on. Widening the scope will contribute to	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.

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				building up a truer picture of care and therefore what best practice should be.	
463	**Compassion in Dying**		41	People with dementia We support that the guidance is actively addressing dementia. Our materials are used by a range of community stakeholders and organisations relevant to people living with dementia who use our materials as a starting point for initiating conversations about end-of-life preferences when they've had a diagnosis of dementia. It is crucial that people are made aware of their end-of-life rights as early on in a dementia diagnosis as possible before their ability to consider their future care is compromised. *"It's part of the National Dementia Strategy, dying well, ensuring 'a good death'. So it's on the Government's agenda. We're well aware that although it's not a key performance indicator at the moment, our commissioners will be asking for it at some point in the future, so we need to get on with it.*" Community Stakeholder East London (My Life, My Decision pilot)	Thank you for your comment and participation in the consultation process.
464	**Compassion in Dying**		123	Economic aspect We recommend an economic analysis of advance care planning	Thank you for your comment. This guideline will focus on the effectiveness and cost effectiveness of service delivery aspects of end

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				– the systemic savings and costs - alongside an examination of the social benefits of planning ahead.	of life care; therefore we will not be looking at the cost effectiveness of individual interventions such as advance care planning but we will look at different ways to deliver care, which may or may not include advance care planning.
499	**Confederation of Registered Essence Practitioners (COREP)**	5	109	The British Flower and Vibrational Essences Association, which forms half of the stakeholder the Confederation of Registered Essence Practitioners, is alarmed to hear that references to Complementary Therapy Services will be removed from the new National Institute of Care Excellence Guidelines for 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. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.**
50	**Confederation**	5	109	Essence therapy is not a treatment for any physical health	**Thank you for your comment. Following**

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0	**of Registered Essence Practitioners (COREP)**			problem, including cancer.	**consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.**
50 1	**Confederation of Registered Essence Practitioners (COREP)**	5	109	However, it has been used for over eighty years to improve people's mental, emotional and spiritual wellbeing.	**Thank you for your 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:**

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					service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
502	**Confederation of Registered Essence Practitioners (COREP)**	5	109	In 1976, Brian Forbes of the Bristol Cancer Clinic Penny Brohn UK reported that essences made a notable difference in the ability of cancer sufferers to cope and come to terms with their condition.	Thank you for your comment.
503	**Confederation of Registered Essence Practitioners (COREP)**	5	109	Essences have also been used to help families and carers manage their stresses, fears and concerns.	Thank you for your comment.
504	**Confederation of Registered Essence**	5	109	Research in 2008 indicated that these positive reactions are not just a placebo effect.	Thank you for your comment.

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	Practitioners (COREP)				
505	**Confederation of Registered Essence Practitioners (COREP)**	5	109	As essences have no effects on the physical body they are absolutely safe to use even with children and animals.	Thank you for your comment
506	**Confederation of Registered Essence Practitioners (COREP)**	5	109	They may also be taken alongside any other treatment whether it is surgery, chemotherapy, radiotherapy or complementary therapy.	Thank you for your comment
507	**Confederation of Registered Essence Practitioners (COREP)**	5	109	We therefore believe it is vital that those responsible for delivering supportive and palliative care for adults with both cancer and other life-limiting conditions should be informed of their potential and usefulness in their work.	Thank you for your comment
105	Craniosacral Therapy Association UK	5	109	The draft scope currently excludes complementary therapies. We feel this is short-sighted, for various reasons as listed below. We note that various commentators in the workshop in December 2015 also raised this concern – eg p22 "Leaving complementary therapies out seems wrong, as there is really strong evidence for certain aspects such as acupuncture. If you look at holistic tools and needs, then what happens if my need is acupuncture? If I	Thank you for your comment. A number of your comments focus on the the proposal to stand down sections of the published guideline. Following consideration of all stakeholder comments this new guideline will focus on service delivery within the last

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				was a patient I would be annoyed that complementary therapies are out", p46 "Add complementary medicines", p67 "Complementary therapies should be included as a general approach because there is some evidence of patient benefits for therapies such as acupuncture", "Concerns complementary therapy services will be dropped". We cannot see any evidence that NICE have addressed these concerns as yet.	12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Thus although they are not being explicitly considered in this guideline, recommendations relating to complementary therapies in the previous guideline will remain in place.
106	Craniosacral Therapy Association UK	5	109	In the workshop in December 2015, concerns were raised on the widest level about a lack of "rationale for why areas are not covered" (p37) - without this being clear, it seems premature to exclude whole sections of care from the guidance.	
107	Craniosacral Therapy Association UK	5	109	In the guidance 'Supportive and Palliative Care' 2004, it is noted that "A considerable proportion of patients express interest in these therapies… This Guidance therefore focuses on the needs of patients to obtain reliable information to make decisions for themselves and on measures providers should take to ensure that patients can access these therapies safely,	

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				should they wish to do so… **Key Recommendation 17: Commissioners and NHS and voluntary sector providers 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. As a minimum, high quality information should be made available to patients about complementary therapies and services. Provider organisations should ensure that any practitioner delivering complementary therapies in NHS settings conforms to policies designed to ensure best practice agreed by the Cancer Network."** We would encourage NICE to at the least retain a paragraph such as this – given that patients are likely to seek out complementary therapies anyway through word of mouth recommendations, surely their needs are better served by being as well-informed as possible. A similar concern was expressed at the workshop (p97) "The group felt that complementary therapies should also be considered for inclusion and patients referred to information on how to access safely."	
108	Craniosacral Therapy Association UK	5	109	Cost effectiveness – many complementary therapies are offered on a voluntary basis within hospice settings – not directly funded by the NHS but still within some NHS settings. At the very least services such as this are providing comfort and support, and anecdotally are felt to be helpful. Cost effectiveness must come into any proper discussion about what is serving patients, and	

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				making use of willing volunteers in a growing area of care needs must make sense as long as feedback is positive. The workshop asked this question (1.4 "Are there any **new practices** that might **save the NHS money** compared to existing practice?") With a little more consultation and research, good quality evidence could be gathered for the outcomes for quality of life for various complementary therapies, rather than dismissing them prematurely.	
109	Craniosacral Therapy Association UK	5	109	Meeting patients' needs and perceived needs - in the December workshop (p5) it was expressed that "Patient perspective is that complementary therapies are important. It is about patient needs not what clinicians need". Similarly p46 "Model to build: patient need rather than organisational structure." This needs to be taken into account – perhaps by a survey of patients to assess what they feel their needs are, and their experiences of different approaches to care. We have been told that many hospice settings do in fact already hold this kind of data.	
110	Craniosacral Therapy Association UK	5	109	Relevant to patients – the workshop lists two main outcomes (1.6) as "Patient reported outcomes including views and satisfaction of those receiving palliative and supportive care and those important to them" and "Health-related quality of life". These are two areas in which complementary therapies especially have a role to play. While research is varied in quantity between different disciplines some therapies have a wide evidence base.	
11	Craniosacral	5	109	Holistic needs – in both the draft guidelines and workshop there	

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1	Therapy Association UK			is acknowledgment of the need for holistic needs to be assessed and met. Complementary therapies have a role to play, as they expressly focus on the whole person and recognise the inter-relation between mind, body and emotions. The concern was raised at the workshop (p51) "Complementary therapies… looking at the whole person. Fear that it is not captured anywhere else. (Christine cancer unit/service delivery)". Peer-reviewed and published qualitative research into craniosacral therapy (Brough. N., *et al.,* Perspectives on the effects and mechanisms of craniosacral therapy: A qualitative study of users' views. (2015) EuJim, 7. 172 -183) found that clients often experience a change in awareness of their own needs and ability to look after themselves, as well as a greater sense of the interconnectedness of 'body, mind and spirit'. While we acknowledge the limitations of any single study, and this was not specific to palliative care, the results are at least indicative of strong potential, and we would therefore encourage NICE to work with the complementary sector to the benefit of patients.	
112	Craniosacral Therapy Association UK	5	109	Assessment of needs – in the workshop there were broad questions about what exactly is being assessed and met by the guidance – eg p18 "How do we identify the supportive and palliative needs of the patient?", p53 "What is the best way to identify and assess supportive and palliative care needs in people with life limiting conditions?" While these very wide questions remain apparently unclear, it seems unwise to remove sections of the guidance which may yet prove to be highly	

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				relevant. We would welcome more consultation with the complementary sector to address this.	
113	Craniosacral Therapy Association UK	5	109	We note that the call for members for the consultation committee has no places for complementary therapies to be represented, which we feel is unfortunate. From our perspective we would like to see more integration of services, and from the patients' perspective as noted above, if many will in any case be seeking out complementary therapies we would consider it safer to include representation and awareness of why patients may seek out these therapies in addition to their other care.	
114	**Federation of Holistic Therapists (FHT)**	5	108-109	This line specifies that 'Complementary Therapy Services' will be removed from the new published guidelines on *supportive and palliative care: service delivery*. **FHT strongly disagrees with this statement because:** **Provision is demanded and valued by patients as part of their supportive and palliative care pathways; removal of this section from the guideline will serve to negatively impact patient experience and choice.** In a survey of our registrants who already provide complementary therapy services as part of palliative and supportive pathways, we asked about changes in patient demand for these therapies as part of their care, particularly in the last 12 months. Of 173 respondents, 79% have seen a marked increase in demand in the last twelve months, with the remaining 21%	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				selecting 'stayed the same' or 'don't know' as their answer. Not one therapist indicated a decrease in patient demand. What's more, of these respondents 84% also privately treat at least one carer or member of a patient's family with complementary therapy treatments. This gives an indication of the value placed on and derived from complementary therapies, by both the patient and their support networks. Anecdotal / respondent specific evidence[1] garnered from the comment fields of the survey also highlight that: • Complementary therapy teams within hospices and hospitals are growing, taking on additional funded and voluntary staff to keep up with patient demand. • Patients regularly comment positively on the provision of complementary therapy, highlighting the emotional and psychological benefits of complementary therapies, which add a 'human' aspect to treatment and provide respite from practical, clinical care. • Both patients and healthcare providers highlight that complementary therapies significantly support emotional well-being and mental strength, highlighting that patients 'cope' better with conventional medical treatment, among other benefits. • In one hospice[1] which audits and measures patient demand, monthly uptake figures indicate that 90% of patients opt for	

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				complementary healthcare treatments. The existing NICE guideline (2004 Supportive and Palliative Care for Adults with Cancer) which this one is set to supersede, highlights that "complementary therapies are used…with the aim of providing emotional and psychological support to the patient" (page 148) and on page 12-13 (recommendation 17), makes recommendation that "at minimum, high quality information should be made available to patients about complementary therapies and services." The same still applies to current care needs, where at the very least patients deserve access to credible information, to make an informed choice on the provision of their care. **Removal of this section from the guideline risks inadequate and insufficient information being supplied to patients to enable them to make their own informed decisions.** [1]Specific comments / results of this survey available on request.	
115	**Federation of Holistic Therapists (FHT)**	5	108-109	This line specifies that 'Complementary Therapy Services' will be removed from the new published guidelines on *supportive and palliative care: service delivery*. **FHT strongly disagrees with this statement because:** **Healthcare professionals value and recommend complementary therapy treatments to their patients, as part**	Thank you for your 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

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				of a holistic, 'patient-centred' approach to palliative and supportive care. Removal of this section of the guideline risks healthcare professionals/commissioners accessing incomplete information for patient care, therefore risking substandard provision of information to patients, and /or delivery of an incomplete, inferior care pathway. More mainstream research into complementary therapy provision is required to quantify the full benefits and effectiveness in supportive and palliative care, however according to a report in the Clinical Medicine Journal in 2012 (which analysed the cumulative results of a number of academic studies), complementary therapy techniques were recommended to patients by 46% of UK Physicians between 1995 and 2011[2]. Similarly, the existing NICE guideline (2004 Supportive and Palliative Care for Adults with Cancer) uses academic references to highlight that "Many hospices and oncology departments in the UK offer at least one complementary therapy to patients, with over 50% of services offering more than five therapies. Almost half of GPs in England provide access to some form of complementary therapy, and two-thirds of oncology departments claim to provide therapies" (page 152). According to our own survey of FHT registrants, as well as supporting patients and their families with complementary therapies, 49% also regularly treat the healthcare professionals that they work closely with[3]. Healthcare professionals would not provide access to these	updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				treatments, or indeed access them themselves, without understanding or appreciating their value. Dr Michael Dixon, Chair of NHS Alliance and the College of Medicine, says "Very many of my palliative patients use complementary therapy and find it very helpful. Indeed in some cases they find this their most helpful intervention. Patients, their carers and primary care clinicians have both the need and the right to know what is available. It would be inexcusable and a huge blow to the credibility of NICE if complementary therapies were omitted from this guidance". Many of our registrants have made similar comment, including one who said "As a nurse as well as a therapist I feel that providing therapies fits into a valuable extension to my role. My colleagues who are therapists but not nurses play a vital role alongside the medical care. Ask the patients, carers, staff and doctors; the support that therapies provide for all these people enhance their ability to cope." As part of this re-assessment, it is important that NICE do not underestimate the value of complementary therapists to healthcare professionals in facilitating orthodox medical care and treatment. One FHT registrant working in a hospital highlights being called to clinical areas between her therapy treatments to support the healthcare providers, for example "relaxing a patient	

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				when they were trying to get a sample of blood, [to] helping someone who was distressed to feel less anxious." This and many other examples have a direct impact on hospital staff efficiencies, patient well-being, and reducing wasted cost within the system, helping patients with needle phobias, the fitting of radiation masks[4] and much more, as a complement to the clinical treatments[3]. Studying the minutes from the workshop used to create the draft scope for this guideline, a consistent theme through the discussion is the contributors questioning why complementary therapy services are being removed and suggesting that this aspect is wrong and needs to be revisited. No justification for removal appears to be forthcoming. We ask that NICE reconsider the removal and identify a viable method to include complementary therapy services as part of the new guidelines. **Removal of this section from the guideline risks unnecessary additional pressures being placed on both healthcare professionals and their patients, and potentially even increased overheads and costs to support patients, their carers and families with additional psychological stresses.** [2]**Source:** http://www.clinmed.rcpjournal.org/content/12/6/505.full.pdf+html	

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				[3]Additional comments / results from practising therapists are available from our survey, on request. [4]The FHT is happy to provide access to relevant case studies of complementary therapists offering non-treatment support, including relaxing patients with needle phobias and those being fitted for a radiation mask.	
116	**Federation of Holistic Therapists (FHT)**	5	108-109	This line specifies that 'Complementary Therapy Services' will be removed from the new published guidelines on *supportive and palliative care: service delivery*. **FHT strongly disagrees with this statement because:** **The existing guideline and pathways developed by NICE (2004 Supportive and Palliative Care for Adults with Cancer) already highlight the benefits of complementary therapy as part of patient-centred care; there has not been sufficient change in the industry and/or newly emerging evidence to warrant its removal from the guideline now. In fact, changes in the industry since 2004 have served to more closely align the industry with the NICE guideline, providing an even stronger argument to retain its inclusion.** According to the 2004 guideline developed by NICE, supportive care "should be given equal priority with other aspects of care and be fully integrated with diagnosis and treatment. It encompasses: …Complementary Therapies" (page 18). Page 52 also states "Patients with cancer use 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. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				because they feel the remedies are non-toxic and holistic, allow them more participation in their treatment and involve supportive relationships with practitioners" and pages 152-153 highlight that "There have been three systematic reviews of randomised controlled trials and studies of other complementary therapies, not limited exclusively to patients with cancer. Two provide some evidence of the benefits of aromatherapy in reducing anxiety and acupuncture in reducing nausea and vomiting. Preliminary results of a systematic review of chemotherapy-related nausea and vomiting is also positive for acupuncture. 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." A growing number of studies and anecdotal evidence have given preliminary indications that complementary therapies have both emotional and physical benefits to the patient. **To date, no studies have emerged to refute these claims, or which specifically evidence harm as a result of complementary therapies, when carried out by professional and appropriately qualified therapist. It is important therefore that complementary therapies be retained in the guidelines.** The 2004 guideline also made a key recommendation for statutory regulation of the CAM/complementary therapy industry if possible, or voluntary if not, which has been addressed in part	

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				by the introduction of a voluntary Accredited Registers programme in the UK, overseen by the Professional Standards Authority for Health and Social Care, a body accountable to Parliament. The FHT's Complementary Healthcare Therapist Register is one example and currently lists more than 10,000 complementary therapists. It is the largest Accredited Register for complementary therapists in the UK. The Accredited Registers programme provides assurance to patients and health professionals/commissioners seeking a non-statutory regulated health practitioner, which includes complementary therapists. It helps to protect patient safety by ensuring that those listed on an Accredited Register are professional, qualified, insured and accountable. In the Professional Standards Authority's own words: "Accredited Registers work alongside employers, commissioners, local authorities, patient and consumer protection agencies as part of a quality assurance network." This is an improvement in the industry since the publication of the 2004 guideline and was a direct recommendation of NICE. **Removal of this section from the guideline will not undermine existing demand for complementary therapies,**	

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				but may result in patients making uninformed decisions when looking for support from a non-statutory regulated professional. There is a need for patients to be signposted to the Accredited Registers programme where they can find a reputable therapist who is properly qualified, insured and accountable. This need can be met by retaining complementary therapies in this guideline and therefore properly informing both healthcare professionals and their patients. Note: FHT appreciates that some of the direct benefits of complementary therapy for specific conditions may be listed in other treatment-specific guidelines that NICE has also published, but that does not mean they should be omitted from this new general guideline on supportive and palliative care.	
162	**Federation of Holistic Therapists (FHT)**	5	108-109	This line specifies that 'Complementary Therapy Services' will be removed from the new published guidelines on *supportive and palliative care: service delivery*. **FHT strongly disagrees with this statement because:** **There is currently limited cost to the NHS, but significant gain to patients and healthcare professionals through the provision of complementary therapies; NICE must therefore discount direct costs and associated value as a parameter for this decision making.**	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				Part of the NICE remit is to provide guidance and support for investment and disinvestment, ensuring that information is evidenced and therefore decisions are cost and benefit efficient. At present, 46% of therapists work in hospitals and hospices on a voluntary basis to support patients, and of those 54% who are paid to work, 50% are funded by a charity, with 40% funded privately or by other means, and just 10% funded by the NHS or local hospital trusts.[5] This, coupled with the cost-savings and improved patient well-being highlighted previously, mean that although NICE must continue to measure the evidentiary base for the provision of complementary therapy in supportive and palliative care, cost should not be a factor which contributes negatively to the decision at this stage. Continued inclusion of complementary therapy services as part of the guideline will also allow existing NHS departments that already have a complementary therapy provision for their patients to continue to do so without concern. **Removal of this section from the guidelines risks the withdrawal of existing NHS and charitable support for the provision of complementary therapies, which will have a direct effect on patient well-being, as well as financial implications for the patient and their families. This in turn may lead to their inability to access complementary therapies, which unnecessarily limits or removes the patient's right to choose.**	

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				Please note: Anecdotal evidence already supports the provision and use of complementary therapies, and there is a duty to patients and their families to quantify this comprehensively. Long-term, NICE needs to confirm appropriate evidentiary methods to quantify the benefits of complementary therapies to support the guidelines, enabling additional research as recommended in the 2004 Supportive and Palliative Care for Adults with Cancer guideline. [5]Results taken from a short survey of 173 therapists currently working in hospitals or hospices. Full results available on request.	
163	**Federation of Holistic Therapists (FHT)**	5	108-109	This line specifies that 'Complementary Therapy Services' will be removed from the new published guidelines on *supportive and palliative care: service delivery*. **FHT strongly disagrees with this statement because:** **The evidence base for the use of complementary therapies has grown. Despite an ever-present demand for further research and evidentiary support, there have been an increasing number of academic studies which directly assess and quantify the medical benefits of complementary therapies, since the 2004 guideline was published. These emerging studies cannot be dismissed and in fact add weight to the argument that NICE must retain**	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				complementary therapy services within the supportive and palliative care guideline, particularly given the previously stated point about no evidence of harm. These academic studies include but are not limited to: • A study which investigated the effects of aromatherapy on coronary intervention patients in ICU; the key conclusion was that aromatherapy reduced anxiety, increased sleep, and stabilised the BP of patients undergoing cardiac stent insertion. Source: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3588400/ • A study into the effects of chair massage on patients with haematological malignancies, found that the qualitative data of the evaluation demonstrated the positive effects and beneficial changes therapies such as massage can have on carers of patients with haematological malignancies. The carers' own words are powerful testimonies to their time during and after a therapeutic intervention and provide adequate validation for the provision of such a service. Source: http://www.ncbi.nlm.nih.gov/pubmed/23890457 • One study looked at whether post-operative massage could reduce pain and anxiety more effectively than a control intervention in this particular patient group. The results showed significant differences between [the] groups for blood pressure and heart rate measures on day two and significant differences between [the] groups for pain, tension, anxiety and	

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				relaxation on both days two and three. Overall, the improvements in the control group were not as pronounced as those of the massage group. Source: http://www.ncbi.nlm.nih.gov/pubmed/26256133 • A study into the use of reflexology to support cancer patients with associated symptoms found that reflexology is effective for the treatment of cancer patients self-selected problems and concerns, and provide clinical benefit. Source: http://www.ncbi.nlm.nih.gov/pubmed/23890460 • Osteopathy and chiropractic: The UK 'back pain, exercise and manipulation' (BEAM) trial was a randomised trial based on 181 general practices. It concluded that spinal manipulation is a cost-effective addition to 'best care' for back pain in general practice. No authors listed; United Kingdom back pain exercise and manipulation (UK BEAM) randomised trial: cost effectiveness of physical treatments for back pain in primary care. BMJ. 2004 Dec 11;329(7479):1381. Epub 2004 Nov 19. The FHT appreciate that this evidence is merely a starting point and is not 100% conclusive as to the effect of complementary thearpy in palliative and supportive care; however these, coupled with the anecdotal evidence supplied, do demonstrate at least some specific benefits. This strongly suggests that NICE should retain complementary therapy within the supportive and palliative care guidelines to ensure patients are not deprived of the opportunity to make their own, informed choice.	

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				Removal of this section from the guidelines risks leaving patients without the relevant information and support they need, particularly for conditions which lack their own specific NICE guidelines. If nothing else, complementary therapy should remain within the guideline as a catch-all to ensure that patients are given relevant information and are supported in their choices, regardless of their condition.	
164	**Federation of Holistic Therapists (FHT)**	5	108-109	This line specifies that 'Complementary Therapy Services' will be removed from the new published guidelines on *supportive and palliative care: service delivery*. **FHT wishes to highlight that:** **Internationally, other countries are increasing the provision of and therefore funding for CAM/complementary therapies as part of the healthcare regimens. Excluding these from the NICE guideline and therefore the recommended pathways for supportive and palliative care will be a retrograde step for the UK in light of growing international demand and popularity.** According to a 2014 review of academic surveys in Germany, annual use of CAM therapies by the general population is between 40% and 62%, with widespread use by physicians also highlighted[6]. Indeed, in recent years, Germany has been pioneering a number of new techniques to support patients, including infrared and light therapies to support patients with	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				immune problems and leukaemia among others. According to a 2011 National Health Statistics report from the US[7], 40% of US adults use Complementary and Alternative Therapies (CAT) and that 41.7% of hospice care providers offered CAT services, had a CAT provider on staff or under contract, or both. What's more, approximately one third to one half of patients used some form of CAT as part of end of life care, despite the need for it to be funded privately or via charitable donations. The most common CAT was massage (71.7%). According to a 2001 study into the use of CAM in cancer patients' worldwide[8] use of CAM to support cancer patients increased from 25% in the 70s / 80s, to 32% in the 90s, and 49% after 2000. These figures were highest in the US and lowest in Italy and the Netherlands. The report concludes that "health care systems ought to implement clear strategies of how to deal with this." **Removal of this section from the guideline risks lesser adoption of relevant techniques emerging in the international marketplace in the future, (no adoption framework will exist) as well as being a retrograde step in terms of patient care provision.** [6]Source: http://www.ncbi.nlm.nih.gov/pubmed/24851848	

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				[7] Source: http://www.cdc.gov/nchs/data/nhsr/nhsr033.pdf [8] Source: http://ict.sagepub.com/content/11/3/187.abstract	
270	**Forest Holme Hospice, Poole Hospital NHS Foundation Trust**	general	general	Thank you for the opportunity to comment on the draft scope of the document. It will help to ensure that appropriate supportive and palliative care is available to all who need it. In particular, the specific inclusion of people with life-threatening non-malignant disease is helpful.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
271	**Forest Holme Hospice, Poole Hospital NHS Foundation Trust**	general	general	The term "guideline" is used throughout. Would "guidance" be more apt? For much of the topic it will not be possible to define the "optimum" service delivery model as this may vary depending on context, and several aspects of the topic will not have been subject to randomised controlled trials.	Thank you for your 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 use of the term 'guideline' is standard across NICE's products, so this term is used for consistency. We do not wish to prejudge the evidence in advance of finalising the review protocols and conducting relevant reviews. The guideline committee will therefore make recommendations on the evidence presented to

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					them.
272	**Forest Holme Hospice, Poole Hospital NHS Foundation Trust**	general	general	Supportive care is clearly very important across healthcare. Might it be helpful to include this aspect of care in all relevant NICE guidance, so that staff from all disciplines recognise it as their responsibility, rather than incorporate it in palliative care guidance? There is a risk that it is then seen only as a "palliative care service" responsibility.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
273	**Forest Holme Hospice, Poole Hospital NHS Foundation Trust**	3	table	Definitions of palliative care, non-specialist palliative care, specialist palliative care: It is not clear whether these definitions have been written specifically for this guideline. The wording is slightly different to that used for instance in the APM guidance on commissioning of specialist palliative care, which used previously defined terms from NICE (2004), WHO or NCPC. Rewording definitions for this guideline may add to confusion and does not clearly add value.	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.

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				"Non-specialist palliative care": many professionals may provide much end of life care in their day to day work and could be considered to have a great deal of expertise, although they are not trained in specialist palliative care per se. The phrase "non-specialist" may be seen as undervaluing professionals and teams with considerable expertise.	
274	**Forest Holme Hospice, Poole Hospital NHS Foundation Trust**	3	55	Who is the focus? Groups that will be covered: "Carers and/or those important to people accessing supportive and palliative care" Family and friends of the person accessing supportive and palliative care may well prefer to be referred to as family and friends, rather than "carers". In clinical practice it is more usual for people to identify themselves as the husband or wife of the person, rather than their "carer". This is not to trivialise the care that is provided by family members, rather to recognise that the relationship is often much more significant, complex and emotionally meaningful than that of "carer".	Thank you for your comment. The terminology used is agreed with the NICE team and will be refined and discussed by the Committee during the development of the guideline. Those important to the person is intended to capture family and friends and will be fully defined in the guideline.
275	**Forest Holme Hospice, Poole Hospital NHS Foundation Trust**	3	59	Settings that will be covered: "All settings where NHS care is provided or commissioned." Does this include independent hospices which receive a proportion of their funding from the NHS?	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.

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				It may be clearer to say, "All settings where care is provided or commissioned in full or in part by the NHS."	
276	**Forest Holme Hospice, Poole Hospital NHS Foundation Trust**	4	66-68	"Holistic needs assessment" This section mentions several specific tools. It seems premature to be so specific about the recommended tools before the guideline has been developed. It would be very helpful if NICE guidance, the Public Health England Palliative Care Data Set and NHS England Palliative Care Funding projects could all be aligned. The latter projects use the Integrated Palliative Care Outcome Scale as a tool to assess needs holistically as well as monitor person-centred outcomes.	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.
277	**Forest Holme Hospice, Poole Hospital NHS Foundation Trust**	5	95	"General palliative care" Does this mean "Generalist palliative care" or "Non-specialist palliative care" or something else?	Thank you for your comment. The terminology used is agreed with the NICE team and will be refined and discussed by the Committee during the development of the guideline.
278	**Forest Holme Hospice, Poole Hospital NHS**	5	169	"Where should palliative care services be delivered (for example, in the community, at home or in acute hospitals)?" This seems an odd question - surely palliative care should be delivered in all settings, whatever the location of the person	The question on where should end of life services be delivered refers to the best setting for service delivery. This should be seen in the context of the other questions contained in the scope (who should be involved in providing

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	Foundation Trust			needing palliative care. Does it mean, "Where should palliative care services be coordinated?" Several of the questions are very relevant to optimising service organisation, but the literature may not provide clear answers.	services, when should services be provided, what type of services should be available) to describe the context of end of life services delivery. Examples of settings have been deleted from the question in the scope. The full review question and protocol will be refined by the guideline committee and any recommendations based on the available evidence.
279	**Forest Holme Hospice, Poole Hospital NHS Foundation Trust**	8	190-1	Main outcomes: Preferred and actual place of care and of death are included in the list of main outcomes. Place of care and place of death are not necessarily of the highest priority for people with life-limiting illness. Other priorities may take precedence (see for example Steinhauser et al JAMA 2000; 284:2476-82).	Thank you for your comment. Place of care and death have been reported in literature as outcome measures of end of life services and have been thus included in the scope. The guideline committee will decide on the relevance of these outcomes and the appropriateness of available evidence when making recommendations. 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.

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165	**Hospice UK**	General	General	*Supportive care* is not a widely recognised term in healthcare – in fact all care should be seen as 'supportive'. It is certainly used in some acute and palliative settings – but often as an alternative term for early palliative care, or services not delivered by nurses or doctors or for ongoing care for those who have been treated and cured. As this guideline refers to those with life-limiting illness, it seems appropriate therefore to use the term 'palliative care' only – which can apply to all care based on holistic needs to support those living and dying with a life-limiting illness. This would be in line with international usage and other initiatives in the NHS (e.g. the development of the new service specification for specialised and core-level palliative care, the Ambitions for Palliative and End of Life Care, and that of the Leadership Alliance for the Care of the Dying Person. All documents need consistency of definition. There is currently no specialty of '*supportive care*" – but we do recognise however that the holistic services offered to newly diagnosed cancers that are potentially curative (e.g. services for newly diagnosed breast cancer patients) have to be labelled – perhaps these are supportive care services – and therefore do not need to be covered by a guideline for life-limiting illness – where all services would fall within the palliative umbrella. We	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The 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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				need to embed and demystify this word '*palliative*' in the minds of health professionals and the public. Palliative care delivered by hospices (which are predominantly charitable) has been and continues to be a huge element of palliative care. Inpatient settings are often the focus of exploration of hospice care – hospices provide over 70% of palliative beds but only 7% of deaths take place in them. However hospices have developed significant outreach programmes to care homes, patients own homes and clinic based services and estimates suggest that hospices are reaching at least 25% of those in the last years of life – maybe half of those who need specialised palliative care. A proportion of their care is commissioned by the NHS but much (around £750m a year of charitable resources) is not. However, the value and impact of these services must be included in the search for evidence. If palliative services are really to be inclusive for all those living with life-limiting illness, then the challenge for resource is huge – and light touch models of support must be included in the evidence reviews.	
166	**Hospice UK**	2	38 - 44	It really isn't clear from the Equality Impact Assessment why dementia, learning disabilities and cognitive impairment have been singled out for special consideration.	Thank you for your comment. It is thought that the groups listed under equality considerations need special consideration to ensure that they have equal opportunities to access services.

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				The largest groups missing from palliative care services are those with advancing heart and lung disease, and elderly patients slowly dying of frailty. Patients with mental health and palliative needs are also often excluded. The Care Quality Commission will soon be reporting on inequalities in end of life care and will highlight poor access for many groups – (black and ethnic minority groups, LGBT, gypsy and travellers) as well as the disease groups outlined above – perhaps all the review questions need to include all those currently excluded from palliative services.	The guideline committee will consider the needs of these populations in terms of recommendations for the delivery of services at the end of life.
167	**Hospice UK**	2	42	It would be helpful to set out what is meant by 'cognitive impairment' that is not covered by dementia or learning disability	Thank you for your comment. The current NHS definition states that dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities. It is a type of cognitive Impairment. We would prefer to be inclusive and include cognitive impairment, dementia and learning disability. 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.
168	**Hospice UK**	3	Tables & Definitions	The definition of palliative care is not in line with any definitions elsewhere in NHS documentation, or indeed with that on Page 12	Thank you for your comment. Following consideration of all stakeholder comments the

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				Line 270 of this document. Palliative care is no longer about care 'towards the end of life'. Increasing evidence suggests the value of early palliative support – and this new guideline is a great opportunity to collate the evidence relating to this. The palliative and supportive care definitions are impossible to differentiate. Non-specialist palliative care – currently called 'generalist', in the future may be called 'core'. The phrase 'without competence' is derogatory!	guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The 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.
169	**Hospice UK**	3	52	Life-limiting needs a definition	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.
170	**Hospice UK**	3	55	Will 'young carers' be covered or only adult carers?	Thank you for your comment. Young carers supporting the dying person will be included when the group considers evidence on service models that provide support for carers and

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					those important to the dying person.
171	**Hospice UK**	3	59	NICE needs to clarify that this refers to NHS patients in all settings e.g. hospitals, care homes, hospices, prisons, hostels etc. This is often an issue currently (i.e. there are sometimes differing views on whether patients in independent hospices or residents in private residential homes are NHS patients).	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. All settings in which National Health services are commissioned and funded are within the remit of NICE guidance and this includes prisons. We also 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.

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172	**Hospice UK**	4	61	This needs clarification as it is a little ambiguous. For instance an older person paying privately in a private residential home, which is their home. They are an NHS patient with an NHS GP and entitled to NHS palliative care, but their day to day care is not commissioned or provided by the NHS. The guideline needs to be clear that palliative services must outreach to all settings where NHS patients with palliative needs are. It is also important to be clear that care and services provided by hospices, which may or may not be 'commissioned' by the NHS, would also be within the scope of 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
173	**Hospice UK**	4	66-76	Tools should be setting and context dependent – there is a growing evidence base for different assessment tools and no single tool will suit all contexts. Some of those listed (e.g. the distress thermometer) is a screening checklist tool rather than a full holistic needs assessment tool.	Thank you for your 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

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				There should be increasing focus on 'person-centred' assessment tools – i.e. to discover what is important to the person, how best to care for them Formal carers assessment is key – e.g. using an evidence based tool such as CSNAT (Carers Support Needs Assessment Tool) – which has a significant evidence base for its value.	updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessments will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
174	**Hospice UK**	4	77 -90	Please see general comments at the beginning. The team and services providing supportive, palliative and end of life care will be similar and will substantially overlap – therefore the evidence and guidance for models should be presented as a single domain	Thank you for your comment. **The Guideline committee will comsider a range of service delivery models.**
175	**Hospice UK**	4	81	It is important to define what is meant by "24/7 provision of care". Does it mean advice, admission or round the clock present care?	Thank you for your comment. The final review question and protocol will be determined by the guideline committee. This will determine what published evidence is critically appraised on this topic and inform the guideline committee's decision making.
176	**Hospice UK**	5	107	Education and training – this is so crucial now to improving palliative care – where else will this be addressed?	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within

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					the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
177	**Hospice UK**	5	109	Palliative care includes all aspects of wellbeing, and many of the symptoms and concerns in life-limiting illness cannot be completely mitigated by medication or psychological approaches. Complementary therapies are frequently used alongside conventional medicine, for instance in help to manage pain and anxiety. Complementary approaches to care, particularly variants of massage therapy and acupuncture provide safe and effective relief to many and have become an embedded and valuable tool in many palliative services – excluding them from a palliative guideline would be a retrograde step. There is evidence to support these interventions. NICE itself concludes that at least 33% of UK cancer patients use complimentary therapies. Complimentary therapies can be monitored and delivered in a safe way with policies and procedures as with any other 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
178	**Hospice UK**	5	110	The lack of evidence established during the guideline development will hopefully provoke new research priorities.	Thank you for your comment .
17	**Hospice UK**	5	112	If the guideline is covering planning services, then user	Thank you for your comment. Following

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9				involvement is crucial – and if embedded in a guideline, then it may actually happen more systematically.	consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally 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
180	**Hospice UK**	5	113	Excluding face to face communication is dangerous. Palliative care is fundamentally based on good person-centred communication to elicit current needs and future plans. Services need to demonstrate that all their staff have these skills. An up to date guideline and evidence base would be extremely important and valuable. Communication with other professionals (i.e. shared decisions and shared care) is also a key part of co-ordination of care and	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and

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				cannot be simply reliant on IT systems.	palliative care for adults with cancer, they will remain within the published guideline. 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.
181	**Hospice UK**	5	114	Excluding all social care support services from a palliative guideline is a major omission. The holistic palliative approach includes attending to the physical, psychological, **social** and spiritual aspects of suffering and loss that accompany life-limiting illness. Social assessment includes addressing employment issues, financial concerns, family care, understanding the network of support around the patient now and in the future – and it cannot be underestimated as a vital domain in holistic 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
182	**Hospice UK**	5	115	Excluding information services is a key omission. There is evidence that a huge concern for many patients and families is the need for high quality information on current and future issues. Perhaps it could be combined with co-ordination 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. We will ensure consistency between the new

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					recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
183	**Hospice UK**	6	118	It is unclear why dementia has been singled out as the only condition with specific palliative needs when the largest groups missing from palliative services are those with advancing organ failure – heart, lung and kidney disease. These should be included too.	Dementia has been added to the list of equalities issues to ensure they have equal opportunities to access services. The guideline committee will consider the needs of this population in terms of recommendations for the delivery of services at the end of life. Guidance related to the management of organ failure in the other conditions mentioned in your comment can be found in other NICE guidelines on specific clinical conditions.
18	**Hospice UK**	6	135	See previous comments re supportive care (comment 4)	Thank you for your comment.

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4					
185	**Hospice UK**	6	137-138	There is no best tool – the guideline needs to identify the evidence for the most commonly used holistic tools. Different tools work in different setting with different population groups.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs 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.
186	**Hospice UK**	6	139 -149	There are tools that assess carer support needs – the CSNAT Tool (Carer Support Needs Assessment Tool) has a growing evidence base	Thank you for your comment.
187	**Hospice UK**	6	142-148	The needs of patients and carers are assessed on referral and thereafter the frequency will be individualised to the patient and carer context and condition –a blanket timescale approach would not be appropriate – well-co-ordinated care will pick up triggers for re-assessment of changing needs	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new

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					recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
188	**Hospice UK**	7	149-163	See previous comments regarding supportive care (comment 4)	Thank you for your comment and contributing to the consultation process.
189	**Hospice UK**	7	156-7	The guideline should ensure that the composition reflects the holistic nature of the multi-professional team needed to meet people's palliative care needs. This would include support to meet a person's physical, psychological, social, and spiritual needs.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					Consequently, the revised scope will include multidisciplinary team composition in the context of service delivery models for end of life care.
190	**Hospice UK**	7	165	This question needs clarification – planning involves a needs assessment, review of existing access and unmet need, perspectives of all stakeholders including users of services	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
191	**Hospice UK**	7	166	This is a vital question – some hospices are now being commissioned to lead co-ordination and centralisation of all palliative services and initial evaluations are very positive. These services need to be explored as part of the co-ordination scope.	Thank you for your comment.

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192	**Hospice UK**	7	167	There is increasing reliance on digital information sharing via EPaCCs systems. These are minimalist essential systems and risk key nuanced but relevant information not being shared. Examples of virtual case conferences e.g. Project `ECHO (Northern Ireland hub) need to be explored.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The revised scope will look at planning and coordinating services, including sharing information between multiprofessional teams. Additionally information sharing across multidisciplinary teams and services is one of the key questions included in the scope. Any recommendation will be informed by available evidence. EPACCS may therefore be eventually considered as part of service delivery models in this area of enquiry, in accordance with available evidence. Thank you for your comment. Any

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					recommendations will be informed by the evidence identified for each review.
193	**Hospice UK**	7	169	Palliative care services should be delivered in all settings and virtually. While patients are mobile, then they should travel to clinics and day services – community, hospice and hospital based. When the patient is less mobile, palliative care needs to be in the setting where the patient lives.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The revised scope will look at the location of services, for example – place of care. We look forward to refining the questions when drafting the full review protocol in conjunction with the guideline committee.
194	**Hospice UK**	7	171	Volunteers currently play a significant role in supporting people, and the role of volunteers should be included in the review evidence. They are providing a wealth of face to face palliative support in institutional and community settings and this needs to be extended.	Thank you for your comment. All settings where NHS care is provided or commissioned are included with the guideline. We intend to review different types of service delivery models, which may include volunteers.

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195	**Hospice UK**	7	174	The evidence for early intervention needs to be included in the review	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.
196	**Hospice UK**	7	176	Unplanned 24/7 care – evidence for types of rapid response, need for urgent palliative medical advice in all settings, hospice at home services and how to provide locality wide expert out of hours advice	Thank you for your comment. We look forward to reviewing the available evidence with the committee.
197	**Hospice UK**	8	186	It is important that outcomes reflect a person's individual circumstances, and the support that has help them to meet their needs and to achieve their own preferences. Patient and carer experience are equally important, but carer reported outcomes will be different from patient reported outcomes (e.g. the patient's pain is better but the carer's experience in hospital was awful). The views of bereaved carers are critical – they have to live on with the memories of care.	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.
198	**Hospice UK**	8	189	Health related quality of life may not be an appropriate outcome for those will deteriorating health – outcomes focussed on well-being and meeting goals are more appropriate.	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.
19	**Hospice UK**	8	190-192	Place of care and death are output measures but not necessarily	Thank you for your comment. These are the

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9				quality or outcome measures.	main outcomes. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee.
200	**Hospice UK**	8	192	Staff satisfaction may not be relevant for this guideline.	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.
201	**Hospice UK**	12	270-280	The distinction between palliative and supportive care is arbitrary and artificial in this paragraph. Moving forward we need clarity – it is palliative care from diagnosis (there is evidence of value – (Temel etc.) and supportive care perhaps if 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the context section of the scoping document has been amended to reflect these changes.

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					Further, 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.
202	**Hospice UK**	13	291	The figure of 171,000 was an extrapolation made from an incomplete Minimum Data Set return from 60% of palliative care services in 2009 (Initial Report of Palliative Funding Group). It needs to be updated.	The context section of the scoping document has been amended to reflect changes made to the scope.
203	**Hospice UK**	14	325-30	This is an over-ambitious and possibly inaccurate statement. Most hospital-based palliative care teams are not integrated with oncology. Oncology treatment and care is far from holistic and there is rarely access to social and psychological and spiritual support even in the large teaching hospital trusts. Much of the holistic care is in the voluntary sector – hospices, Maggies Centres, carer support, charities and bereavement support charities.	The context section of the scoping document has been amended to reflect the changes to the scope.
117	**International Observatory on End of Life Care, Lancaster**	General	General	Terminology. The terminology used must be much clearer and consistent. There are terms such as supportive, palliative, life limiting, end of life, used throughout the document in not always consistent ways. This is an ongoing issue in this area and it would be most helpful for this guideline to have a section on definitions and clear up these issues so that what is meant 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. We will ensure consistency between the new recommendations in End of life care: service

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	University			clear to those using the document.	delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The 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.
118	**International Observatory on End of Life Care, Lancaster University**	1	19	This guideline will also be useful for those evaluating care and conducting research in supportive and palliative care.	Thank you for your comment. The NICE template advises us to specify service providers in this section although we agree researchers will find the guideline of interest.
119	**International Observatory on End of Life Care, Lancaster University**	2	44	Other groups who, from the literature, appear less likely to access palliative care include those who live in institutions including care and nursing homes, and prisoners.	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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120	**International Observatory on End of Life Care, Lancaster University**	3	Table	End of Life itself is not defined and this is a particularly problematic term. Life limiting illness is also not defined. The definition of specialist palliative care is rather narrow, especially in its mention of only nursing and medical staff, when, for example, allied health professionals and social care professionals are equally important team members.	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.
121	**International Observatory on End of Life Care, Lancaster University**	3	52	The term life limiting is problematic and ambiguous. It could be argued that this is also 'death denying'. Might a term such as serious progressive or similar be more helpful. Life limiting can equally mean an illness, such as paraplegia which hinders or limits the usual daily activities 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 wording in the scope has been amended to read "progressive life limiting."
122	**International Observatory on End of Life Care, Lancaster University**	4	61	How many providers of palliative care might this exclude from the guidance? Are there specialist providers (such as some hospices or other charities) which do not receive any NHS funding, but who would feel excluded by this condition?	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Thank you for your comment. We recognize

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					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	**International Observatory on End of Life Care, Lancaster University**	4	74	Why are cognitive and sexual functioning singled out in addition to the usual domains of physical, social, psychosocial and spiritual needs? Why not issues such as financial needs for example as another 'sub issue'?	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
124	**International Observatory**	5	107	Why is education and training omitted. This seems a major omission given that much of the evidence points to issues of	Thank you for your comment. Following consideration of all stakeholder comments the

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	on End of Life Care, Lancaster University			education and training being at the heart of some of the major problems with care (such as the LCP) in recent years. In particular there are also issues with face to face communication (see later line) which are also omitted and which are essential elements of training and provision.	guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
125	**International Observatory on End of Life Care, Lancaster University**	5	110	The omission of research and evaluation as integral to the provision of supportive and palliative care is a serious one. How can this specialty claim to be evidence based (as I am sure that this guideline will be) if we omit any mention of the production of such evidence from the guideline itself. As a research active organisation we feel that this is a serious omission which needs to be urgently rectified.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in

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					evidence, further research will be recommended.
126	**International Observatory on End of Life Care, Lancaster University**	5	114	Why is this to be removed when on page 2, line 29 it states that the guideline may also be relevant for 'providers of social care as part of 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
127	**International Observatory on End of Life Care, Lancaster University**	6	131	The emphasis on needs assessment is welcome, but this seems only one part of the story. Surely how these needs are then met is central to this guideline, and yet whilst models of care are to be included, direct clinical and social care is not.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessments will

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					not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
246	**Keech Hospice Care**	5	109		Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
247	**Keech Hospice Care**	5	109		Thank you for your comment.
248	**Keech Hospice Care**	5	109	Many establishments throughout the UK – both NHS and charities - offer complementary therapies. These are highly valued by the patients as they can help with the experience of their diagnosis and associated symptoms by facilitating relaxation. As referenced in 11.23 of the current guidelines, the aim complementary therapy services is to offer "a means of improving their (the patient's) quality of life and controlling symptoms".	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will

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				In 2004 when the original NICE guidelines were written, the wider complementary therapy industry was undergoing a state of change following the 2000 House of Lords Science and Technology Select Committee *Sixth Report into Complementary and Alternative Therapies* and its recommendations. Soon after the *National Guidelines of the Use of Complementary Therapies in Supportive and Palliative Care (*Tavares) was published in 2003. This provided a framework for safe practice along with reference to the evidence base for the use of the modalities described. Since this time, palliative care establishments and professional associations such as the Federation of Holistic Therapists (FHT) have taken on board both the recommendations of the House of Lords report and adopted the guidelines as the basis of their service. Many professional associations now require evidence continued professional development for ongoing membership, akin to the standards required by nursing staff. The creation of the Complementary and Natural Healthcare	remain within the published guideline.

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				Council (CNHC) in 2008 as a voluntary accredited register also demonstrated the willingness of therapists to adhere to a standard. Subsequently, in 2014, the FHT has also set up its own accredited register. In 2014 Dr Michael Dixon, a GP and Chairman of NHS Alliance, said: 'Patients and GPs need to be assured about competence and safety when choosing the services of a professional complementary healthcare therapist. Anything that contributes to providing assurance is a step forward. It is therefore very good news to hear that FHT's Complementary Healthcare Therapist Register has now been accredited by the Professional Standards Authority under the new Accredited Registers programme. That is good for patients, good for professional complementary healthcare therapists, and also good for those who might want to signpost a patient towards a registered therapist.'	
249	**Keech Hospice Care**	5	109	In addition to the individual therapists taking responsibility for their own good practice, the National Association of Complementary Therapists in Hospice and Palliative Care (NACTHPC) has been established with the aim of promoting good practice and continued professional	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service

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				development in the field of palliative care. Its membership includes hospices and supportive establishments at the coal face of delivering this support. Complementary therapies were historically regarded with caution, due to a perceived lack of quality standards and the potential for inexperienced therapists working with palliative patients was a possible area of concern. Since the publication of the last NICE guidelines in 2004, those therapists working in the field of palliative care have worked towards both creating and maintaining standards of training and service delivery to address these concerns. The removal of any reference from the future guidelines would leave this area of support unreferenced and could lead to patients seeking advice and support from inexperienced therapists who may be unaware of the adaptations required to support palliative patients safely. Instead an update to the existing guideline, referring patients to seek advice from recognised professional associations or national groups such as NACTHPC might be more beneficial.	delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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250	**Keech Hospice Care**	5	109	Research and Supportive Evidence Since the current NICE guidelines were issued in 2004, there has also been a great deal of research and reporting on the efficacy of complementary therapies in palliative care. Major cancer hospitals such as the Christie in Manchester and the Royal Marsden in London have produced a lot of work of this field. Hopefully this will address the perceived lack of supporting evidence. Please find references appended to this statement. The costs of providing complementary therapies The NHS does not fund many of the complementary therapy services that are available to palliative patients across the country. This is the case at Keech Hospice Care where the service is entirely supported by donations. At many locations, volunteers provide the support with very few paid staff working within these teams. These volunteers are required to have the same level of training and work to the same standards as their paid colleagues. As such many complementary therapy services offer a low-cost, but popular and highly valued part of our support of	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				patients and their families. Looking forward It is important that the Complementary Therapy Services section of the NICE guidelines are kept in place as it would continue to ensure the future quality of services offered to patients and to also that accurate information is available to those who chose this kind of support. It is stated in the current introduction to the Complementary Therapy Services section of the NICE guidelines that "considerable proportion of patients express interest in the use of complementary therapies and a significant number report they have used complementary therapies for their condition" and this situation remains the same. Having this area represented within the future NICE guidelines would support the view that there should be a quality standard for those patients who choose complementary therapies as part of their support. Like any other means of supportive care, it is important that standards of delivery and good-quality information on this subject is available to allow patients to make informed decisions. Inclusion of complementary therapy in the	

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				guidelines would not necessarily serve as a recommendation for its use. Rather it would provide a signpost to those who wish to access these therapies in locations such as Keech Hospice Care.	
251	**Keech Hospice Care**	5	109	Appendices **PAPERS FROM THE CHRISTIE HOSPITAL TEAM** **ARTICLES** Bardy J Finnegan-John J Molassiotis A Mackereth P (2015) Providing acupuncture in a breast cancer and fatigue trial: the therapists' experience. Complementary Therapies in Clinical Practice.21:217-222 Donald G Lawrence M Lorimer K Stringer J Flowers P (2015) The meaning and perceived value of mind-body practices for people living with HIV: a qualitative synthesis. Journal of the Association of nurses in AIDS care. 26(5): 660-672. Mackereth P Ferguson A (2015) Gloves off. Internationalist Therapist. 113: 22-24. Mackereth P Hackman E Knowles R Mehrez A (2015) The value of stress relieving techniques. Cancer Nursing Practice. 14(4): 14-21. Mehrez A Maycock P Stringer J Mackereth P (2015) Managing hospital malodours with essential oils. In Essence. 13(4):14-16. Mackereth P (2015) Being curious: the touch therapy researcher. The Art of Healing. 1(50): 28-31. Bardy J Finnegan-John J Mackereth Molassiotis A (2015) Training in and performing self-needling as part of a clinical trial: the practitioner and patient experience. Acupuncture in Medicine. 33: 210-216. Mackereth P Bardy J Finnegan-John J Farrell C Molassiotis A (2015)	Thank you for your comment. Following

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				Legitimising Fatigue After Breast Cancer Treatment: The 'Coping with Fatigue' Booklet British Journal of Nursing. 24(4): S4-12. Mehrez A Orrett L Tomlinson L Manifold J Mackereth P (2015) Meet CALM and carry on. The International Therapist. 111:29-31. Mackereth P Tomlinson L (2014) Procedure-related anxiety and needle phobia: rapid techniques to calm. Nursing in Practice. 80:55-57. 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. Mackereth P Maycock P (2014) Aromatherapy and the SYMPTOM model. In Essence 13(3):9-12. Mackereth Bardy J Finnegan-John J Molassiotis A (2014) Receiving or not receiving acupuncture in a trial: the experience of participants recovering from breast cancer treatment Complementary Therapies in Clinical Practice. 20(4): 291-296. Mackereth P Hackman E Knowles R Mehrez A (2014) The value of complementary therapies for carers witnessing patients' medical procedures. Cancer Nursing Practice. 13(9):32-38. McLaren N Mackereth P Hackman E Holland F (2014) Working out of the 'toolbox': an exploratory study with complementary therapists in acute cancer care Complementary Therapies in Clinical Practice. 20(4): 207-21. Mackereth P (2014) Focus on smoking cessation: Calm the craving in cancer care. Practice Management. Sept Issue, 12-13. Maycock P Mackereth P Mehrez A Tomlinson L Stringer J (2014) Self-soothing in a tube. International Therapist. 109: 21-23 Roberts D Wilson C Todd C Long Af Mackereth P Stringer J Carter A Parkin S Caress a-L (2013) Complementary therapies in cancer: Patients' views on their purposes and value pre and post receipt of	

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				complementary therapy—A multi-centre case study. European Journal of Integrative Medicine. 5: 443-449. Mackereth P Chaudhry S (2013) On reflection. International Therapist. October Edition 106: 20-22 Molassiotis A Bardy J Finnegan-John J Mackereth P Ryder WD Filshie J Ream E Richardson A (2013 published on-line) A randomized controlled trial of acupuncture self-needling as maintenance therapy for cancer-related fatigue after therapist-delivered acupuncture. Annals of Oncology.24(6: 1645-52. Nightingale L Stringer J (2013) Carers complementary therapy project on a haematology and transplant unit. Complementary Therapies in Clinical Practice . 19(3): 119-127. Hackman E Mak T Mackereth P Tomlinson L Mehrez A (2013) Reducing "Bert's" distress: a CALM model of dementia care in oncology . British Journal of Nursing. 22(4) S20-24. Molassiotis A, Bardy J, Finnegan-John J, Mackereth P, Ryder DW, Filshie J, Ream E, Richardson (2012) Acupuncture for cancer-related fatigue in patients with breast cancer: a pragmatic randomized controlled trial. A.J Clin Oncol. 2012 Dec 20;30 (36):4470-6. Hackman E Mackereth P Maycock Orrett L Stringer J (2012) Expanding the use of aromasticks for surgical and day care patients. International Journal of Clinical Aromatherapy 8; 10-15. Mackereth P (2012) Pandiculation: releasing anxiety during procedures. Anxiety Times. 83:14. Mackereth P Parekh J Donald G (2012) Providing therapies to the opposite sex: views of complementary therapists working in clinical and private practice settings. Complementary Therapies in Clinical Practice. 18:154-158. Mackereth P Tomlinson L Orrett L Manifold J Hackman E (2012)	

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				Needle with Ease: rapid stress management techniques. British Journal of Nursing. 21(14): S18-22. Mackereth P Tomlinson L Maycock P Donald G Carter A Mehrez Lawrence Stanton T (2012) Calming panic states in the Mould Room and beyond: a pilot complementary therapy head and neck service. Journal of Radiotherapy in Practice. 11(2):83-91 Mackereth P Mehrez A (2012) Super-vision: helping to develop and support your practice. International Therapist 99: 30-32 Carter A Tomlinson L Maycock P Mackereth P Hackman E (2011) Anchoring aromasticks using sensory language. In Essence. 10(3): 24-26. Carter A Maycock P Mackereth P (2011). Aromasticks in clinical practice. In Essence. 10(2): 16-19.	
252	**Keech Hospice Care**	5	109	Hackman E Mak T Mackereth P Tomlinson L Mehrez A (2013) Reducing "Bert's" distress: a CALM model of dementia care in oncology . British Journal of Nursing. 22(4) S20-24. Molassiotis A, Bardy J, Finnegan-John J, Mackereth P, Ryder DW, Filshie J, Ream E, Richardson (2012) Acupuncture for cancer-related fatigue in patients with breast cancer: a pragmatic randomized controlled trial. A.J Clin Oncol. 2012 Dec 20;30 (36):4470-6. Hackman E Mackereth P Maycock Orrett L Stringer J (2012) Expanding the use of aromasticks for surgical and day care patients. International Journal of Clinical Aromatherapy 8; 10-15. Mackereth P (2012) Pandiculation: releasing anxiety during procedures. Anxiety Times. 83:14. Mackereth P Parekh J Donald G (2012) Providing therapies to the	.

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				do aromatherapists in cancer care need specific training to do this work? In Essence. 9: 20-22. Mackereth P Maycock P (2010) Clinical reflexology and cancer: are you contraindicated? Reflexions: Journal of the Association of Reflexologists. Sept Edition, 14-15 Mehrez A Mackereth P (2010) Saying 'no' to nocebo. The Therapist. 9: 10-12. Maycock P Mackereth P (2010) Going smoke-free: can aromatherapy help? In Essence 8(4):9-12. Mackereth P A Parkin S Donald G Antcliffe N (2010) Clinical supervision and complementary therapists: an exploration of the rewards and challenges of cancer care. Complementary Therapies in Clinical Practice. 16: 143-148. Donald G Mackereth P Tobin I (2010) Medical students and acupuncture: a short, sharp treatment experience! Acupuncture in Medicine - BMJ 28: 12-15. Carter A Mackereth P Tavares M Donald G (2009) Take me to a Clinical Aromatherapist. International Journal of Clinical Aromatherapy. 6 (1): 3-8. Mackereth P Carter A Parkin S Stringer J Roberts D Long A Todd C Caress A (2009) Complementary therapists' training and cancer care: a multi-site study. European Journal of Oncology Nursing. 13: 330-335.	
253	**Keech Hospice Care**	5	109	Mackereth P Carter A Parkin S Stringer J Roberts D Long A Todd C Caress A (2009) Complementary therapists' motivation to work in cancer/supportive and palliative care: a multi-centre case study. Complementary Therapies in Clinical Practice. 15: 161-165. Mackereth P Booth K Hillier V Caress A (2009) What do people talk	

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				about during reflexology? Analysis of worries and concerns expressed during sessions for patients with multiple sclerosis. Complementary Therapies in Clinical Practice.15: 85-90 Maycock P Mackereth P (2009) Helping smokers to stop. The International Therapist. 86: 18-19. Mackereth P Booth K Hillier V Caress A (2009) Reflexology and relaxation training for people with MS: a controlled trial. Complementary Therapies in Clinical Practice. 15: 14-21. Mackereth P Marland L (2009) Clive O'Hara (1948-2008) – pioneer of reflexology. Complementary Therapies in Clinical Practice.15:52. 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. Stringer J Swindell R Dennis M (2008) Massage in patients undergoing intensive chemotherapy reduces serum cortisol and prolactin Psycho-Oncology. 17: 1024-1031. Mackereth P (2007) Touch Therapies: the curious researcher Journal of Holistic Healthcare Journal of Holistic Healthcare 4(4) 32- 36. Wilson K Ganley A Mackereth P Roswell V (2007) Subsidized complementary therapies for staff and volunteers at a regional cancer centre: a formative study. European Journal of Cancer Care. 16, 291-299. Bott J (2007) An analysis of paper-based sources of information on complementary therapies. Complementary Therapies in Clinical Practice. 13, 53-62. Mackereth P Carter A (2006) Clinical leadership: developing the role of complementary therapy coordinators. Complementary Therapies in Clinical Practice. 12, 80-82.	

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				Mackereth P Carter A (2006) Nurturing Resilience: touch therapies in palliative care. Journal of Holistic Healthcare.3 (1), 24-28.	
254	**Keech Hospice Care**	5	109	**BOOK/CHAPTERS** Mackereth P Carter A Stringer J (2014) Complementary therapy approaches to pain. (Ed. H van Griensven) Pain – a Textbook for Clinicians Elsevier Science Tiran D Mackereth P (Eds) (2010) Clinical Reflexology: a guide for integrated practice 2nd Edition. Elsevier Science. Cawthorn A Mackereth P (Eds) (2010) Integrated hypnotherapy: a complementary approach to clinical practice. Elsevier Science. Mackereth P Carter A (2008) Complementary Therapies. In: Payne S, Seymour J & Ingleton C (Eds). *Palliative Care Nursing: Principles and Evidence for Practice.* 2nd edition McGraw-Hill Press: Maidenhead Mackereth P O'Hara (2007) Reflexology. In: Enhancing cancer care: complementary therapy and support (Ed. J Barraclough) Oxford University Press. Oxford Mackereth P Stringer J (2007) Massage. In: Enhancing cancer care: complementary therapy and support (Ed. J Barraclough) Oxford University Press. Oxford Stringer J (2007) Aromatherapy. In: Enhancing cancer care: complementary therapy and support (Ed. J Barraclough) Oxford University Press. Oxford Mackereth P Carter A (Eds). (2006) Massage & Bodywork: adapting therapies for cancer care. Churchill Livingstone, London Cawthorn A Mackereth P (2006) Complementary and Alternative Therapies in Rheumatology. In: Rheumatology Nursing (Ed.Hill, J) 2nd Ed Whurr Pub; London. Molassiotis A Cawthorn A Mackereth P (2005) Complementary and	

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				Alternative Therapies in Cancer Care. (Eds Kearney & Richardson) Nursing Patients with Cancer Elsevier Science. London. Mackereth P Campbell G (2003) Research and Chair Massage In: Pyves G Woodhouse D (Eds) NOHANDS Chair Massage. Shizen Publications. Halifax. Mackereth P Tiran D (Eds). (2002) Clinical Reflexology: a guide for health professionals. Churchill Livingstone, London	
255	**Keech Hospice Care**	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 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	

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				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 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	
19	**Macmillan Cancer Support**	General	General	We welcome the focus on holistic needs assessments, but do not feel that these should be evaluated for the guideline in isolation. Needs assessments can be very helpful in enabling patients to highlight needs which would otherwise not be acknowledged, but an assessment should only be seen as one step in addressing	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service

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				these needs. Addressing how the needs assessment will be used is crucial. Macmillan views needs assessments as part of a wider "Recovery Package" of interventions which also, crucially, uses the holistic needs assessment to craft an individual care and support plan. It is the delivery of this plan which will lead to needs being addressed. It is worrying that this is not mentioned at all in the draft scope – as without such a plan the results of a needs assessment could easily not be addressed. A well-rounded supportive care package should also include a treatment summary, a health and well being educational event, a care review with primary care clinician, a key contact point for rapid re-entry into the system if necessary, and signposting to services/ information about likely ongoing care needs. All of the above should be covered in this guideline, but are not currently referenced in the scope at all.	delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessments will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
20	**Macmillan Cancer Support**	General	General	There should be a greater emphasis on bereavement support and care in this 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not

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					updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.
21	**Macmillan Cancer Support**	General	General	Will there be any reference to the contribution of third sector organisations in this guidance? Most third sector organisations receive an NHS payment. What value do they add?	The revised scope lists among the key areas to be covered by the guideline, service delivery models for end of life care, including those covering both acute community and third sector settings.
22	**Macmillan Cancer Support**	General	General	In the guidance there is room to raise awareness of information being available in different formats, i.e. CHANGE easy read materials, Macmillan audio resources, video resources and that there is information in different languages.	Recommendations related to information provision can be found in the NICE patient experience guideline. Health care professionals are encouraged to establish the most effective way of communicating and sharing information with all patients. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v.
23	**Macmillan Cancer Support**	General	General	It would be helpful to see the guidance include some reference to exploring the benefits of Advance Care planning within 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. We

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					will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The revised scope includes a draft key question to explore the best models to support advance care planning in the last year of life.
24	**Macmillan Cancer Support**	General	General	The Learning and Development needs of those in the MDT who provide direct care should be included in the guidance. Without being included, Learning and Development is likely to be an area that is overlooked due to budgetary, time commitments etc.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Thank you for your comment. 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

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					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.
25	**Macmillan Cancer Support**	2	41-45	Other groups to include are: • those with mental health problems e.g. Schizophrenics etc prisoners. • people who's second language is English • the frail - a recent audit shows that frailty is poorly recognised and these people are conveyed to hospital via 999 or 111 • vulnerable migrants – this group should be investigated further	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.
26	**Macmillan Cancer Support**	4	84	**Add "Out of Hours Services"**: I appreciate specific education aspects will be outside of the scope, but guidance and advice on **education resources** for Out of Hours services to direct their GPs to will be helpful to include. For example E-ELCA *End of Life Care E-Learning for Health Care* and Macmillan's Out Of Hours Palliative Care E-Learning programme, recent RCGP End of Life Toolkit. There also needs to be guidance on ensuring **Out Of Hours Drugs access systems** are developed as this will help guide Clinical Commissioning Groups and Out of Hours Providers to set minimum 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. . NICE has recently published a guideline on

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					Care of dying adults in the last days of life. This guideline addresses the clinical aspects of care of dying adults including anticipatory prescribing – details can be found at: https://www.nice.org.uk/guidance/ng31.
27	**Macmillan Cancer Support**	4	87	We are assuming the guidance will be looking at Health and social care provision 24/7. We hope this will emphasise the need for 24/7 Community nursing and well trained OOH doctors plus co-ordinated specialist palliative care services 24 hr helplines etc	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The revised guideline will cover out of hours, weekend and 24/7 availability of services when service delivery models for end of life care is covered.
28	**Macmillan Cancer**	5	88	As noted under "general comments" there is very little emphasis on bereavement.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within

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	Support			In the last guidance there was a pyramid model which explained the proportion of bereaved people who may need professional support. It would be good to build on this evidence in order to explain how the needs of the bereaved can be better addressed. Including identification and referral of people at risk of complex bereavement is important but this group excludes the majority of people who will not experience complex grief and need specialist bereavement support.	the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.
29	**Macmillan Cancer Support**	5	91-98	We welcome the inclusion of all areas of the published guideline to be updated, including rehabilitation and psychological support in particular. However, it is worrying that this has not been updated to also include the specific supportive needs of people with consequences of treatment. Psychological services in particular require improvement to ensure there is equity of access. There is not currently equity for access to psychological assessment and support for cancer patients for services currently set up for long term conditions. This issue should be addressed in the guideline, as well as an acknowledgement that some people will have condition specific psychological needs – for example, people who have had a cancer diagnosis may well experience anxiety due to fear of recurrence	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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

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					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.
30	**Macmillan Cancer Support**	5	100	We welcome the inclusion of transitional care for young adults (aged 18-25) moving from children's services to adult services. Alongside the provision of psychological services, mentioned above, this is an area which we feel requires improvement as existing services are not able to meet demand.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Transition from paediatric to adult services will no longer be addressed in the guideline as an individual review question. NICE has produced a guideline on Transition from children's to adults' services for young people using health or social care services (NG43). The guideline will not focus on clinical

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					conditions and the key areas to be covered and draft questions have been amended to reflect this.
31	**Macmillan Cancer Support**	5	102	It's not clear if holistic needs assessment includes that of bereaved people. I think it would be important to include this group within assessment issues	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs 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. Recommendations on bereavement can be found in the 2004 guideline.
32	**Macmillan Cancer Support**	5	107	We do not agree that education and training should not be included in the new guidance. It is crucial that all health care professionals who carry out holistic needs assessments are given at least some training in how to conduct the assessment,	.

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				and how to ensure that needs are addressed. It would also be helpful to provide guidance on the types of training that healthcare professionals could have to enable them to recognise unmet supportive care needs more generally.	
33	**Macmillan Cancer Support**	5	108-115	Without any additional information provided it is difficult to understand why these areas will be removed from the updated guidance. We would welcome the inclusion of social support services and information.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended. User Involvement in planning, delivering and evaluating services, face to face communication

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					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.
34	**Macmillan Cancer Support**	5	113	I am concerned that face to face communication is being removed from the scope of this document. I understand that it may be an education and training need, but I still think that it should be highlighted as a priority for staff to receive guidance, particularly in the area of end of life conversations and advance care planning.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Face to face communication 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.
35	**Macmillan Cancer**	5	117	It is understandable that the guidance will not cover condition specific holistic needs assessments, in terms of recommending different assessments for different conditions.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within

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	Support			However, we would recommend that holistic needs assessments which are created for specific conditions, but could be repurposed for more general usage, should be taken into consideration. An example of this would be the widely used electronic Holistic Needs Assessment which was initially developed for cancer patients.	the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs 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.
36	**Macmillan Cancer Support**	6	All	Although it is helpful to have an understanding of the key questions which will inform new topics for the guideline, we would welcome a list of questions which will inform how sections of the existing guidance will be 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
37	**Macmillan**	6 to 7	131 - 182	There appears to be no question around bereavement services:	Thank you for your comment. Following

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	Cancer Support			how and when these should be available, and how they can be accessed. I think that further clarification around this should be included as a key question for the guidance.	consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.
38	**Macmillan Cancer Support**	6	139	This talks about holistic needs for supportive care of carers. The earlier definition includes bereavement in supportive care. Using this definition then assessment of bereavement needs for those affected by a death following a life limiting illness should be included in this 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.

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39	**Macmillan Cancer Support**	6	134-148	We would also recommend the inclusion of the following questions: • How should healthcare professionals be prepared/trained to undertake an HNA? • Which healthcare professional should undertake the holistic needs assessment? • What is the best method for ensuring that an HNA leads to greater access to supportive services (e.g. is this through the development of an individual care and support plan)?	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
40	**Macmillan Cancer Support**	6	142	This is not an easy answer. It is largely dictated by the patient's clinical condition and the stage they are at in their journey (see definition of supportive care on page 3). Also is there any evidence base to support a recommendation. The minimum should be that the needs are reviewed at least at every Multidisciplinary Team (MDT) meeting about the patient, or more frequently if the patient's clinical condition dictates. This makes	Thank you for your 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

ID	Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				the assumption that MDTs are held in secondary and primary care (GSF meetings) which can vary between 2 weekly to 8 weekly in some practices. Is there a role for the EPaCCS to be mentioned here. Patients should be followed up and assessed by their key worker whether this is DN or Community Matron etc Also if the patient is receiving Continuing Health Care then should this not be assessed every 3 months?	updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessments will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence. Information sharing across multidisciplinary teams and services is one of the key questions included in the scope. Any recommendation will be informed by available evidence. EPACCS may therefore be eventually considered as part of service delivery models in this area of enquiry, in accordance with available evidence.
41	**Macmillan Cancer Support**	6	144	In the dying phase, more frequent review are needed both to support the patient and their carers. From personal experience this review can vary from twice a day to every 72 hours, averaging once every 24 hours. From a guidance perspective, perhaps " Review frequently depending on the patient's clinical condition" (comment from GP) From my experience I would review daily even if phone review –	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and

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				if syringe driver then it may be twice daily (comment from GP)	palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessments will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
42	**Macmillan Cancer Support**	6	146	We tend to review this at every MDT meeting (comment from GP) Our DN's maintain contact if a GP doesn't but this is also discussed at our MDT (comment from GP)	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.
43	**Macmillan Cancer Support**	6	148	Suggest an additional question to ensure bereavement is adequately covered: when and how often should bereavement 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. We

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					will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.
44	**Macmillan Cancer Support**	7	152	Electronic Palliative Care Coordination and Support (EPACCS)	Thank you for your comment. Information sharing across multidisciplinary teams and services is one of the key questions included in the scope. Any recommendation will be informed by available evidence. EPACCS may therefore be eventually considered as part of service delivery models in this area of enquiry, in accordance with available evidence.
45	**Macmillan Cancer Support**	7	154	All of those settings mentioned– Also wherever the patient chooses	The revised scope includes location of services, for example place of care, on the list of key areas to be covered.
46	**Macmillan Cancer**	7	156	MDT in Secondary Care, Primary Health Care Team in Primary Care.	The revised scope will cover service delivery models for end of life care, including those covering both acute community and third sector

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	Support				settings, one of the areas to be addressed is 'multidisciplinary team composition'.
47	**Macmillan Cancer Support**	7	159	Supportive Care services should be OFFERED at point of Diagnosis or soon after, and **Anticipatory Care Planning** should be initiated. How can they be accessed? Via a key worker in hospital, via GP in Primary Care, or via CNS if specialist services are needed in Primary 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
48	**Macmillan Cancer Support**	7	161	24/7 District Nursing Service, appropriately trained OOH GPs, OOH Drugs access including opiate access, Social Care support, Equipment support including access to Oxygen, 24/7 Specialist Palliative Care Advice, Access to urgent hospice beds, Hospice at Home services (comment from GP). We have a real problem with personal care needs – so social care input for personal care would be ideal, but not the usual 3 calls a day at whatever time suits but tailored to the patient, so if they go to the toilet at 8am every morning then so be it (comment from GP).	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
49	**Macmillan**	7	167	Same as comment 6	Thank you for your comment.

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	Cancer Support				
50	**Macmillan Cancer Support**	7	169	Same as comment 7	Thank you for your comment.
51	**Macmillan Cancer Support**	7	171	Same as comment 8 plus OOH services	Thank you for your comment.
52	**Macmillan Cancer Support**	7	174	Once patient is recognised to be at End of Life	The draft questions for the guideline have been edited to reflect changes to the scope.
53	**Macmillan Cancer Support**	7	176- 178	**Non Specialist** – basic symptom control, District Nursing, Social Care, OOH Drugs access including oxygen, EPACCS, low level psychological and bereavement support. Personal Care – overnight support – may only need 2 nights but some patients are complex and may need anticipatory meds in the night. **Specialist** - complex symptom control, interventional procedures (e.g. transfusion, pleural tap, paracentesis), hospice care, complex psychological and bereavement support.	The draft questions for the guideline have been edited to reflect changes to the scope Information sharing across multidisciplinary teams and services is one of the key questions included in the scope. Any recommendation will be informed by available evidence. Recommendations on bereavement can be found in the 2004 guideline.
54	**Macmillan Cancer**	7	179	1. Effective and timely handover of clinical information and patients' holistic needs assessment/anticipatory care plans from Paediatric to Adult services.	Thank you for your comment. Following The draft questions for the guideline have been edited to reflect changes to the scope

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	Support			2. Communication of process to patient and family 3. Provide a point of contact for patient and family during the transition (could be a CNS) 4. Effective and timely communication to Primary Care 5. Ensure any necessary drugs are supplied during the transition and in reasonable amounts to ensure there is no break in End of Life care 6. Swift review by adult team (within 24 hours) as soon as care transition has occurred.	Additionally, 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).
55	**Macmillan Cancer Support**	8	183	Suggest adding as a main outcome "Anticipatory/Advance Care Plans" being in place as this would indicate good planning and preparation for high quality Supportive and Palliative Care.	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.
56	**Macmillan Cancer Support**	8	187	Suggest adding as a main outcome "Views and satisfaction of the patient's carers" which is a bit different from "those 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 after discussion with the Guideline Committee.
57	**Macmillan Cancer Support**	8	188	Suggest that based on the need to include the bereaved fully in this scope adding.......' including the bereaved', at the end of this 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. We will ensure consistency between the new

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					recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently a new overview diagram will be developed in line with the content and rational of the revised scope. The revised scope will not include bereavement support as an individual topic area but adopt a wider focus on service models that provide support for the carers or those important to the people accessing end of life services.
58	**Macmillan Cancer Support**	8	190, 191	These two outcomes could be considered as the same. If a patient does not die in their preferred place of death, then they have also failed to achieve their preferred place of care. The Term Preferred Place of care is also easier to communicate with patients rather than "Preferred Place of Death" so interpretation of these two terms by Health Care Professionals may be taken as synonymous.	These are the main outcomes. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee.
59	**Macmillan Cancer**	8	192	How can this be measured and do providers really care if their staff have job satisfaction or is it just a number crunching	These are the main outcomes. When the full review protocols are developed additional

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	Support			exercise (our DN's seem to spend more time filling in audit data than caring for patients).	outcomes may also be included after discussion with the Guideline Committee.
60	**Macmillan Cancer Support**	12	All	We would welcome more detail in this section on the context surrounding the use of the term rehabilitation. The term can be used in several different ways, and a definition for the types of rehabilitation that this guidance will cover would be beneficial.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the context section of the scoping document has been amended to reflect these changes.
61	**Macmillan Cancer Support**	12	258	Need to add ' and those important to them' in this sentence so it's clear the context is 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and

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					palliative care for adults with cancer, they will remain within the published guideline. Consequently, the context section of the scoping document has been amended to reflect these changes.
62	**Macmillan Cancer Support**	12	268-269	The Guidance states that *"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 true to an extent, but there are some care needs which may fall under the banner of supportive care which are specific to cancer patients – in particular the management of health consequences of cancer and its treatment, which include mental health issues and sexual dysfunction, incontinence and bowel problems and difficulty swallowing. Other condition areas which will also be covered by this guidance will also have condition specific consequences, including diabetes, renal disease and heart disease. Whilst the guideline does include rehabilitation, there is no mention of management of consequences of cancer and its treatment (or any other condition). There is also no mention of the needs of adults who have consequences of treatment as a result of treatment in childhood. There are some NICE cancer guidelines which include reference to consequences of treatment (eg Prostate 2014), there 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the context section of the scoping document has been amended to reflect these changes. 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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				nothing generic in any NICE guideline which covers consequences of treatment management across the board for cancer patients. The update of this guideline provides a major opportunity to address this huge gap, but as it stands the scope does not extend beyond the 2004 guideline. Therefore, we would recommend that the scope is adapted to include reference to consequences of treatment. We feel that this guideline should include an analysis of existing services to support people experiencing the consequences of long term conditions and their treatment, including cancer, and determine whether existing mainstream services are currently equipped or commissioned to provide the right support.	
63	**Macmillan Cancer Support**	12	279	Supportive care should also explicitly cover bereavement, using the earlier definition.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					Consequently, the context section of the scoping document has been amended to reflect these changes. Recommendations on bereavement can be found in the 2004 guideline.
85	Marie Curie	General	General	Overall Marie Curie supports the underlying notion that supportive and palliative care services go together, that the scope of individuals who receive these services should be widened beyond those with cancer, and that provision of this care should be based on individual needs as determined by comprehensive holistic needs assessment, not the stage of disease or prognosis (lines 331-334). It is our view that the concept of 'end of life care' as a service in and of itself - which may be variably interpreted as applying to the last year or the last days of life – is often unhelpful, and will increasingly become redundant when adequate provision for supportive and palliative care is defined. This is particularly true given our knowledge that prognostication (i.e. estimated length of survival) in most conditions is deeply problematic – not only technically, for the doctor, but emotionally, for the patient and their family. This problem is rooted in the fact that even the most accurate estimates are probabilistic, and	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				based on information about populations rather than that particular individual. It follows that service provision tied firmly to prognosis cannot be accurately targeted. We therefore welcome this approach to service delivery, which should consistently be based on individual needs rather than proximity to death.	
86	Marie Curie	1	12	We propose to replace 'life-limiting conditions' to 'other conditions in need of this care', or to include a comprehensive definition of life-limiting.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The 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 wording in the scope has now been amended to state: progressive life limiting conditions.
87	Marie Curie	1	20	It should be sufficient to say: 'Healthcare professionals in primary	Thank you for your comment. The scope states

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				and secondary care' to make clear that the guideline is applicable to all healthcare professionals. The concept of a generalist compared to a specialist healthcare professional is peculiar to policy in palliative care and can be unhelpful (for example, it seems odd to refer to a cardiologist as a generalist, but according to this division this is what they would be if they lacked specialist training in palliative medicine). We have concerns that applying the term 'generalist' to a professional on this basis may add to confusions about roles and responsibilities.	both generalist and specialist with the intent to be comprehensive, however 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.
88	Marie Curie	1	26	We suggest amalgamating these lists (lines 20-29). We are unclear why there is a distinction between 'who this guideline is for' and who 'it may also be relevant for' – surely it should aim to be relevant for all the listed groups?	Thank you for your comment. Guideline scopes are drafted to a template provided by NICE the section on 'who the guideline may also be relevant' is reserved for groups or organisations that are outside of NICE's influence or remit but who may also be interested in the guideline. This list could include groups or organisations that will not be acting on the recommendations but may be affected by them – for example, private sector or voluntary organisations, or people working in related services.
89	Marie Curie	2	38-44	We welcome the special consideration that this guideline will give to groups that face unequal access to services. However, we are	Thank you for your comment. We will discuss the equalities issues you raise with the

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				concerned that those listed are apparently a random selection from a wider group. Research by the London School of Economics and Political Science [Dixon, J et al. (2015) Equity in the provision of palliative care in the UK: Review of evidence] found that inequalities of access to palliative care services exist for people who: have a condition other than cancer (and rare conditions in particular); are aged 85 years or over; are from a Black, Asian or minority ethnic background; live in deprived areas; are single or live alone. We would welcome special consideration of how services can be equitably delivered to these groups.	guideline committee who will consider the needs of these populations in terms of recommendations for the delivery of services at the end of life.
90	Marie Curie	12-13	260-277	We are very supportive of these sections on supportive care and palliative care and feel they provide a comprehensive description 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
91	Marie Curie	3	Table – 'Palliative care'	We suggest that the definition of palliative care echoes the WHO definition and the description set out in the Context section of this document (270-277) so that it reflects the holistic nature of this care, and its suitability early in the course of illness alongside	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We

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				investigations and therapies to prolong life. We have some concern that the definitions as set out here suggest an unhelpful division between supportive and palliative care in practice. We oppose the phrase 'care towards the end of life' for the reasons set out in comment 1. There is the potential for serious confusion about professionals' roles and access points into services if this terminology is to be used. Suggest replacing existing definition with: 'Active, holistic care of people with advanced, progressive illness that aims to provide relief from pain and other distressing symptoms, integrate the psychological, social 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.'	will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the 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.
92	Marie Curie	3	Table – 'Non-specialist palliative care'	Within the context of this guideline and its focus on service delivery, we suggest that an approach which focuses on roles and responsibilities rather than a definition of care would be more helpful. As set out in comment 3, the generalist or non-specialist/specialist divide, when used in this way, is unique to palliative care and may lead to confusion about who is responsible for which aspects of a person's care if not given further explanation. The Association of Palliative Medicine [2008, Palliative Medicine in Supportive, Palliative and End of Life Care: A Strategy for	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				2008 to 2010; p.18.] sets out a description of the role of the doctor in palliative medicine (based on consensus of the APM membership) as such: 'All doctors, whether general practitioners or specialists in any setting, hold clinical responsibility for the treatment of their patients and have a role in providing medical leadership in their patients' palliative care'. This contrasts to the role of the palliative medicine physician, whose core role includes the medical assessment of distress, symptom management and care for patients with complex clinical needs due to advanced progressive or life threatening disease, and medical leadership within palliative care services. We encourage NICE to consider adopting this sort of approach.	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.
93	Marie Curie	3	Table – 'specialist palliative care'	We welcome this definition of specialist palliative care. We would like to emphasise that specialist palliative care should be considered as the safety net available to everyone whose needs for palliative care cannot be met in any other context.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the 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.
94	Marie Curie	5	109	We acknowledge the fact that there is limited conventional evidence on the efficacy of complementary therapy services for people with palliative care needs, and recognise that some complementary therapies may pose risks to patients, as well as benefits. However, for specific therapies (such as acupuncture used for breathlessness) there is a growing evidence base which we suggest may warrant future consideration. We suggest that it should be acknowledged (as it is in the 2004 guideline) that many NHS and voluntary sector organisations offer complementary therapy services and that it is important for patients to be empowered to make their own decisions about complementary therapies and therapists through the provision of high quality information.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
95	Marie Curie	5	112-115	We strongly oppose the removal of user involvement and information from the new guideline as there are all important aspects of care that those with supportive and/or palliative needs should be able to expect services to deliver. We are not aware of these aspects of care being sufficiently covered 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not

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					updated within CSG4 Improving supportive and palliative care for adults with cancer, they 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.
96	Marie Curie	5	114	We are also strongly opposed to the removal of social support services, and actively encourage the inclusion of services that seek to integrate the delivery of health and social care. Considering the wider policy environment, promulgating the distinction between the two is likely to make the guideline obsolete in the future.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
97	Marie Curie	6	123	We are very supportive of the inclusion of economic analyses in the development of the guideline. A lack of valuable economic data has historically hindered progress in service development.	Thank you for your comment.
98	Marie Curie	6	134…	In our view, holistic needs assessment for supportive and	Thank you for your comment. Following

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				palliative care should be combined and there is no obvious merit in this division. Combining the two is more coherent with the approach set out in the rest of the guideline, which places individual need before prognostication, and it avoids the potential errors where an individual misses out on appropriate care because the wrong tool is used due to difficulties with prognostication.	consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs 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.
99	Marie Curie	6	144-148	We emphasise that ultimately, how often supportive and palliative care needs should be reviewed must be based on individual needs, rather than prognosis.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					Consequently, 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.
100	Marie Curie	8	186	This should include Patient Reported Outcome Measures and qualitative data.	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.
101	Marie Curie	8	General	Another important population-level outcome should be coverage, ie. the proportion of people with needs that are eligible for supportive and palliative care (including families and carers) who receive adequate care.	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.
102	Marie Curie	4	65	The document does not appear to comment on tools/strategies for the identification of patients who may need to be assessed.	Thank you for your 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

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					updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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 for a progressive life-limiting condition.
103	Marie Curie	General	General	We feel that there is insufficient consideration of the needs of families and carers throughout this document. Supportive and palliative care services should formally be required to support families, carers and those important to the person needing 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. On the revised scope, the list of people who the guideline is for, includes people using services, families and carers and the public. Additionally, the views and satisfaction of those receiving end of life care and of those important to them is included on the list of main outcomes.

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104	Marie Curie	General	General	We are pleased to see the inclusion of the 5 Priorities of Care.	Thank you for your comment.
221	**National Institute of Medical Herbalists (NIMH**			Medical Herbalists support people suffering from a broad spectrum of chronic and degenerative health conditions. Medical Herbalists support and enhance the mainstream healthcare offered to people living with cancer, their carers, families and friends. The objective is to provide care and comfort for people on their cancer journey, by providing easy access to specialist information, help and herbal medicines that can help with the side-effects of treatment, relieve anxiety, and mental and emotional health issues surrounding chronic illness. Medical Herbalists help to improve quality of life, to promote well-being and to encourage a strong resolve to take measures to enhance health and boost their morale. Many herbalists currently work for Independent charities that work alongside the clinical care of the NHS in partnership with hospital and community healthcare services. Cancer continues to be a priority for the NHS, and the last decade has seen real progress in the diagnosis and treatment of many different types 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. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				Survival rates in this country are now significantly better than before, but the number of cases is rising each year and national resources are stretched and thus there is an unsatisfied need and a growing demand for the support Medical Herbalists can provide.	
222	**National Institute of Medical Herbalists (NIMH**			One medical herbalists working at a cancer charity centre says: "I work with each person to establish where they are vulnerable, experiencing depleted energy/fatigue, lacking in important nutrients & I work with them to make good their needs where identified; also to nourish & support their energy reserves, resistance to stress & their digestive system health. The aim is to enable their body to have improved resilience using health promotion and targeted support. "I simply work to support the individual toward better health. Their body is then potentially in a better position to heal from whatever their particular ailment."	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
223	**National Institute of**	4	62	Care is provided to NHS patients. NHS patients may access care in a variety of settings. Guidelines need to	Thank you for your comment. Following consideration of all stakeholder comments the

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	Medical Herbalists (NIMH			cover all settings and not be limited to NHS settings. Clinical/supportive care is care irrespective of where it takes place or how it is funded. Clinical guidelines should aim to cover all settings. Private sector healthcare should be included. Clinical care does not stop when it occurs outside the NHS. NICE guidelines should not be for the NHS commissioning only. They are intended for patients, their families, healthcare professionals in private settings and all involved in the health and well-being of the population. All of those groups may access different types of care and at different times. They need to know that reliable information is available and how to access reliable information.	guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
224	**National Institute of Medical Herbalists (NIMH**	5	108	It would be useful to see the rationale for removing these sections. Communication is vital in all aspects of care and should not 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. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will

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					remain within the published guideline. 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
225	**National Institute of Medical Herbalists (NIMH**	5	109	Removal of complementary medicine services. About 20% of the population report accessing some form of complementary healthcare. Patients report that they derive benefit from this treatment. They will find removal of complementary medicine unacceptable, and their choices, preferences and specific needs will be adversely affected	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
226	**National Institute of Medical Herbalists (NIMH**	5	109	Patients access complementary medicine, often being directed to specific clinics and practitioners or practitioner associations through information from their hospital/ oncologist/ specialist nurse. Removal of this may lead to patients seeking complementary medicine from unknown sources.	Thank you for your 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

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				Patients use herbal medicine and many self-medicate, some take herbal medicines without the knowledge of their cancer care team, or at the suggestion of their care team. Patients would benefit from being directed to expert and reliable sources for support through their treatment; support from professional medical herbalists would ensure that those taking herbal medicines take herbal medicines which will not interfere with medications prescribed by e.g. their oncologist. Medical herbalists are likely to offer support with side effects of radio and chemotherapy. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3065283/ http://www.ncbi.nlm.nih.gov/pubmed/25387799 http://www.ncbi.nlm.nih.gov/pubmed/23040545 http://www.ncbi.nlm.nih.gov/pubmed/21185719	updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
227	**National Institute of Medical**	5	109	Original guidelines give reasons why patients needs are not always met. These included patients and carers being unaware of the existence of services that might help them	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within

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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	Herbalists (NIMH			and professionals being unaware of the potential benefits of existing services, and consequently not offering access or referral to them. If complementary medicine is removed, the problem of not knowing about a service which may benefit patients and their carers/families may be exacerbated.	the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
228	**National Institute of Medical Herbalists (NIMH**	5	109	Removal of complementary medicine runs counter to government policy and the development of Accredited Registers. The Health and Social Care Act (2012) extended the role of the Professional Standards Authority (PSA) to accredit voluntary registers through 'right touch' regulation. Removing CAM from the NICE guidelines undermines the PSA Accredited Register scheme and is a disincentive for the registers already accredited by the PSA to renew accreditation, and for those applying for accreditation to proceed. In the 2015 PSA report to parliament specific mention was made of the benefit offered by complementary medicine for patients, and how the complementary medicine workforce can contribute to achieving the aim of improving the nation's health.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
229	**National Institute of**	6	124	Economic aspects are important but clinical guidance must be holistic and patient centred, taking into account the	Thank you for your comment. Following consideration of all stakeholder comments the

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	Medical Herbalists (NIMH			needs of the individual patients.	guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
230	**National Institute of Medical Herbalists (NIMH**	8	183	Patient reported outcomes need to be inclusive of all treatment, care and support. The National Cancer Patient Experience Survey focuses on medical treatment. And does not include e.g. spiritual support. What tools will be used to asses satisfaction with complementary medicine support? Complementary medicine is well known to be under-researched. Lack of funding is often cited as the reason for this but is a valid reason. 20% of people access complementary medicine and report benefit. How will this patient reported outcome and patient view/satisfaction be included in the Guidelines and halt the exclusion of complementary 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. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, these are the main outcomes. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee.

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231	**National Institute of Medical Herbalists (NIMH**	8	186	We recognise the existing problem of lack of evidence in evaluating cost effectiveness in supportive and palliative care in general. We would welcome participation in research to examine whether professional treatment with herbal medicine can improve outcomes for patients with cancer, undergoing cancer treatment and can save money for the NHS in the care of people living with cancer.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
232	**National Institute of Medical Herbalists (NIMH**	8	186 / 187	"A year ago my brother died suddenly of a head injury and it broke my heart. Honestly it felt like physical pain. My herbalist showed great wisdom, experience and compassion and gave me a mixture of herbs for shock and grief. That simple mixture of herbs helped make the unbearable endurable, as did the care of the kind beautiful herbalist." Patient identity withheld for confidentiality purposes	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
233	**National Institute of Medical**			We feel the composition of the GDG should include a broader range of representatives providing supportive care i.e. more than one representative from Allied Health, a	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We

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	Herbalists (NIMH			representative from complementary medicine, a representative from the charitable sector and a patient who has accessed complementary medicine for supportive care.in	will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the constitutency of the guideline has been expanded to include Acute Medical clinician and a geriatrician.
401	**NHS England**	1	13	I was on the editorial board for original cancer version and it spanned whole pathway – not just palliative care and end of life. The scope for this version is not clear The 2004 version was a cancer-focused guidance so starting from diagnosis, or even pre-diagnosis in the form of supportive care, was appropriate. This is a less useful approach for non-cancer conditions, and things have moved on considerably since 2004.	. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
402	**NHS England**	3	48	If we are including 'supportive care' within scope, then this defines supportive care as from diagnosis. If so, this scope needs to relate directly to the relevant pieces of the new National Cancer Strategy and its deliverables and timescales as many of	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

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				the topics overlap. Acknowledge that the scope is for all conditions. Also palliative care and end of life care recommendations are made in the Strategy and need to link I really don't think the use of the term 'supportive care' is helpful – given that the guidance has to limit its scope, a focus on supportive care appears to be at the expense of end of life care, so it's not helpful.	life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, 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.
403	**NHS England**	4	65	There is an accepted and national HNA for cancer that is not mentioned. Mandated as part of the cancer recovery package Although this is a clinically focused approach which sits oddly with service guidance, and has overlap with the existing NICE guidance on patient experience. Quality Statement 10 of the NICE patient experience Quality Standard states "Patients have their physical and psychological needs regularly assessed and	Thank you for your comment. Since the revised scope will foucs on service delivery, holistic needs assessment is no longer a priority area for the guideline and 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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				addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety."	
404	**NHS England**	5	102	Needs to link with HNA mentioned in comment 3 – accepting that condition specific assessment tools can't all be detailed (See Second comment above)	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessment is no longer a priority area for the guideline and will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
405	**NHS England**	5	109	Whilst the evidence is varied, complementary therapies are widely used and should be managed with good advice/guidance. Should not be removed although would probably not be viewed	Thank you for your comment, Complementary therapies will remain in the published guideline.

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				a high priority	
406	**NHS England**	5	110	Must acknowledge the wide body of evidence that is available	. The Guideline committee will review all published evidence pertinent to the revised scope. Additionally, 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.
407	**NHS England**	5	113	Social care is such a vital part of supporting people with LTC – it should be referenced in the guidance	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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408	**NHS England**	6	132-148	Already answered for cancer	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessment is no longer a priority area for the guideline and will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
409	**NHS England**	7	149-163	Parts of this covered for cancer by Strategy	Thank you for your comment. We will ensure that, where relevant, the Cancer strategy is brought to the committee's attention.
410	**NHS England**	14	339	If the title of this guidance remains 'supportive and palliative care' then there is no reference to National Cancer Strategy in Context	Thank you for your comment. Thank you for your comment. Following consideration of all

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				or Policy, regulation and commissioning This whole section should be on 'end of life care' and the term 'end of life care' should be used here (i.e last year(s) of life, not last days of life)	stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The 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. The title of the guideline has been changed to: End of Life Care: Service delivery for adults in the last year of life.
411	**NHS England**	15	348	If the title of this guidance remains 'supportive and palliative care' then guidance is expected to be published in 2018. 5 year Cancer Strategy implementation will be well underway by then (2015-2000) and deliverables will be	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

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				interdependent and need to relate to each other See comment about in relation to terms used.	life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. We will ensure that, where relevant, the Cancer strategy is brought to the committee's attention The title of the guideline has also been revised to: End of Life Care: Service delivery for adults in the last year of life.
412	**NHS England**	4	80	There are some hospices that are still NHS funded so need to be clear that these are covered within this guidance.	One of the key areas the revised scope has highlighted for inclusion is service delivery models for end of life care, including those covering both acute community and third sector settings (for example Hospices in receipt of NHS funding).
413	**NHS England**	7	170	Add to this section "or in hospice care"	One of the key areas the revised scope has highlighted for inclusion is service delivery

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					models for end of life care, including those covering both acute community and third sector settings (for example, hospices in receipt of NHS funding).
414	**NHS England**	6	136 and 138	How will this tool integrate with other assessment tools used in the generalist environment so the patient is not being asked the same questions twice	Following revisions to the scope with a stronger focus on service delivery, holistic needs assessment is no longer a priority area for the guideline and will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
415	**NHS England**	7	155	Or primary care?	One of the key areas the revised scope has highlighted for inclusion is service delivery models for end of life care, including those covering both acute community and third sector settings. This will address several areas, including location of services, for example place of care.
416	**NHS England**	general	general	Survivorship needs to be considered in the plan	Survivorship will not be specifically addressed by any review question as it is outside the remit of the guideline.

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417	**NHS England**	general	general	The assessments need to link to the diagnosis and action about severe frailty as a predictor of a need for palliative and supportive care.	Thank you for your comment. The included population of this guideline are those that have received a diagnosis and are thought to be in their last year of life. As this is service delivery guidance no clinical reviews will be included. However if published evidence is identified for service delivery models that detail specific populations such as those with severe frailty, this will be reviewed by the guideline committee and recommendations developed.
418	**NHS England**	3	47	Need to consider education and training needs of those delivering non- specialist palliative care, especially in community and primary care.	Thank you for your comment.
419	**NHS England**	1	4 and 11-12	The title 'Supportive and palliative care: service delivery' is very unhelpful, as the term 'Palliative and End of Life Care' is now commonly used and is what this service guidance should be updated to reflect. It will also help to emphasise the fact that this guidance (unlike the 2004 guidance) is not confined to 'adults with cancer' but refers to 'adults with life-limiting conditions' – though I would add the word 'progressive' (to reflect that this is not about stable chronic conditions) – i.e. 'adults with progressive life limiting conditions'. If the term 'supportive' has to be retained in the title for historic reasons, then I would suggest the title is expanded to 'Supportive, palliative and end of life care: service delivery' as the new title	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. The revised title of the guideline is: End of life care: service delivery for adults in the last year of life.

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420	**NHS England**	2-3	45-48	The definitions here should include 'end of life care' and should reflect (or at least cross-refer) the definitions in the glossary of 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) given that NICE as a signatory to this report in which the signatories committed to using the same glossary as far as possible. The term 'supportive care' is not common parlance anymore and risks adding further confusion about terminology and semantics, especially if the table excludes 'end of life care'. Whatever criticisms there may be about 'end of life care', the term exists and is widely known and used, so it should not simply be omitted. Clarification that the term 'end of life care' refers to last year of life (rather than last days would be important) – the published GMC definition should be used here.	. 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.
421	**NHS England**	4	65-76	Although not inappropriate in itself, I don't think 'holistic needs assessment' is a new priority area to include in this service guidance. There is also quite an overlap with NICE guidance and Quality Standard on patient experience.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will

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					remain within the published guideline. Consequently, holistic needs assessment is no longer a priority area for the guideline and will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
422	**NHS England**	5	102	See above comment	Thank you for your contribution to the consultation process.
423	**NHS England**	5	114	I don't understand the rationale for removing 'social support services' when this is such a critical component of palliative and end of life care.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. .

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424	**NHS England**	12	252-255	There should be an explicit to the national report 'One Chance to Get it Right' here as this was a system-wide response to the review of the Liverpool Care Pathway, and both NICE and NHS England were signatories.	The context section of the scoping document has been amended to reflect these changes.
425	**NHS England**	12	260-267	This is precisely why I think the term 'supportive care' should be removed from this service guidance, or at least, its prominence reduced. Its association with cancer, though not inevitable, makes this guidance less accessible to professionals, service providers and service users of non-cancer conditions.	Thank you for your comment. The context section of the scoping document has been amended to reflect these changes.
426	**NHS England**	13	285-287	There has to be a reference to the term 'end of life care' – simply ignoring its existence creates a confusing vacuum for people	The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.
427	**NHS England**	General	General	We welcome this update covering additional conditions to cancer as the care for those who die of kidney failure is variable and can be distressing for patients and their families	Thank you for your comment.
428	**NHS England**	5	112	Please explain why the new published guideline will remove user involvement in planning, delivery and evaluation services, user involvement being so important	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and

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					palliative care for adults with cancer, they will remain within the published guideline. 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.
429	**NHS England**	7	150	The ranges of questions ask 'what is the best model…?' We suggest that you change this to 'models' as there may be more than one and it is restrictive to pre-determine that there is only one model which is best.	All questions will be refined when drafting full review protocols in conjunction with the guideline committee. Recommendations will be drafted based on the best available evidence.
430	**NHS England**	10	228	NICE Chronic Kidney Disease Quality Standards (QS5) will also need updating – they include end of life care	Thank you for your comment. We will pass your comment to the NICE Quality Standard team for their consideration and action.
431	**NHS England**	8	1.6	We would welcome clarity on what these guidelines will a) produce or b) lead to in terms of advice and guidance on supportive and palliative care for people with renal disease. For people who opt for 'conservative' or supportive care, it is likely that they will die within a few months to two years, while those who discontinue dialysis will die within a few days. We believe that both groups and their families deserve and need planning,	Thank you for your comment. Thank you for your comment. Following con The aim of the guideline is to describe models of care and service delivery arrangements that need to be put in place for people as they approach the end of life. This guideline aims to describe end of life care services for all

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				counselling, specialist pain management and many other services either in the community or in hospital settings and would like to see a statement by NICE on its intentions for them.	conditions and diseases, including renal disease. We will be unlikely to make disease specific recommendations, pending available evidence.
432	**NHS England**	4	70	Considering the scope of the definition of supportive care on page 3 vocational and occupational (including educational) needs should be included in the bulleted list here	Following revisions to the scope, 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.
433	**NHS England**	4	82	There is a need to consider the variation that exists in the age that young people will transition into adult services – the lower age limit is not always 18 years (often 16) and dependant on the wishes and needs of the young person in the context of local services could be younger than 16 years. The guidance needs to allow for local flexibility to enable services to respond to the individual needs of young people	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).
434	**NHS England**	5	89	See comment 2	Thank you for your contribution to the consultation process.
435	**NHS England**	5	96	Rehabilitation services should include vocational and occupational outcomes	Thank you for your comment. The scope includes a list of the main outcomes that will be considered for the guideline. When the full review protocols are developed additional outcomes may also be included after discussion

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					with the guideline committee.
436	**NHS England**	5	100	See comment 2	Thank you for your contribution to the consultation process.
437	**NHS England**	5	104	Sharing of information between MDTs must include people using services and people important to them (consent permitting) as part of the MDT.	Thank you for your comment. The guideline committee will consider the evidence and make recommendations for the populations relevant to the guidleine, and this includes people using services, families, carers and the public.
438	**NHS England**	5	112	Co-production in service design and evaluation is vital for person centred services and therefore should be included	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, User involvement in planning, delivering and evaluating services has been

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					covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.
439	**NHS England**	5	114	Social support services are important part of supportive care and should not 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
440	**NHS England**	6	123	The economic value of rehabilitation in supportive care should be considered	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 rehabilitation but we will look at different ways to deliver care, which may or may not include rehabilitation.

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441	**NHS England**	7	152	See comment 6 re including people who use services in information sharing	Thank you for your contribution to the consultation process.
442	**NHS England**	7	167	See comment 6	Thank you for your participation in the consultation process.
443	**NHS England**	12	269	Vocational/occupational and education outcomes must be considered here	Thank you for your comment. The remit and scope of this guideline has been changed and the context section of the scoping document has been amended to reflect these changes. The guideline will now focus on the delivery of services to adults in the last year of life.
444	**NHS England**	general	general	Rehabilitation is a vital part of both supportive and palliative care for people with life limiting conditions and must be considered in all care pathways and individual care plans to enable people to achieve the goals that are important to them and the people who are important to them.	Thank you for your comment. Since the revised scope now focuses on service delivery, this guideline will not be looking at individual interventions such as rehabilitation but we will look at different models of service delivery, which may or may not include rehabilitation.
445	**NHS England**	general	general	There is no reference to the National Cancer Strategy and implementation of the recommendation included in that strategy. There will be significant overlap and this guidance will need to make reference to and recognise these areas.	Thank you for your comment. We will ensure that, where relevant, the Cancer strategy is brought to the committee's attention life.
446	**NHS England**		52	**Groups that will be covered** Will the scope explicitly exclude individuals and those important	Thank you for your comment. Following consideration of all stakeholder comments the

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				to them who live with a life limiting mental health condition/s which may lead to an earlier or more sudden death than in peers not living with that condition/s?	guideline will focus on service delivery within the last 12 months of life for all conditions. All life limiting conditions will include populations who live with a life limiting mental health condition.
447	**NHS England**		113, 4	**Areas from the published guideline that will be removed** If face to face communication is being removed from the guideline, are there alternative ways to signpost resources which help with, for example, advance care planning conversations? "The proportion of GPs reporting they had never initiated a conversation with a patient about their end of life wishes from more than a third (35%) in 2012 to a quarter (25%) in 2014". Source: National End of Life Care Intelligence Network, What we know now 2014, page 15, 2.6.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, 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.
448	**NHS England**		131-182	**Key Issues and Questions** When determining the best way to share information between	Thank you for your comment.

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				professionals, it will be important to be aware of the existence of and ambitions for Electronic Palliative Care Coordination Systems (EPaCCS) and the need to deliver the NHS Five Year Forward View, supported by the digital agenda set out in Personalised Health and Care 2020 This supports realisation of Item 17 on Page 19 of Delivering the Forward View: NHS planning guidance 2016/17-2020/21, published December 2015. "How quickly will you implement your local digital roadmap, taking the steps needed to deliver a fully interoperable health and care system by 2020 that is paper-free at the point of care? How will you make sure that every patient has access to digital health records that they can share with their families, carers and clinical teams?"	Information sharing across multidisciplinary teams and services is one of the key questions included in the revised scope. Any recommendation will be informed by available evidence. EPACCS may therefore be eventually considered as part of service delivery models in this area of enquiry, in accordance with available evidence. The development and delivery of electronic information systems is beyond the remit of this guidance.
449	**NHS England**		180	Where an end of life care service is mentioned, can it always include the word care, not just end of life?	Thank you for your comment. Thank you for your suggestion this has been amended throughout the scope where appropriate.
450	**NHS England**	General	General	Are staff psychological safety, support and Resilience evident enough? (Ambition for Palliative and End of Life Care 5, All staff are prepared to care)?	Thank you for your comment Concerns related to staff safety and support will have to be considered and managed on an individual setting basisTthis is outside of service

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					delivery guidance and therefore beyond the revised scope of this guideline.
451	**NHS England**	General	General	Is there scope for an additional single/overarching or linking guideline on a page?	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
454	**NHS England**	General	General	I think the subsequent aims of the guidance (e.g. What is the best model for planning/co-ordinating supportive/palliative care services?) are highly ambitious. I find it difficult to imagine that one answer to the above questions would be found that would be applicable to all patients at all ages at all stages in all diseases in all geographical areas supported by robust evidence and I think it inevitable that significant provisos or alternatives would need to be provided within the guidance. This view	Thank you for your comment. The scope has been revised to focus on service delivery in the last 12 months of life. The guideline committee will agree protocols to direct the search for evidence. Published evidence of service delivery models will then be critically appraised and recommendation made based on what is identified.

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				is supported by CKMAPPS data (above). I would suggest defining principles underlying how to achieve such aims and minimum acceptable standards (perhaps including working examples) would be more realistic, achievable and generally applicable.	
455	**NHS England**	General	General	I disagree that social support services should be removed from the existing published guideline. I think that this flies in the face of current initiatives to have seamless transition between health and social care. Those with life limiting conditions or at the end of life are among the most in need of social care and to remove this from the guideline would risk driving co-operation between health and social care providers and would miss an opportunity to define the minimum level of social care that these patients might expect to receive	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
456	**NHS England**	General	General	I disagree that the scope should remove from the existing published guideline current evidence and recommendations for direction and design of future research. I think the drafting of the guideline should lead to a thorough systematic review of available evidence and I am certain there will be areas which do not have sufficient evidence on which to give anything other than opinion-	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and

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				based guidance. I believe the omission of a section outlining the most important areas where evidence is lacking would be a missed opportunity to develop the field and shape effective research for the next generation of service users.	palliative care for adults with cancer, they will remain within the published guideline. Additionally, 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.
457	**NHS England**	14	333-324	I welcome the review of this guideline, particularly the recognition that palliative care should be extended beyond its traditional boundaries of managing cancer patients in the last 12 months of life and the explicit recognition that there has been progress in the management of patients with advanced and end stage kidney disease. This obviously reflects much hard work within the specialty. However, recent work within our specialty (CKMAPPS; a NIHR-sponsored UKCRN portfolio study) has shown that effective palliative care is delivered to CKD patients across the country, but using different models of service delivery and co-ordination (see below).	Thank you for your comment.
458	**NHS England**	3		I particularly welcome the efforts to clearly state what	Thank you for your comment.

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				supportive and palliative cares are, and I think these definitions will be very helpful for specialists and non-specialists to refer to in the future.	
351	NORTH LONDON HOSPICE	3	47	Differentiation between Supportive Care and Palliative Care difficult to understand, particularly for those outside the medical domain. If we are providing 'holistic care' we shouldn't be differentiating. We are seeing patients in context of their eco system/their relationships. The support system stated under palliative care may be provided by those important to them stated under supportive care, for example. All parts of the system needs support. I think if it was one definition it would assist MDT working for the whole patient/carer system. It would make MDT working more 'systems focussed'	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The 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.
352	NORTH LONDON HOSPICE	4	61	re above - more of a holistic language would make this more accessible to those who do not have NHS funding, e.g. adult care involved in end of life.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus

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				Patients and carers wouldn't have to navigate 2 language systems across NHS and social care	on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
353	NORTH LONDON HOSPICE	4	65	Is this 'needs' or 'strengths'?	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will

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					remain within the published guideline. Consequently, holistic needs assessment is no longer a priority area for the guideline and will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
354	NORTH LONDON HOSPICE	4	66	should we be aiming for one collaborative tool, that is holistic, addresses the system, is a stage/change tool. Please see Outcome Stars used in other domains of work. NLH currently exploring development of an End of Life Star (would not be title). This would not just be a measure of static points but a tool to enhance conversation and mark change even within a diminishing window of opportunity.	Thank you for your comment.
355	NORTH LONDON HOSPICE	4	70	list needs to include 'relational wellbeing' i.e. this is different to 'social', 'psychological' and 'emotional'	Thank you for your comment.
356	NORTH LONDON	4	71 onwards	Need to include 'Relational' wellbeing. This is different to social, emotional and psychological. Do	Thank you for your comment.

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	HOSPICE			we need to capture diverse experience (how does this list orientate professionals to attend to race, sexual orientation age/life stage?)	
357	NORTH LONDON HOSPICE	6	134	(See P4 Pt 66 above). Need to develop new collaborative tool, that is tangible and owned by service users (i.e. not something to guide professionals work). Use and timing (review) of tool should be worked out through user consultation	Thank you for your comment.
358	NORTH LONDON HOSPICE	7	150	Services need to be planned with social care	Thank you for your comment.
359	NORTH LONDON HOSPICE	8	186	Patient and Carer/significant other outcomes - again if we are using terms such as holistic, we have to refer to what is around the patient as outcome, e.g. for carer will affect patient outcome. If we don't always pair this, it leads to services that only focus on patients and identifies solutions in professional systems	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.
360	NORTH LONDON	8	192	need to include volunteers	Thank you for your comment. These are the main outcomes. When the full review protocols

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	HOSPICE				are developed additional outcomes may also be included after discussion with the Guideline Committee.
361	NORTH LONDON HOSPICE	12	249	good to have context at the beginning as a 'context' to the document	Thank you for your comment. The guideline's scope is based upon a standardised NICE template. We will pass your feedback on to the NICE editing team.
142	**Northern England Strategic Clinical Networks (NESCN)]**	1	11	We welcome extending the population as this is appropriate to the work of specialist palliative care teams and will enable non-cancer patients to benefit from the same levels of support and care as those with cancer.	Thank you for your comment.
143	**Northern England Strategic Clinical Networks (NESCN)]**	4	73	Holistic assessment with the distress thermometer can be a very valuable process, when implemented well. Adequate assessment of psychological wellbeing needs supplementary screening questions/tools. Level 2 training, as outlined in the Peer Review Measures, supported with ongoing psychological supervision, can enable development of the appropriate skills in this area.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					Consequently, 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.
144	**Northern England Strategic Clinical Networks (NESCN)]**	5	88	We welcome inclusion of people at risk of complex bereavement in this scope as clinically it is recognised as an important area of need	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.
145	**Northern England Strategic Clinical**	5	93	The outline of a 4 level model for professional psychological support has been enormously useful in communicating the need for every health and social care professional to share responsibility for psychological care and of the need for people with moderate to severe psychological distress to be referred to	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new

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	Networks (NESCN)]			appropriately qualified and skilled professionals. There is considerable overlap between the levels in the existing model and some revision is timely. Regionally and nationally there are many practitioners now trained in cognitive therapy "first aid" skills,(a level of training between levels 2 & 3), who provide very valuable support to patients. A local example of research, evidencing both clinically and statistically significant reduction in anxiety, through intervention at this level, is Heslop, K (in preparation).	recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, psychological support 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	**Northern England Strategic Clinical Networks (NESCN)]**	5	102	We welcome inclusion of holistic needs assessment as clinically we have found it is beneficial for people implementing this to be trained in level 2 psychological skills for screening, assessment and basic intervention. Holistic assessment and screening for psychological distress can usefully be carried out in the same contact with the patient.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs 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.
147	**Northern England Strategic Clinical Networks (NESCN)]**	5	103	Clinically it is recognised that carers and those important to the patient also have needs that should be assessed, and this has to be formally recognised in commissioning and providing support services and resources	Thank you for your comment. . In the revised scope carers are listed under the section: 'groups that will be covered'. Additionally, the main outcomes for the guideline includes: 'views and satisfaction of those receiving end of life care; and of those important to them.'
148	**Northern England Strategic Clinical Networks (NESCN)]**	5	104	An enormously important area and the subject of a lot of patient distress and complaint. This is increasingly important as we care for an more people with multiple health problems and needs	Thank you for your comment. The revised scope lists planning and coordinating of services, including sharing information between multiprofessional teams, among the key areas to be covered.
149	**Northern England Strategic Clinical Networks (NESCN)]**	5	113	We are very concerned that face to face communication will be removed from the guideline as it is the foundation for good care and remains a very big source of dissatisfaction and complaint within the NHS. The Department of Health training in Advanced Communication Skills was highly valued and well implemented in our region. It is also a pre-requisite for level 2 training in psychological screening, assessment and basic intervention, and	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not

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				the lack of backing and provision for this training makes developing psychological skills and support much more of a challenge. Other initiatives like shared decision making, rely on good communication skills in order to be implemented successfully.	updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Face to face communication is covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.
150	**Northern England Strategic Clinical Networks (NESCN)]**	6	128	There is existing evidence that would be useful to draw on that psychological interventions are cost-effective in the overall care of people with physical illness.	Thank you for drawing our attention to this area of economic literature. If there is literature relevant to end of life care service delivery then it should be picked up in our broad economic literature search and review. We will also be conducting a call for evidence later on in the development stage, so if there is any existing evidence outside of the public domain that you believe would be specifically relevant for this guideline then please do bring it to our attention during this process.
151	**Northern England Strategic Clinical**	6	135	Identifying best screening tools is useful but these should not take the place of clinical assessment in the context of an empathic professional relationship with the patient/carer.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new

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	Networks (NESCN)]				recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessments will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
152	**Northern England Strategic Clinical Networks (NESCN)]**	6	142	It may be difficult to stipulate one size fits all guidance here, as different pathways may have different points when assessment is more appropriate and helpful. Therefore some flexibility would be useful.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs 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.
153	**Northern England Strategic Clinical Networks (NESCN)]**	7	151	Psychological support may be most efficiently and effectively coordinated through referral to a single point of access, to levels of psychological support above level 2. Referrers often find it difficult to know which level of psychological support they should refer to. Psychosocial teams, which include psychological practitioners (level 3) and clinical psychologist and liaison psychiatrists (level 4), may be most appropriate.	Thank you for your comment. Following revisions to the scope, psychological support will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
154	**Northern England Strategic Clinical Networks (NESCN)]**	7	161	Supportive services need to include clinical health psychologists, liaison psychiatrists, level 3 psychological practitioners and other health care practitioners with training in psychological skills. Not all of these professions necessarily need to be available 24 hours a day. A model that enables services to be accessed both within an acute hospital setting and community settings, depending on the presenting problems of the patient/carer and stage of disease pathway, would be most appropriate.	Thank you for your comment. The revised scope will look at the service delivery models for end of life care and will address out of hours, weekend and 24/7 availability of services.
155	**Northern England Strategic Clinical Networks (NESCN)]**	9	196	It would be helpful to link the current guidance to NICE 91 Depression in Adults with a Chronic Physical Health problem, as both are concerned with screening of patients for psychological distress and there is overlap between the populations. Both sets of guidance contain tiered models of psychological support. It would be helpful for health care practitioners to understand how the 2 sets of levels/tiers map on to each other.	Thank you for your comment. Following revisions to the scope, psychological support will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
15	**Northern**	12	278	It is most helpful to acknowledge that access to professional	Thank you for your comment. Following

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6	**England Strategic Clinical Networks (NESCN)]**			psychological care at every stage of the patient pathway is necessary. The current guidance refers to the year following diagnosis and advanced disease, but patients (and carers) at every stage of disease need access to supportive care, according to clinical need.	revisions to the scope**, the context section of the scoping document has been amended to reflect these changes.**
492	**Nottinghamshire Healthcare NHS Foundation Trust**		general	Complementary therapies at John Eastwood Hospice Specialist Palliative Care Service are an integrated, respected, and essential part of the support services. They fall under the category of symptom management, and psychological and emotional wellbeing for patients(and their carers) who access our sevices. Complementary therapy interventions are often used as non-pharmacological symptom management of symptoms, as recommended by NICE guidance, for the final 2-3 days of life. Complementary therapies being included in the 2018 guidelines will maintain the standards of these interventions, and ensure future commissioning of these services. Consultants within our service, successfully use acupuncture for symptom management, and it does feel like a backward step to remove ,from the guidelines, complementary therapies including reflexology and aromatherapy that have a growing evidence base of effectiveness for symptom 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
214	**Pancreatic Cancer UK**	4-5	106-121	Pancreatic Cancer UK strongly welcomes that holistic needs assessments are included within the draft scope.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within

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				Ensuring that all patients receive a holistic needs assessment, which can help identify when a patient should have access to supportive and palliative care services should be treated as a priority. It is also vital that these are carried out early on and regularly to ensure that patients' supportive needs are identified quickly. Involving supportive and palliative care teams early on in the care pathway is important for improving quality of life by ensuring the correct management of pain and other symptoms throughout the patient journey. It also helps optimise patients' physical and psychological condition from the outset, so that they are in a better condition both physically and psychologically to undertake treatment. Through our services, we frequently hear from patients that they are very unwell at the point of diagnosis, but that their condition improves through the provision of good quality information and the correct intervention for their symptoms. For example, many patients have lost weight and muscle mass at the time of diagnosis but a prescription of Pancreatic Enzyme Replacement Therapy (PERT) at this point and dietary advice can ensure they are able to regain some weight and muscle mass, enabling them to better tolerate appropriate treatments. Worryingly, we too often hear of supportive care not being introduced until it is too late. We therefore also welcome that the scope questions when and	the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessment will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence. Although no specific review on social wellbeing is intended, service delivery models may include this as part of our evidence review. Any appropriate published evidence meeting our protocols will be considered and inform the guideline committee's decision making.

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				how often supportive care needs should be addressed. Whilst we are pleased that the draft scope considers what the most effective interventions in meeting patients' needs are, it is of concern that it fails to list social wellbeing as an aspect of life on which life-threatening and terminal illnesses can impede. Chronic and terminal illnesses can have a considerable impact on patients' social wellbeing by limiting their ability to socialise and engage in community activities. For example, we often hear through our support services of how, pain, the side effects of treatment and dietary symptoms can hinder patients' social lives by making them not want to leave the house. Consequently, quality of life suffers and it is important that the correct interventions are taken to ensure social wellbeing is maintained.	
215	**Pancreatic Cancer UK**	General	General	An essential part of supportive and palliative care for many life-threatening and terminal illnesses is dietary support. As such, it is important that the consultation allows room for discussion around the importance of dietary support as a component of supportive and palliative care as this is often a neglected issue in the care of pancreatic cancer patients. Pancreatic cancer patients often face complex dietary support needs, including weight loss, diabetes and Pancreatic Enzyme	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				Insufficiency. It is vital that these symptoms and side effects are managed as ensuring patients receive the correct dietary intervention has been shown to increase survival time, by making patients better able to tolerate treatment, and to improve quality of life. A study by The Christie NHS Foundation Trust Hospital found that the median overall survival among patients where dietetic intervention was taken was 14.6 months. It was less than half this, 6.9 months, in patients were no action was taken to address dietary complications[37]. A 2013 study[38] into the supportive care needs of pancreatic cancer patients found that a major quality of life theme was "difficulty in managing gut symptoms and complex dietary issues". In particular, the study exposed a lack of information about malabsorption and managing symptoms of pancreatic exocrine insufficiency, which was "compounded by a lack of routine dietary consultation: perceived reluctance of clinicians to prescribe enzyme supplements and poor understanding of dose to diet guidelines". As such, the study concluded that enzyme supplement therapy with clear dosage guidelines and dietary	Clinical treatment is no longer included in the scope of the guideline, 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.

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[37] McCallum et al., 2014, Pancreatic Malignancy and Nutrition: a study of clinical practice. file:///C:/Users/leah.miller/Downloads/1535P.pdf
[38] Gooden & White, 2013

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				advice could "markedly improve quality of life", and was "an essential supportive care" for pancreatic cancer patients. Unfortunately, we know that far too often patients do not receive the specialist dietary advice they need. A sub-analysis of the 2014 Cancer Patient Experience Survey for England, looking at the experience of just pancreatic cancer patients, found that only 48% (313 out of a total of 655) of pancreatic cancer patients said they had seen a dietitian. In addition, it is concerning that we currently hear that when drug rationalisation comes as part of the end of life pathway dietary supplements, such as Pancreatic Enzyme Replacement Therapy, is often not considered an essential treatment, so is often one of the first treatments removed. This needs to change, so patients at the end of their life can still absorb the nutrients they need from food and continue to enjoy eating without experiencing digestive problems such as pain and bloating as both of these factors will help ensure a better quality of life for as long as possible.	
216	**Pancreatic Cancer UK**	5	88	The draft scope refers to the identification and referral of people at risk of complex bereavement. Whilst this is a welcome recognition of the importance of identifying and addressing the carers' support needs following the death of a loved one, the consultation should also consider anticipatory bereavement 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. We will ensure consistency between the new recommendations in End of life care: service

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				Anticipatory mourning can effect patients and family members who are facing death or the death of a loved one. It can cause complex support needs with sufferers not only grappling with feelings of loss and grief, but also the financial, legal, medical and personal responsibilities associated with preparing for a death. It is vital that people experiencing anticipatory grief are identified and offered the support they need during this time.	delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.
217	**Pancreatic Cancer UK**	5	112	We are concerned that the draft scope proposes removing areas of the published guideline that look at user involvement in planning, delivering and evaluating services. Involving service users in the planning, delivery and evaluation of services is essential to ensuring that services are fit-for-purpose and patient-centred. The patient voice is also vital to monitoring the delivery of services to ensure provision remains adequate and that any new concerns are addressed. We continue to hear examples of poor and patchy provision of supportive and palliative care. The 2011 Pancreatic Cancer UK report A Study for Survival highlighted some positive experiences, but also many stories of disjointed care and inadequate treatment relating to the management of pain and other serious side effects. Continued user involvement is essential to identifying and addressing these ongoing failings in	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, 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:

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				service provision. Removing reference to user involvement from the guideline risks side-lining patient engagement as an important aspect of service planning and delivery.	https://www.nice.org.uk/guidance/cg138v.
218	**Pancreatic Cancer UK**	5	113	The draft scope currently proposes removing areas from the published guideline that mention face-to-face communication. This is worrying as we continue to hear stories of poor diagnosis experience, with patients not having their diagnosis communicated to them sympathetically. A Pancreatic Cancer UK online survey of patients and carers found that 37% felt their diagnosis had not been given in a sympathetic manner. We also hear stories of patients being given their diagnosis in inappropriate places and without family members present. 28% of survey respondents told us their diagnosis had been given in a hospital ward with other patients nearby, whilst 5% of were given the news over the phone. This clearly demonstrates that there is an ongoing need to improve face-to-face communication when it comes to diagnosis. The guidelines should clarify that that a diagnosis of a life-threatening or terminal illness should be done as sympathetically as possible and in an appropriate location. Privacy should be	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, 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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				respected, patients should be given the opportunity to have a family member present and a diagnosis of a terminal condition over the phone simply should not happen. In addition, patients often feel they receive a "nihilistic" attitude to their treatment and care once they receive a terminal diagnosis, which can lead to treatment options not being well explained. For example, we hear of patients only being told that chemotherapy might give them an extra two months "if they are lucky", but that the treatment may cause more symptoms and side effects than it is worth. Whilst it is important that patients decide for themselves whether to have treatment or not and that quality of life is taken into account, we do know that in the care of pancreatic cancer patients chemotherapy can sometimes help control symptoms. It is important that people receive balanced information to enable them to make informed decisions, and that they feel healthcare professionals have not given-up on them and are focused on helping them stay well for as long as possible. It is therefore vital that the guideline clarify that all communications with patients and carers must be of a high standard, with patients and family members given all the information and support they need.	
219	**Pancreatic Cancer UK**	General	General	We welcome in the draft scope the inclusion of the coordination of supportive and palliative care services.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus

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				Currently, there are variations in access to palliative care services between different areas of the country, GP practices and even GPs within the same practice. There are also variations in the type and level of care available for each person. This can be due to whether there is a hospice in a patient's local area, whether the patient has access to a team of community nurses (Macmillan, hospice or palliative) and whether the clinician is aware of how to refer the patient to such services. Through our support services, we hear of patients who receive a diagnosis, and if no active treatment is going to be given, are discharged with no proper care plan in place with either primary care or supportive and palliative care teams. Consequently, responsibility for contacting and accessing supportive and palliative care services is transferred to the patient or carer. This can result in delays to accessing the support they need, meaning patients may be left suffering painful and uncomfortable symptoms, and without psychological and practical support. This can also happen if patients are discharged from active treatment as their disease progresses. It is essential to ensure patients are not discharged without having first been given contact details for help and support in the community, and without a referral for this support being made.	on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				Better coordination is needed between secondary and palliative care services to address these issues and ensure patients receive timely supportive care.	
220	**Pancreatic Cancer UK**	5	104	We strongly welcome that the draft scope will look at the sharing of information between multi-professional teams. This is essential to ensuring a joined-up patient experience, preventing delays and making sure patients receive the correct treatment. Cancer patients will often move between hospitals, receiving different treatments at each. For example, patients may have to travel to a different hospital for chemotherapy. Currently, we hear stories of poor coordination and information sharing between teams at different hospitals, meaning that patients' symptoms can go unnoticed or deteriorate. This can lead to patients' support needs not being properly identified, and may result in patients who need supportive or palliative care not being referred to those services. For example, one carer told us of his sister having to travel 40 miles to receive chemotherapy, only to arrive too unwell for the treatment as no-one at the hospital had noticed that she was losing weight and required dietary 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. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations 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

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				As such, the draft scope's reference to multi-professional information sharing is an important recognition of the need to ensure that all professionals involved in a patient's care are aware of changes in their condition, ensuring their wider support needs are not overlooked.	
84	**Penny Brohn UK**	5	109	Penny Brohn UK notes the removal of complementary therapy services from the guideline. We would like to point out that this would be a loss to the best practice in the area of supportive and palliative care for cancer, as there is good evidence for the use of some CAM therapies for people with cancer. The reputable CAM Cancer evidence based medicine resource refers to good evidence for some therapies, for example: • The use of Acupuncture/Acupressure to relieve chemotherapy associated nausea and vomiting:http://www.cam-cancer.org/CAM-Summaries/Mind-body-interventions/Acupuncture-for-chemotherapy-associated-nausea-and-vomiting • Hypnotherapy to reduce cancer therapy related pain, anticipatory nausea and vomiting, and anxiety:http://www.cam-cancer.org/CAM-Summaries/Mind-body-interventions/Hypnotherapy	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				- And Yoga has small beneficial effects on quality of life and wellbeing of cancer patients:http://www.cam-cancer.org/CAM-Summaries/Mind-body-interventions/Yoga Whilst we recognise that other useful areas have been included in the Improving Supportive and Palliative Care scope, for example: the holistic needs assessment, we feel that removing complementary therapies is not helpful as it is widely used in cancer care. Penny Brohn UK would welcome a review of the removal of complementary therapies, and its reinstatement in the scope. If complementary therapies are to be removed, as a minimum, we feel there needs to be reasons for why this is the case in the scope document.	
465	**Primrose Hospice**	general	general	I have grave concerns about the omission of complementary therapies from the draft revision. I have noted that complementary therapies are not the only omission and can surmise therefore that this may have been a decision which, to the Committee, is one of rational editing. My fear is that the reasoning behind the decision will be overlooked by those who will, wilfully or mistakenly, misconstrue an *'omission'* as an *'exclusion'* or *'withdrawal of approval'*	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will

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				With or without inclusion in the guidelines, those within the profession will continue to strive for the highest standards of safety in delivery of complementary therapy. They will continue to add to the growing body of evidence to support the efficacy and perceived benefits of complementary therapies. They will continue to make a valuable and valued contribution to the holistic philosophy of the hospice movement in particular and to end of life care in general. It is my belief that the potential for damage in this situation is the likely *perception* by some that complementary therapies do not have the backing of NICE – worse, that approval once given is now being removed. This would undoubtedly be a major step backwards for those working in the profession, would be damaging to the status and recognition we have worked so hard to attain, would be powerful ammunition for those seeking – for whatever reason – to discredit complementary therapies, and worst of all might discourage patients from engaging with the service from which many derive such benefit at end of life. Sadly, many health professionals lack knowledge and understanding about how complementary therapies operate in a modern day health care setting. Many patients have no prior experience and rely on advice from those they see as 'experts'. Non-inclusion in the guidelines may remove confidence and reassurance for both parties and result in fewer patients accessing the service.	remain within the published guideline.

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				For all of these reasons, I strongly urge the Committee to reconsider their decision in view of the potentially damaging inferences which may be drawn from non-inclusion of complementary therapies in the final document.	
256	**RCGP**	General	General	It would be important to include lines of responsibility and accountability in the guideline. So many initiatives: on discharges and transitional care but so little enacted. An example is over Personal care Budgets – there is a provision gap and I have been told that GPs locally cannot initiate until next year. (JA)	Thank you for your comment. . Where evidence exists to support lines of responsibility and accountability, the guideline committee may use that to inform their recommendations.
257	**RCGP**	General	General	Thoughtful and sensitive and in particular a tailor made plan for the dying person agreed with them their family and the caring team regularly updated and with agreed objectives, standards and anticipated milestones is ideal. There is reluctance to discuss alternative therapies-homeopathy, acupuncture, meditation and the evidence base is scanty but some patients and their families are determined to try and may need support and help. The costs can be high, false hope seductive but equally other patients want to try and feel an element of control over their illness. There is much controversy around euthanasia and physician assisted suicide. Some palliative care may speed the 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The revised scope includes a draft key question

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				process. The issue needs to be acknowledged. (PS)	that explores the best models to support advance care planning in the last year of life. With reference to your note on euthanasia: both active euthanasia and assisted suicide are illegal under English law and we are unable to address this in NICE guidance. .
258	**RCGP**	General	General	First of all, the definition of supportive care is so wide as to include all care for anyone with a long-term condition. The form of words in the opening table (line 48) is: *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.* If this is taken together with the components (physical, psychological, social & emotional, cognitive, sexual, and spiritual), then it looks as if the guideline is trying to write a text to cover every aspect of care (barring clinical – see line 106). Second, it is trying to cover every life-limiting condition. This in itself poses two problems. First as most clinicians are aware the trajectory of these conditions is so variable that guidelines are unlikely to be of little help, except in the most general fashion. But this problem is exacerbated by trying to cover such a huge range of conditions that what results is likely to be very bland. Taking these two objections together, my own feeling is that any	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.

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				resulting guideline risks being no better than a undergraduate student's guide to good clinical care for patients with long-term conditions. Third, the list of questions that are to be addressed seem entirely reasonable; they are for the most part the questions that general practitioners and community nurses are asking themselves all the time. One possible outcome from this exercise would be to see this as a specialist problem and thus further risk deskilling GPs and community nurses. (DJ)	
259	**RCGP**	General	General	Palliative care should include care after death and not stop on death I would recommend referencing Care after Death – Guidance for staff responsible for care after Death. Wilson J. Hospice Uk 2015 Second Edition. www.hospiceuk.org/what-we-offer/publications (MH)	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.
260	**RCGP**	2	41-44	People with chronic mental illness should also be highlighted as requiring special consideration to ensure equal access. (CJ)	Thank you for your comment. We will discuss the equalities issues you raise with the guideline committee who will consider the

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					needs of these populations in terms of recommendations for the delivery of services at the end of life.
261	**RCGP**	3	table	Definition for palliative care should be re-worded. It uses 'towards end of life' rather than 'life limiting illness' (which is used as definition for supportive care) – there should be consistency across both definitions. (CJ)	Thank you for your comment. . Thank you for your comment. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope. 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.
262	**RCGP**	5	108-115	There is no rationale given for removing these areas. (CJ)	Thank you for your comment. Following a number of comments from stakeholders, the Clinical Guideline CSG4 Improving supportive and palliative care for adults with cancer will now remain on the NICE website. The recommendations relating to these areas will therefore remain in the published guideline for adults with cancer. We will now be developing a new guideline which will focus on service delivery for end of life care services. The revised scope includes a draft question on

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					the best models to support advance care planning in the last year of life.
263	**RCGP**	6	131	How can we actively encourage the general public and in particular the over 50 year olds to think about advance care planning and in particular lasting power off attorney for Health and Financial matters? Could this be done through the tax system with people getting a refund for having an advance care plan? (MH)	Thank you for your comment. The context section of the scoping document, to which you refer, has been amended to reflect changes to the scope.
264	**RCGP**	8	Point 7	Resources should include documentation, including discharge summaries and responsibilities for prescription of drugs. Practical problems often cause service users the most heartache. (JA)	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.
265	**RCGP**	8	187	The guidance does refer to carers but there are no carers related outcomes in 1.6. (MH)	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.
266	**RCGP**	13	294-295	This illustrates the point made above about the scope. The draft states: *In 2015, supportive and palliative care services are focused on people with cancer and those important to them.* If the definition given in the document (Line 48) is accepted, then it's quite clear that GPs & community nurses spend a great deal	Thank you for your comment. . The context section of the scoping document, to which you refer, has been amended to reflect changes to the scope.

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				of time giving supportive care to this group of patients. Palliative care services continue to be more focused on those with cancer for the reason stated above, that the trajectory of illness is more predictable, and therefore providing palliative care is more straightforward. (DJ)	
267	**RCGP**	14	325- 330	The guideline should not state that only teaching hospital trusts provide excellent supportive care for people with cancer. This is often problematic as patients may live some distance away. There is nothing like continuity of care with a trusted GP team local to the patient as well as a trusted specialist. With co-ordination this can work well. The term "equity of service" is confusing as this often means the "lowest common denominator" rather than the most excellent. There will always be some degree of inequity although we should always strive for the best possible for the patient – this depends on leadership, timing, other resources and how the teams work with the patient and family. (See Atul Gawande's book after the Reith lectures 2014 on Being Mortal). (JA)	Thank you for your comment. The context section of the scoping document, to which you refer, has been amended to reflect changes to the scope.
268	**RCGP**	14	334 - 338	It may be advisable to look to supporting present provision rather than starting new. Please emphasise personal care (see the Service User mental health guideline which is excellent). (Picker guidelines). (JA)	Thank you for your comment The context section of the scoping document, to which you refer, has been amended to reflect changes to the scope.
341	**Rowcroft Hospice**	4	61	We are concerned that this guidance does not cover non-NHS funded care, whereas the NICE standard for care of the dying covers these. We suggest that this guidance may also be useful	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus

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				for non-NHS funded settings	on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
342	**Rowcroft Hospice**	4	66-67	We are not aware of the benefit of SPARC or its utilisation in specialist palliative care services generally and therefore suggest this holds less priority as an example.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will

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					remain within the published guideline. Consequently, holistic needs assessment is no longer a priority area for the guideline and will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
343	**Rowcroft Hospice**	4	77 - 84	The delineation of 'supportive care' and 'palliative care', which are perceived in clinical practice as one and the same, is not helpful in this scoping or the guidance. This is evidenced in identical sections on 'service organisation'.	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.
344	**Rowcroft Hospice**	5	88	Identifying complex bereavement is also 'supportive care'	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service

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					delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.
345	**Rowcroft Hospice**	5	109	We are concerned that Complementary Therapy, a service that adds quality to patients and their families' lives and improves their well-being, is not being included in this scope. There is a growing body of research from institutions such as The Royal Marsden, Christies Hospital, Haven of the benefits of this service. Including complementary therapy in the guidance would support commissioners, providers and patients in how to access safe complementary therapy services. We feel strongly that the previous chapter on complementary therapy in 2004 should be updated and included in the revised 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. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
346	**Rowcroft Hospice**	5	114	We feel that the chapter on social support services should be included in the scope. Without social care support we cannot deliver clinical palliative care. As a component of holistic care social care requires evidenced based guidelines in palliative care provision.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not

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					updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
347	**Rowcroft Hospice**	6	134	We would suggest there will not be evidence for just one *best* 'tool' to assess the holistic palliative/supportive care needs of patients, but rather a suite of suitable tools, which can be chosen from to suit the care setting and/or patient/carer. We suggest the following rewording of this set of questions to: What are the best tools to……	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, key questions only have been provided for the scope document. The questions will be refined when drafting the full review protocol in conjunction with the guideline committee. Recommendations will be based critical appraisal of published evidence.
348	**Rowcroft Hospice**	7	149 (2) - 164 (3)	We feel that these questions could be grouped together as one set. They are delivered by the same services.	Thank you for your comment. Thank you for your comment. Following consideration of all

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					stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The draft list of questions have been amended to reflect these changes.
349	**Rowcroft Hospice**	8	189	We are concerned that the scope is only proposing assessing 'health related quality of life' as an outcome. As holistic beings social aspects of quality of life impact on health and vice versa. We feel the scope should look at 'quality of life' as 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.
350	**Rowcroft Hospice**	8	193	We suggest including hospice length of stay as well as hospital	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.
12	**Royal College**	Genera	General	The Royal College of Nursing (RCN) welcomes proposals to	Thank you for your comment.

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8	**of Nursing**	l		update these guidelines. The RCN invited members who care for people in palliative care to comment on the draft documents. The comments below reflect the views of our members.	
129	**Royal College of Nursing**	General	General	The scope seems comprehensive and achievable.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
130	**Royal College of Nursing**	General	General	Improvement and modification is always desirable and should be aspired to.	Thank you for your comment.
131	**Royal College of Nursing**	5	109	*Complementary therapies*: Some of our members who work with patients in palliative care know that some patients choose and are offered complementary therapies. Some of these members therefore, consider that elements of complementary therapies where proven to be effective, could be offered to some patients as part of their palliative care. In their view, the proposal to completely remove complementary therapies from palliative and supportive services could be seen as a backwards step and appears to go against 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. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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132	**Royal College of Nursing**	5	110	Research is essential to systematically capture effective practice and areas for improvement. In this regard, it would be helpful to include recommendations which would encourage further research involving qualitative and quantitative study which would support holistic and high quality supportive and palliative care. This would build on the very fabric upon which the NICE guidelines are formed which is to continuously improve evidence based practice and quality of services.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
133	**Royal College of Nursing**	8	186	It would be helpful to include people's stories and their own reported outcomes including how different treatments and therapies have benefited them. Such research would be valuable in supportive and palliative care where there is paucity of evidence in the use of complementary therapies.	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.
13	**Royal College**	8	187	Patient's views should be taken into account. Many hospices	Thank you for your comment. .

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4	**of Nursing**			currently offer complementary therapies to patients and their relatives.	
135	**Royal College of Nursing**	8	192	Working in palliative care is very demanding area. It is important that staff feel that they can support patients and their relatives in the best possible way including offering evidenced based and effective treatments and therapies that would improve the quality of care.	**Thank you for your comment.**
136	**Royal College of Nursing**	General	General	The guidance should encourage research in both conventional medicine and use of complementary therapies to support evidence based practice.	Thank you for your comment. Tthe 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.
137	**Royal College of Nursing**	General	General	The guidance should allow for patient choice i.e. a person's right to choose what kind of treatment they wish to have. A blanket rule out of access certain treatments and therapies could lead to people being denied the right, having consulted with their healthcare professional, to choose what they consider best to support their needs.	Thank you for your comment.
204	**Royal College**		69-70	Suggest supportive and palliative care needs (including the requirement for specialist expertise) of the person.	Thank you for your comment. Following consideration of all stakeholder comments the

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	of Psychiatrists				guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs 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.
205	**Royal College of Psychiatrists**		65-76	Define term used for psychological support: improvement of mental wellbeing in all patients, identification and treatment of mental disorders related to the illness, management of prior mental illness, all utilising pharmacological, psychological and social interventions.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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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. 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.
206	**Royal College of Psychiatrists**		65-76	State need Liaison Psychiatrists as well as psychologists or therapists since Liaison Psychiatrists have expertise in biopsychosocial assessment and management of physical and mental health commorbidities and illness reactions from physical illness as well as the ability to manage associated risks.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs 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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207	**Royal College of Psychiatrists**		73	Suggest psychological and emotional symptoms, functioning and wellbeing.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs 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.
208	**Royal College of Psychiatrists**		93	Suggest that the name of these services is altered as support is something that should be provided by all staff; suggest psychological and psychiatric 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.
209	**Royal College of**		110	I am not sure why this is being removed. Will any comments on the evidence base/problems with it/need for research be discussed?	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within

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	Psychiatrists				the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, 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.
210	**Royal College of Psychiatrists**		114	Social work is very important in this area, may be being covered 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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211	**Royal College of Psychiatrists**		135	There is no mention of 'what is the evidence for the effectiveness of holistic needs assessment tools' – It is important to add 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.– Consequently, Holistic needs 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. The list of questions included in the scope are also draft versions and will be refined when the full review protocol is drafted in conjunction with the guideline committee.
212	**Royal College of**		149-164	Use psychological and mental health support services.	Thank you for your comment. Following consideration of all stakeholder comments the

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	Psychiatrists				guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, psychological support will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
213	**Royal College of Psychiatrists**			The scope could benefit from a definition of "psychological support". There is a danger that the level of "support" does not include the function to deliver evidence based treatment of mental disorders arising co-morbidly with cancer and other life limiting illnesses. Such support must both include the capacity to treat mental disorders, which have an adverse effect on wellbeing, and wider health outcomes, and the ability to ensure that patients with severe mental illness can be appropriately supported within oncology and palliative care settings. A poorly defined construct of "psychological support" that does not include liaison psychiatry expertise will not be able to meet these needs.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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31/12/15 to 29/01/16

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				In a similar vein, I would question whether "psychological support services" offers the most appropriate terminology in the document. The original SPC document lacked clarity, in my view, as to the required structures required to support the mental health needs of patients in oncology and palliative care settings. While having a lot to offer, clinical psychologists, working in a uni-professional manner, lack the ability to manage complex mental health presentations involving organic aetiology and risk, and those requiring medical interventions. I would suggest that "psychological and mental health support services" would be a more appropriate term to use when considering the scope. Added to the above, I would suggest that liaison psychiatry is so integral to the management of complex cases, that a definition of liaison psychiatry should be included within the scope. This would make it very clear that liaison psychiatrists are uniquely placed to work and formulate across psychological and physical domains, while also having a skill set which allows for the safe and effective treatment of patients who are physically compromised and at higher risk of mental disorder I would additionally argue that a key question for inclusion should be: What is the best model for providing Psychological and mental health support within this context? The next iteration of this guidance offers an opportunity to clarify and cement the role	Consequently, psychological support will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline.

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				of liaison psychiatry at level 4 of the stepped care model. There is strong evidence that such configurations can produce excellent outcomes, even in advanced cancer and the guideline should further explore, and reflect this.	
157	**RoyalTrinity Hospice**	5	109	The draft scope is proposing to remove complementary therapy services from the guidelines. We strongly recommend that this is reconsidered. Complementary therapies have been an integral part of patient care at Royal Trinity Hospice for many years. Between 800 and 950 complementary therapy sessions have taken place each year for the past 3 years and if current trends persist we would expect these numbers would be in excess of 1000 sessions for next year. To the hospice complementary therapies are an essential part of providing a patient- centred holistic care, care which fulfils the definition of supportive care and of palliative care which is given at line 48 of the scope. Whilst limited resources have restricted our ability to collect outcome data in previous years we have collected data for the past year which we will analyse and use to further develop our service. We do however have a wealth of feedback from patients. This feedback suggests that patients	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				• Find complementary therapy relaxing, managing both anxiety and increasing feelings of well-being. *"I have gained peace of mind", "More peaceful within myself", "I feel so much less stressed and anxious now than at any time since I was first diagnosed"* • Feel safe and supported by the time spent with the therapist and the physical effect of touch *"I feel I can relax with you because I feel safe", "I feel that someone cares".* • Experience something positive, especially patients with low mood. This often comes at a time when patients are faced with their own mortality for the first time or with limitations of their physical bodies. *"It's the one thing that I have to look forward to", "I feel more in touch with my body and more alive".* • Experience relief from a range of symptoms including -- Muscle tension and peripheral neuropathy *"The treatment was very effective. The tingling and numbness in my hands went and I am now able to use the bathroom taps"* Breathlessness *"My breathing always feels easier after a session"* Insomnia *"I slept better than I have done in months"* • Experience time and space for themselves for reflection,	

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				a sense of peace or to connect with their sense of spirituality where applicable. *"Like heaven, and I'm a priest, so that's saying something!", "It has given me a sparkle in my soul".*	
158	**RoyalTrinity Hospice**	5	109	Complementary therapy services are often also offered to carers. Within our service 52 carers' sessions have taken place over the past 3 months. Again the definition of supportive care used in the draft scope states that care should help the person and people 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. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
159	**RoyalTrinity Hospice**	5	109	The 2004 NICE guidelines acknowledge that complementary therapy, along with other non-pharmalogical clinical interventions, does not have the evidence base of those interventions that can be measured by RCTs, although it does make reference to certain studies. The 2004 guidelines do however support patients in accessing reliable information on 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. We will ensure consistency between the new recommendations in 'End of life care: service

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				and guide commissioners in determining what complementary therapies, if any, they should fund. Since these guidelines were written in 2004: • The evidence base has increased, including research carried out within services such as the Royal Marsden and the Christie (for example 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) • The Complementary and Natural Healthcare Council (CNHC) has been established for the regulation of complementary therapists and the agreed national occupational standards. • Complementary therapy services have established networks within Cancer networks to ensure standards of good practice are consistent. Royal Trinity Hospice works with the London Cancer Alliance Complementary Therapy Community of Practice. The 2004 guidelines acknowledge the growing recognition for the place of complementary therapies within healthcare settings over the previous 10 years. The positive developments in the 11-12 years since these guidelines were written suggest that there is now more reason to include complementary therapies in the	delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				guidelines rather than less.	
160	**RoyalTrinity Hospice**	14	331	The draft scope talks about providing more equitable and consistent support however if complementary therapies are excluded from the guidelines this could have significant impact on funding, therefore preventing many patients from accessing a supportive service of their choice. One of the aims of the 2004 guidelines was that complementary therapies be provided by trained practitioners with sufficient awareness of the clinical and psychological issues for this client group. If the provision of complementary therapy services within NHS and charitable sector services is reduced more patients may seek treatment privately from complementary therapy practitioners without sufficient awareness of their specialist needs. In addition, more patients may feel their only option is to seek treatment from alternative therapy practitioners with the associated risks this may pose. The 2004 NICE guidelines noted that at that time approximately one third of cancer patients accessed complementary therapies, the majority of those being women from higher socio-economic backgrounds. At Royal Trinity we work hard to ensure equal access to all our services, including complementary therapy. Exclusion of complementary therapies from the NICE guidelines has the potential to lead to a reduction in provision of these services within both the NHS and charitably funded services.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				This would inevitably impact on equality of access, as patients who have to seek these treatments privately are likely to be much less diverse demographically.	
1	**Shiatsu Society (UK)**	5	109	We strongly believe that Complementary Therapy Services (CTS) should remain in the Guideline as so many patients, carers and bereaving families benefit from CTS – one of them being Shiatsu.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
2	**Shiatsu Society (UK)**	5	109	We strongly believe that Complementary Therapy Services (CTS) should remain in the Guideline. Berrywood Hospital, Northants, fund a Shiatsu Service for In-Patient Adult Acute Psychiatric, and another Psychiatric Unit. Shiatsu has been delivered in the In-patient Adolescent Service in Northants too. A recent report from the hospital is very positive showing that the aims of the project are being fulfilled successfully. The Maudsley have funded Shiatsu for many years and would not have done this if it was not effective to patients and cost-effective.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
3	**Shiatsu**	5	109	We strongly believe that Complementary Therapy Services	Thank you for your comment. Following

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	Society (UK)			(CTS) should remain in the Guideline. Taken from the Berrywood Hospital report on their Shiatsu Funded project: Shiatsu and Current Government Directives 'The direction in the NHS (as illustrated by the Forsyth Report, the latest Government White Paper on Health and the NHS (No Health Without Mental Health), WRAP and Staying Well Programmes) is increasingly on Preventative care, Service User choice, Health Maintenance, Self-empowerment and Care of Carers. These are important parts of the Shiatsu Service. Increasingly attention is being paid to Recovery and Wellbeing throughout the NHS, and Shiatsu again is in line with these principles. With improved mental, physical, emotional health, Shiatsu can help individuals confidence, and capacity for social and vocational inclusion may be increased.'	consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
234	**Skills for Care**	2	38	The emphasis on addressing the inequalities in provision is much welcomed	Thank you for your comment.
235	**Skills for Care**	2	44	Wonder if the scope should include prisoners as they are often an excluded group for health care related issues. Numbers probably small but not insignificant.	Thank you for your comment. The guideline will be relevant to all settings in which National Health services are commissioned and funded. A separate guideline is currently in development that considers health care provision within prisons.
23	**Skills for Care**	3	59	Concerned that this is limited to NHS commissioned care and	Thank you for your comment. Thank you for

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6				excludes social care, self-funded arrangements. There are many situations where supportive and palliative care is not commissioned by NHS. Also in many cases even if there is some NHS funded care, the majority could be funded from elsewhere, or self-funded, so it seems limiting to exclude other services / care from these guidelines. It is not helpful to have some care covered but not other aspects of care in the same scenario, just because of who funds it.	your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, 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.
237	**Skills for Care**	4	65	Agree that holistic needs assessment is extremely important. This gives weight to comments above as NHS funded care will rely on other care providers, other services and other carers to engage with this assessment to ensure it is accurate and supports the individual, but guidelines do not apply to those other services and carers?	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where

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					recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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. 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 their services however, non NHS or care funded settings are beyond the remit of NICE in relation to guidance provision.
238	**Skills for Care**	5	102	Agree this is really important aspect of modern day supportive and palliative care	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service

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					delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
239	**Skills for Care**	5	104	Agree this is vital aspect of care to ensure good experience for individuals and their families and carers. Information sharing has become a key element of holistic and integrated care and this has strong overlaps with other NICE guidelines and standards, e.g. transition between acute and community settings. There are many local agreements / arrangements for information sharing but still no consistent approach. Including this in these guidelines will support greater consistency and hopefully grater implementation of information sharing. This aspect is especially useful with regard to Advanced Care Plans and DNR	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The revised scope will look at the planning and coordinating services, including sharing information between multiprofessional teams.

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240	**Skills for Care**	5	107	Education and training is vital to the implementation of the proposed guidelines. We are disappointed that this area is not included. Without the inclusion of, or reference to, guidance around education and training across health and social care, we feel this can limit the effectiveness of the 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
241	**Skills for Care**	5	112	We are surprised about this exclusion as the emphasis on service organisation for both supportive and palliative care must take into account the voice of the patient / service user in planning, delivery and evaluation to ensure services remain fit for purpose and enhance wellbeing.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. In addition User involvement in planning, delivering and evaluating services has been covered in the NICE Patient experience

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					guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v.
242	**Skills for Care**	5	113	Again surprise that his element will be removed as communication is one of the most vital elements in supportive and palliative care and practitioners are still not always getting this right. Skills development in this area is still a challenge.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, 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.
243	**Skills for Care**	7	149	Any service model must include the wide range of social care services that are already providing supportive care, even when not NHS commissioned. Involvement of individuals and other non NHS commissioned services is absolutely necessary and they	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

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				must be involved in the planning as well as the delivery.	services however, non NHS or care funded settings are beyond the remit of NICE in relation to guidance provision.
244	**Skills for Care**	7	164	Any service model must include the wide range of social care services that are already providing palliative care, even when not NHS commissioned. Involvement of individuals and other non NHS commissioned services is absolutely necessary and they must be involved in the planning as well as the delivery.	Thank you for your comment. The guideline is now focused on service delivery and will consider a range of service delivery models. .
245	**Skills for Care**	14	331	The widening of the scope for supportive and palliative care beyond cancer is very welcome and has long been needed, though we are aware that in many areas cancer services /standards have been applied to non-cancer situations..	Thank you for your comment.
280	**Southern Health and Social Care Trust**	General	General	The proposed guideline development has been very strongly welcomed by a range of health professionals working across different 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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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281	**Southern Health and Social Care Trust**	1	14/15	Strong endorsement to extend the population beyond adults with cancer to all adults with a life-limiting condition. Suggest including frailty.	Thank you for your comment. Following changes to the scope with a stronger focus on service delivery, this guideline will not focus on condition specific clinical details. .
282	**Southern Health and Social Care Trust**	3	Definition table- Supportive care	Definition is confusing- the statement is contradictory "cope with life-limiting illness….to cure". This definition has not been embraced in NI	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.
283	**Southern Health and Social Care Trust**	3	Definition table- Palliative care	"care towards the end of life" again this statement is confusing. Within NI we have been advocating that palliative care commences from the diagnosis of a life-limiting illness. Suggest using World Health Organisation definition. Palliative Care can be for weeks, months or years.	Thank you for your comment.
284	**Southern Health and Social Care Trust**	3	Non-specialist palliative care	It was suggested that this should be changed to generalist palliative care and the term competence should be removed from the sentence alongside, so it just reads 'without specialist knowledge and skills in palliative care' rather than' specialist knowledge, skills and competence in palliative care'. Suggest including the word generalist.	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.

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285	**Southern Health and Social Care Trust**	3	53	Suggest including the word 'social' care professionals and referring to specialist and generalist palliative care services.	Thank you for your comment. This has been amended.
286	**Southern Health and Social Care Trust**	3	81 and 87	Focus on 24/7 provision of care access to specialists welcomed	**Thank you for your comment.**
287	**Southern Health and Social Care Trust**	4	80	Suggest more detail to include Primary Care, Independent sector, community and voluntary sector.	Thank you for your comment. Evidence will be searched for across a range of settings and service delivery models (including primary Care, Independent sector, community and voluntary sector). All published evidence will be considered by the guideline committee when developing recommendations.
288	**Southern Health and Social Care Trust**	5	99	Suggest adding section of role of the palliative care key worker included in this update.	Thank you for your comment.. Where the evidence of services reviewed describes clinical and cost-effective roles, the guideline committee may choose to make recommendations in support of those functions. We do not feel any amendment to the text of the scope as you suggest is required at this point.

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289	**Southern Health and Social Care Trust**	5	107	It is unclear why Education and training will not be covered as this will be a critical factor in the implementation of the completed guideline. We would strongly suggest that it should be included int the guidelines.	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.
290	**Southern Health and Social Care Trust**	5	109	Unclear why complementary therapy services removed. Acupuncture now falls under the remit of physiotherapy rather than complementary therapy.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
291	**Southern Health and Social Care Trust**	5	112	Strongly suggest that user involvement should not be removed but revised. Also strongly suggest that face to face communication should not be removed.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not

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					updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. 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.
292	**Southern Health and Social Care Trust**	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. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of

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					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.
293	**Southern Health and Social Care Trust**	6	142	Point 1.4 missing from section 1.5	Thank you for your comment. The scope only provides draft key questions, the questions will be refined when drafting the full review protocol in conjunction with the guideline committee. Please note that resource use is included in the list of outcomes in section 1.6
294	**Southern Health and Social Care Trust**	7	164	Suggest change in terminology. There are specialist palliative care services, however generalist palliative care can be provided within a health care model but not necessary a service per se i.e. GP, District Nurse, 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. Any published evidence on relevant service delivery models that meets our protocols will be considered by the guideline committee when developing recommendations.
295	**Southern Health and Social Care**	7	169-170	Suggest need to include reference to care homes	Thank you for your comment.. The revised scope has listed service delivery modes for end of life care, including those

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	Trust				covering both acute community and third sector settings as a key area and this includes care homes.
296	**Southern Health and Social Care Trust**	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.
297	**Southern Health and Social Care Trust**	14	331-333	Very strong support for this statement.	Thank you for your comment. Following changes to the scope, **the context section of the scoping document has been amended to reflect these changes.**
298	**Southern Health and Social Care Trust**	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. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions.
299	**Southern Health and Social Care Trust**	General	General	It would also be important that the guidance document addresses the care interfaces where often these systems are failing our patients at present.	Thank you for your comment. Our revised scope linked to service delivery at end of life will include a specific review on the coordination of services and it is anticipated that care interfaces may be addressed as part

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					of that work.
332	**St Christophers Hospice**	2	41-44	The EIA link did not work, and so there is no access to an explanation about other groups with protected characteristics who are excluded from the scope.	Thank you for your comment. We will amend the link on the final version of the guideline.
333	**St Christophers Hospice**	4	66	Include person centred assessment tools, for example Helen Sanderson Associates tools.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessment is no longer a priority area for the guideline and will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
33	**St**	4	82 /89/	In our experience of supporting a young adult's service, planning	Transition from paediatric to adult services will

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4	**Christophers Hospice**		100	for transition is more successful if commenced early. Could the age range be extended to 16- 25?	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).
335	**St Christophers Hospice**	5	109	There is no reasoning for the removal of complementary therapies. Our experience and patient reported outcomes evidence the value of this service to patients and carers. Evidence from patients and the multi-professional team indicates that CT improves general wellbeing and helps people better cope. The demand for CT at the hospice indicates patients and carers want access to CT services – referrals for 2015 has increased to 1248, demand met by 3 paid staff and increasing numbers of volunteer therapists. **Complementary Therapies Study for St Christopher's Hospice Final Report – May 2006** Patient Views: "*49 of 54 patients believed CT had helped them and the remaining patients said they enjoyed the therapy but could not identify a specific benefit"* – 70 cited the most common benefit as increased relaxation, calmness and decreased anxiety – 41 stated it reduced their pain – 48 stated CT had no negative effects on them – the others noted minor effects such as feeling sleepy, or achy	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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				IP1 "*The last time I had it I had severe pains in my lower back and I was almost in a pain cycle where the pain increased and I'd need more drugs and then the pain would increase again and I'd need more drugs and I couldn't get away from the pain. When the therapist actually did the massage it enabled the cycle to be broken and enabled me to relax which stopped the pain being so severe"* *C5 "Another important aspect is letting someone else see your scars actually when you're having a massage, because it can be, I was very loath to look at my lung scar…..just someone touching an area that's been traumatized really through surgery, it had lots of benefits really. It helped me to accept it"* *C10 "It felt like a good experience really. I think that here they're extremely in touch with you, with your particular needs and it's used to bring out, you know, something quite private, whereas for a long time I couldn't cry and I didn't feel at all normal, so you know the normal responses weren't there so crying was actually a plus point. So it helped get a lot of stuff out from inside which had been trapped"* *C18 " I think it was more the tiredness and just something to help me relax because my brain was like a hamster on a wheel you know it goes round and round and round. Just been able to switch off"*	

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336	**St Christophers Hospice**	5	109	The multi-professional team provide further information about the benefit of complementary therapies: **Ward Manager – St Christopher's** Complementary Therapy and it's use for patients on In Patient Unit (IPU) In the many years that I have worked on the IPU of the hospice I have seen at first hand the positive and beneficial effects that CT can have for patients with complex physical symptoms and psychological distress. Some patients have had experience of CT treatments prior to being admitted here and have a wish to continue and for others it is something very new. A large number of patients have had to undergo several cycles of chemotherapy and/or radiotherapy as well as surgical interventions in the past. Having a non-pharmacological choice to offer these patients to help alleviate their symptoms is a valuable resource. **Social Worker – St Christopher's** As a Social Worker seeing in-patients and out-patients as well as their carers I am very aware of the benefit Complementary Therapy brings. A high proportion of palliative patients are anxious and concerned about their illness and the impact on their lives. I often referred patients and carers who are inhibited verbalising their anxieties or have difficulty articulating their worries and concerns. I have observed patients relax and look	Thank you for your comment.

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				visibly calmer and re-invigorated following a treatment. I am also aware that many patients no longer have touch within their day to day experience. Time spent receiving massage and attention to physical complaints that cannot be medically managed and the relief this provides, is often commented upon from the recipients. This alternative therapy totally complements the medical, physical and talking therapies offered at the Hospice to give a truly holistic service to patients and carers alike. **Research:** Mitchinson. A; Fletcher; C.E., Kim. H.M;Montagnini. M; Hinshaw.D.B., (2014). Integrating massage therapy within the palliative care of veterans with advanced illness: an outcome study. *American journal of hospice and palliative medicine.* 31 (3); 6-12. "Inhibitions about touch in cancer caregiving may lead to unnecessary physical and emotional distancing at a time when patients need touch the most. Brief instruction may be a feasible intervention to increase caregiver efficacy, patient satisfaction, quality of life, and quality of the relationship".	
337	**St Christophers Hospice**	5	109	Keir ST; Saling JR., (2012). Pilot study of the impact of massage therapy on sources and levels of distress in brain tumour patients. *BMJ supportive & palliative care*. 2 (4):363-366.	

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				"This study further documents that brain tumour patients report high levels of distress across the disease course. However, participants in this study reported improvements in distress level and total number of sources of distress while receiving massage therapy". Cronfalk BS; Ternestedt BM; Strang P. (2010). Soft tissue massage: early intervention for relatives whose family members died in palliative cancer care. *Journal of Clinical Nursing.* 19 (7-8): 1040-8. "Soft tissue massage was experienced as a commendable source of consolation support during the grieving process. An assumption is that massage facilitates a transition toward rebuilding identity, but more studies in this area are needed". Beck I; Runeson I; Blomqvist K. (2009). To find inner peace: soft massage as an established and integrated part of palliative care. *International Journal of Palliative Nursing.* 15 (11): 541-5. "During the massage the patients felt dignified, while memories from past massage sessions were about becoming free. These experiences of dignity and freedom brought hopes for the future. The conclusion is that soft massage ought to be offered in the ordinary palliative care".	

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				Osaka I; Kurihara Y; Tanaka K; Nishizaki H; Aoki S; Adachi I. (2009) Endocrinological evaluations of brief hand massages in palliative care. *Journal of Alternative & Complementary Medicine.* 15 (9): 981-5. "The brief hand massage appears to reduce levels of stress according to the salivary CgA ($p < 0.05$). In addition, we found statistically significant changes in patient satisfaction with hand massage". Downey L; Engelberg RA; Standish LJ; Kozak L; Lafferty WE. (2009) Three lessons from a randomized trial of massage and meditation at end of life: patient benefit, outcome measure selection, and design of trials with terminally ill patients. *American Journal of Hospice & Palliative Medicine.* 26 (4): 246-53. "benefit from the study intervention, suggested significant gains from massage-the treatment patients gave their highest pre-assignment preference ratings. The authors conclude that adding a menu of complementary therapies as part of standard end-of-life care may yield significant benefit" Cronfalk BS; Strang P; Ternestedt BM; Friedrichsen M. (2009) The existential experiences of receiving soft tissue massage in palliative home care--an intervention. *Supportive Care in Cancer.* 17 (9): 1203-11. "The patients experienced the massage to give meaning and to	

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				be important as it generated feelings of an inner respite. Soft tissue massage appears to be an appreciated source of support to dying patients in palliative home care".	
338	**St Christophers Hospice**	5	108-115	Our main concern is the removal of complementary therapy services from the guideline, but there is also no explanation for the removal of other important areas, such as research, and user involvement. In our experience involving people in planning and evaluating services can be therapeutic and empowering. User involvement is often essential to encourage engagement in supportive care activities. Emerging models of support highlight the value of user involvement, and wider community engagement, e.g. St Joseph's compassionate neighbours, St Christopher's schools programmes. The guideline scope as it stands is limited, and does not address innovative practise.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended. User involvement in planning, delivering and evaluating services has been covered

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					in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
339	**St Christophers Hospice**	6	123	Economic analysis as described would be useful to apply to innovative and developing supportive care projects (examples above).	Thank you for your comment. Economic analyses will be conducted for this guideline based on the prioritisation of areas for economic analysis made by the Guideline Committee.
340	**St Christophers Hospice**	8	193	Hospice is not included in the resource list. Involvement of the hospice as part of the care coordination framework will impact on overall resource use and cost.	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.
493	**St Joseph's Hospice Hackney**	General	General	It is worthy to note that all life limiting conditions are supported by Complementary therapies (CT) at St Joseph's Hospice Hackney. For example the neurological support group is led by CT and is a unique service designed to introduce people living with neurological conditions such as MND, CBD, PSP, HD, MSA to wider hospice services such as respite, physiotherapy speech and language, OT. This was established in response to the House of Commons Committee of Public Accounts Services for people with	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will

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				neurological Conditions Seventy-second Report of Session2010–12 which stated that despite the publication in 2005 of the National Service Framework (NSF) for Long-term Conditions to improve Service provision for people with neurological conditions. Implementation of the Framework lacked leadership at both national and local level, which led to a lack of impetus, focus and direction. This is a clear example of CT leading service delivery to a marginalised population who have historically had poor supportive care, advance care planning and palliative & end of life care. This care is also offered to relatives and carers. It is especially beneficial for isolated patients and elderly patients – with no family or close friends as it provides an additional support network. The opportunity of receiving complementary therapies is a significant draw to bring people to the group which sets it apart from other type of community groups	remain within the published guideline.
494	**St Joseph's Hospice Hackney**	General	General	CT at St Joseph's hospice is an integrated part of person centred holistic care. In the period 2014 – 2015 the CT team totalled 5,911 interventions. 1,722 were massage, 1,531 acupuncture, 1,258 Reiki other therapies made up the remaining 1,400 comprised other complementary therapies. Recipients responded in the following way: *"It's interesting meeting different people from all over the world. I like the volunteers, all different ages and experience in life. I*	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will

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				meet people from the Motor Neurone Disease Association, I want more people to understand what MND is like, especially the friends who don't come to see me now" Lawrence patient with MND *"When I first came to the group people were very friendly and attended to me. Giving information, I didn't know much about MND when I first came. My condition wasn't explained to me by my GP. I like coming for massage and acupuncture. You can always talk to people about how my condition is changing. I like the environment, a really friendly place".* Raj patient with MND *"I like the group I enjoy everything. All the people and the complementary therapy. I like the staff, everything is beautiful. I'd like to come more than every two weeks. I am very happy here, you can see that I am happy. If you saw me tomorrow at home I would look very different".* Filomena patient with MND *"Love, warmth, safety, continuity. New approaches to address issues, being cared for in a non-intrusive way. Something nice you can count on every time I come, even if everything else is difficult".* *Meeting new people, meeting people who have similar experience. Talking with other recipients of treatment about things it is not possible to talk about with people who have not had to deal with serious illness".* Anne patient with MS	remain within the published guideline.

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				"It's just fantastic that S can get out and do this on his own. The neuro group is something I've been looking for for him for a long time. Means a lot to us that this service exists. It does his confidence so much and is a great reminder that he can do stuff without me. Thanks again to you and everyone at the neuro group. I think this will be a regular 2 weekly trip for S Cheers S". *"Opportunity to socialise with people with similar conditions (no difficult questions) Relaxed and pleasant social outing for patients and carers Complementary therapies are worth waiting for!* *Opportunity to compare notes & get tips on useful work around & health issues Referrals are easy to identify & make happen Encouragement for all Mobilisation of the "support community"* Brigid – carer for husband with MND	
495	**St Joseph's Hospice Hackney**	General	General	Economic Aspects – are there initiatives that will save the NHS money? Without doubt CT has a role in providing supportive care in the community delivered in a cost effective way. For example, there is a growing number of people diagnosed with dementia and is one of the biggest global public health challenges facing our generation. Over 35 million people worldwide are currently	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and

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				living with a diagnosis of dementia. This is projected to double by 2030 and more than triple by 2050 to 115 million. (Alzheimer's Disease International 2013). The Namaste project at St Joseph's Hospice recruits, trains and supervises volunteers to visit people with advanced dementia in their homes to offer a befriending service of which CT is an integral part. Hand massage and therapeutic touch is part of the Namaste training offering an extensive package of care to patients and carers in their own homes ultimately improving quality of life and well – being and reducing dependency on acute medical services. The Dying for Change document by Demos (Garber and Leadbeater 2010) states quite clearly that "*To allow people the deaths they want, end of life care must be radically transformed…"* at St Joseph's Hospice Hackney the CT team are leading this radical transformation by developing services that allow people to stay at home longer if that is their preferred place of care (PPC) and/or preferred place of death (PPD). The Demos YouGov poll indicated that 66% of people said they would prefer to die at home. Compassionate community models of care such as compassionate neighbours, the empowered living team and Namaste volunteers are pioneering safe & cost effective models of social care and well – being. These services	palliative care for adults with cancer, they will remain within the published guideline.

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				will be essential in the future as we care for an aging population with complex health and social needs.	
496	**St Joseph's Hospice Hackney**	General	General	Safe and cost effective service models at St joseph's hospice include a team of volunteer complementary therapists. These therapists are: • Qualified, Professional therapists in their own right. • Affiliated with a complementary therapy governing body such as the British Acupuncture Council (BAcC) Complementary Therapy Association (CThA), Complementary and National Health Council (CNHC). • Fully insured • Experienced The recruitment process: • Formal application • 2 references • Formal interview • Enhanced DBS • One day hospice induction • CT induction including a practical session with a CT team lead • Regular supervision at case study meetings (CSM) • Training • Practitioner development session/workshops • Monthly Schwartz Round ® • Weekly seminar • Peer support networks	Thank you for your comment. .

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				• Mentorships The value of the service provided by volunteers for patients, relatives and unpaid carers amounts to £150,000 pa.	
497	**St Joseph's Hospice Hackney**	General	General	Patients undergoing palliative care experience a heavy symptom burden. Family members also experience suffering, anxiety and grief. According to WHO, palliative care is defined as providing - Relief from pain and other distressing symptoms - Enhancing quality of life and may also positively influence the course of illness.	Thank you for your comment.
498	**St Joseph's Hospice Hackney**	General	General	In the course of complementary therapies services at St Joseph's Hospice, records are kept of symptoms that patients, nurses and doctors request support from Complementary Therapies. These conditions are reported in our database and influence treatment protocols. Some of these symptoms and conditions that Complementary Therapies helps address are: - Muscular Skeletal Pain - Internal Pain - Breathing - Sleeping problems - Stress/Anxiety	Thank you for your comment.

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				- Grief - Nausea/Vomiting - Swelling/Oedema - Tiredness/Low energy - Pins and Needles/Numbness - Sweating/Hot flushes - Headaches/Migraines - Digestive Troubles - Relaxation/Wellbeing By addressing these conditions, Complementary Therapies are able to support other medical professional - doctors and nurses and help the hospice achieve these WHO objectives. This is particularly in cases when patients are especially mentally/emotional upset or anxious and also in cases when patient's symptoms are not completely alleviated by their medications.	
314	**St Luke's Hospice**	3	48	We suggest clarifying the definition of supportive care as currently this appears ambiguous in that patients have a life limiting illness but then the definition also includes reference to cure.	Thank you for your comment. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is a common understanding of terms used in the guideline. The terms 'end of life services' and 'care at the end of life' are now being used within a revised scope.

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315	**St Luke's Hospice**	3	59	To add 'contracted' to care settings as some Hospices receive grant funding rather than being commissioned.	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.
316	**St Luke's Hospice**	4	80 & 86	Add 3rd sector organisations to service delivery models	Thank you for your comment. The revised scope lists service delivery models for end of life care, including those covering both acute community and third sector settings as key areas for the guideline.
317	**St Luke's Hospice**	4	82	More and more cancer units are empowering young persons to be actively engaged in their disease management notwithstanding the current legal status it may be beneficial to widen the age parameters for transitional care at the lower end.	Thank you for your comment. This guideline will consider young adults (that is those 18 and over). Indirect evidence for those younger may be considered, pending discussion with the guideline committee. Additionally, 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

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					people using health or social care services (NG43).
318	**St Luke's Hospice**	5	89	As in 4 above.	Thank you for your contribution to the consultation process.
319	**St Luke's Hospice**	5	88	It would be helpful to define what complex bereavement is to clarify whether this is complex due to family or cultural circumstances or something else.	Thank you for your comment. Following a review of all stakeholder comments the focus of the guideline is now on service delivery. 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
320	**St Luke's Hospice**	5	109	We are concerned that the removal of complementary therapy (CT) will have a negative effect in terms of commissioning these services which in turn in our experience would impact on patient care and satisfaction. We appreciate that hard scientific evidence may not be available for all branches of complementary therapy, but a blanket approach of removing is unhelpful. In our experience CT has been absolutely invaluable in helping patients manage their fears, anxiety, loneliness, emotional distress, and	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not

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				other associated physical symptoms which may be unresponsive to medication. We have also had some very good experience with acupuncture which does have an evidence base in this area. Quotes from patients receiving CT at our Hospice are positive for instance one patient stated "I haven't felt this relaxed in months" and another said "I don't want to feel numbed by my medication. This has helped me relax so much, without that numbness. I still feel alive". Many times we hear a patient say that the only thing they look forward to and the thing which gives them the most benefit/ relief is their CT treatment.	updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
321	**St Luke's Hospice**	5	114	We note that social care aspects including management of the loneliness agenda are reflected in the previous NICE guidelines for adults with cancer and feel that it is important that it is recognised that such support networks play a significant part in supportive, palliative and end of life care.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
32	**St Luke's**	7	150,151,	How id quality measured as part of the 'best model' criteria as	Thank you for your comment. Thank you for

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2	**Hospice**		165, 166	defined in each of these lines of the scope. Does this map into the Care Quality Commission new 5 year strategy that is out for consultation.	your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, the list of draft key questions in the scoping document have been amended to reflect these changes. The questions given will be further refined by the guideline committee. Published evidence will be reviewed by the guideline committee and recommendations based on strength and quality of evidence available, according to the NICE guidelines manual.
323	**St Luke's Hospice**	8	186	Patient reported outcome measures (PROMs) as well as patient reported experience measures (PREMs) to be included.	Thank you for your comment. These are the main outcomes. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee.

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269	**Star Throwers cancer support**	5	109	The organisation I work for has volunteer therapists that provide complementary therapies to terminally ill cancer patients and their carers. We see the benefits and receive positive feedback from these vulnerable groups every day. Complementary therapies are a fundamental part of our provision of supportive and palliative care. More research and guidelines are needed to better inform patients of their options and provide organisations of the best practice for providing appropriate complementary therapies. Excluding it from the guidelines is a regressive rather than progressive move towards providing better palliative and 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. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
324	**The Association for Family Therapy and Systemic Practice in the UK**	4	65 to 76	Holistic needs assessment needs to include 'relationships' as a key area for assessment: the relationships that are important to the person and their relatives/carers; the impact of illness on these relationships; and any supportive or therapeutic work that might be indicated.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessment is no longer a priority area for the guideline and will

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					not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence. The questions will be refined when drafting the full review protocol in conjunction with the guideline committee.
325	**The Association for Family Therapy and Systemic Practice in the UK**	General	General	The involvement of a systemic family therapist would be helpful in planning holistic care and providing support to the person and their family as well as support to the wider multi professional care team. "Family-centred care is relevant to cancer genetics, paediatrics and especially palliative care and bereavement, where the stress of illness reverberates through the family and its members come into close relationship with the treating team…. Therapy seeks to foster open communication, rally mutual support and optimise conflict resolution so that by adaptive coping and eventually shared grieving, the family has the capacity to deal with the many losses and transitions involved. Family focused grief therapy has proven efficacy in reducing rates of distress and depression across 13 months of bereavement. Therapeutic skills, techniques and processes are well exemplified herein to guide therapists in	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessment is no longer a priority area for the guideline and will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with

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				the application of this model" (Kissane & Zaider, 2011). Kissane, D. W. and Zaider, T. I. (2011) Focused Family Therapy in Palliative Care and Bereavement, in Handbook of Psychotherapy in Cancer Care (eds M. Watson and D. W. Kissane), John Wiley & Sons, Ltd, Chichester, UK. doi: 10.1002/9780470975176.ch16	available evidence. Recommendations on bereavement can be found in the 2004 guideline.
326	**The Association for Family Therapy and Systemic Practice in the UK**	4	77 to 80 and 84 to 86	A systemic perspective in the planning and delivery of both supportive and palliative care services would benefit the person, the people important to them, and the relationships between them. Life-limiting and life-threatening illness can lead to significant changes in relationships, for example in the roles in relationships, and the sustaining of relationships is likely to significantly benefit the person's experience. This, of course, needs to include impact on children of a parent's illness. Services could consider: how to include people important to the person; how to share information; how changes might be managed. Different families may find different approaches helpful. Services could include educational programmes, which include a focus on relationships (see below), and access to systemic family. Carr (2014) in a review of the evidence for systemic interventions concludes that in chronic physical healthcare, relationship focused family interventions tend to be more effective than	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Family therapy may be included under review of service delivery models, if published evidence is identified.

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				exclusively educational interventions, and that: "*These findings suggest that systemic services for people with chronic illness deserve development as part of multi-modal programmes for people with such conditions, a conclusion consistent with those from other systematic reviews and meta-analyses*" p180. Carr, A. (2014) The evidence base for couple therapy, family therapy and systemic interventions for adult-focused problems. Journal of Family Therapy (36), p. 158-194. A case example: A woman was referred to family therapy through a local hospice. She had advanced cancer with metastatic disease. She was keen to make amends with her co-resident son. There was lots of anger in the household with the son using alcohol to cope with some of the stresses of the situation. Family therapy proceeded with 6 sessions, where mother and son were supported to communicate with each other about the meaning of the illness, and likely prognosis. The therapist worked with them to discuss adaptive coping strategies for the son, allowing the mother to 'complete' her parenting of him prior to her death. Mapping their experience of illness, caring, substance use and thoughts of the future equipped the woman and her son to facilitate a better death for her by managing both of their psychosocial symptoms of distress.	

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327	**The Association for Family Therapy and Systemic Practice in the UK**	6	135 to 141	Tools derived from systemic family therapy would be effective at considering the needs of the person and carers in the context of their family and social networks.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessment is no longer a priority area for the guideline and will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence. Family therapy may be included under review of service delivery models, if published evidence is identified.
328	**The Association**	7	156 to 158 and 171 to 173	Supportive and palliative care services would benefit from the inclusion of a Systemic Family Therapist in the multidisciplinary team, or access to a Systemic Family Therapist for the 1) the	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within

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	for Family Therapy and Systemic Practice in the UK			opportunity for reflective practice about the impact of illness on communication and relationships, 2) the provision of a relational and systemic perspective in educational programmes, and 3) the provision of systemic family therapy.	the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, any recommendations will be informed by the evidence identified for each review. Family therapy may be included under review of service delivery models, if published evidence is identified.
329	**The Association for Family Therapy and Systemic Practice in the UK**	8	183	Measuring outcomes. SCORE-15 Index of Family Functioning and Change SCORE is a self-report outcome measure designed to be sensitive to the kinds of changes in family relationships that systemic family and couples therapists see as indications of useful therapeutic change. It is intended to be serviceable in everyday practice; short, acceptable to clients and usable across the full range of our work - the full range of presenting problems, the clientele, and the formats of work: including individual,	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. Family therapy may be included under review of service delivery models, if published evidence is identified.

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				couple, family and multi-family groups. It is free to use. See: SCORE-15 Index of Family Functioning and Change, The Association for Family Therapy in the UK website: http://www.aft.org.uk/view/score.html	
330	**The Association for Family Therapy and Systemic Practice in the UK**	8	183 to 189	'Relationships' (e.g. functioning, communication, support) needs to be included in outcomes.	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.
331	**The Association for Family Therapy and Systemic Practice in the UK**	11	(247, 248)	Supportive and palliative care needs, needs to include 'relationships' (functioning and wellbeing). Perhaps 'close relationships and social well-being' would be a more useful descriptor.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					Consequently, a new overview diagram will be developed in line with the content and rational of the revised scope.
138	The Chartered Society of Physiotherapy	2	41-44	The Chartered Society of Physiotherapy welcomes the opportunity to comment on this draft scope. We are pleased to see that NICE will be considering inequalities in access to care for people with dementia, cognitive impairment, learning disabilities, or for people who are homeless.	Thank you for your comment.
139	The Chartered Society of Physiotherapy	3	51-55	We are also pleased to see a more inclusive scope of who is covered by this guidelines (i.e. adults with life-limiting disease rather than cancer 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
140	The Chartered Society of Physiotherapy	5	109	Whilst we welcome the inclusion of a holistic needs assessment, we are unclear as to why complementary therapies have been removed from the scope. Other areas have been removed from the scope as they are covered by other guidelines (e.g. communication would be covered adequately in the patient experience guidance CG138). However, it is less clear why	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service

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				complementary therapies have been removed. Further clarification on the rationale behind this is required.	delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, holistic needs assessments will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
141	The Chartered Society of Physiotherapy	5	110	It is also unclear as to why "research recommendations" has been removed – does this mean that if an area of uncertainty arises where the evidence is inconclusive, that recommendations around further research into the area won't be made? Further clarification on this may be 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each

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					review area, the committee sees a gap in evidence, further research will be recommended.
4	**The Disability Foundation**	5	109	The removal of complementary therapy services from the guidance document without any rational for this is astonishing. We would have expected an explanation for the reason for this backed up by evidence. There is a small but growing evidence base for the benefits of complementary therapy services in supportive and palliative care, and many patients look for these treatments. By removing from the guidance it is not helping service providers or patients navigate their way through this area. The fact that there may be inequitable provision of these services to those with a cancer diagnosis compared to others in supportive & palliative care should be flagged if this is the reason. At our centre we offer complementary treatments to anyone in need irrespective of their condition, and have feedback of the benefits that have been experienced by those with a range of conditions to help them deal with the daily side effects of their illnesses, so we would support more equitable guidelines. However by removing mention of these therapies without explanation is perplexing.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
5	**The Disability Foundation**	6	131	Key Issues and questions – we believe that a key issue is what should supportive and palliative care services consist of not just how should they be provided – it is not clear who should make these decisions if recommendations are removed from the	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We

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				guidance, which in term may lead to an inequality of service being offered by location.	will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
64	The Patients Association	1	25	The Patients Association welcomes the NICE guidelines on supportive and palliative care: service delivery. Patients and their relatives often have difficulty understanding the palliative care system and what is available to them. It can be a difficult system to understand and navigate. Measures to make this clearer are warmly welcomed by the Patients Association. The Patients Association's national helpline hears stories of excellent care by NHS palliative care staff which are testament to the hard work of NHS staff. However the Patients Association also receives concerns around access and service co-ordination. There should be equality of access to supportive and palliative care, with all patients and their relatives treated with dignity, respect and kindness regardless of where they live. There also needs to be a commitment to assess and identify the supportive care and palliative care plan that is most appropriate to each patient, regardless of cost. Early and careful end of life planning has to occur for all.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
65	The Patients Association	2	38	The Patients Association agrees that it is important to look at inequalities amongst groups that need special consideration to	Thank you for your comment.

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				ensure they are provided with equal opportunities to access services. People with dementia are a particularly vulnerable group, with patients often distressed and disorientated. Provisions should be made for people with dementia to have their relative staying close to them for reassurance beyond visiting hours if needed, as highlighted by Johns' Campaign. For example, University Hospital Bristol Trust demonstrates good practice through ward staff initiating daily conversations with carers about patient needs. The Patients Association calls for other vulnerable groups to be considered within the guidelines. Patients without relatives often do not have anyone to act as an advocate for them and their individual needs. Such patients should not be disadvantaged by their family circumstances.	
66	The Patients Association	3	53	There should be consideration of the wide variety of staff involved in delivering supportive and palliative care to patients. Delivery of end of life care is highly complex and frequently involves many different organisations and staff.	Thank you for your comment. The groups that will be covered in the revised scope include: adults over 18 with progressive life-limiting conditions thought to be entering the last year of life, health and care professionals delivering end of life services to NHS patients, and carers and/or those important to people accessing end of life services.

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67	The Patients Association	4	64	Key issues that callers have highlighted to us through the Patients Associations helpline include symptom control and access to pain relief. The Patients Association has heard cases of hospitals failing in their medical and nursing competency when diagnosing, delivering and monitoring pain relief.	Thank you for your comment. NICE has developed guidance on pain management and anticipatory prescribing, recommendations on these areas can be found in the Care of dying adults in the last days of life guideline. More details are available at the following link: **https://www.nice.org.uk/guidance/ng31.**
68	The Patients Association	4	78	The Patients Association has heard from a number of patients and their relatives who felt that the service was reactive and in some cases uncoordinated, with relatives forced to act as advocates to pull the service together. Patients and their relatives have also voiced concerns around transfers and discharge from hospitals, with incidences of long waiting times for transport, sometimes in unsuitable conditions without adequate food and drink. Waiting can be particularly distressing to vulnerable groups, such as those with dementia or for lone patients who lack the support of family members, carers or those important to them. Disorientating and disruptive events, such as transfers home or to different wards, should be made as safe and efficient as possible.	Thank you for your comment. The guideline will cover planning and coordinating services, including sharing information between multiprofessional teams and service delivery models for end of life care, which will address location of services, for example place of care.
69	The Patients Association	4	81	24/7 provision of care and access to specialist services is a vital aspect of care that needs to be covered. Patients have often reported to our helpline that out-of-hours service responses can	Thank you for your comment. The revised scope will include service delivery

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				often be less responsive. A rapid response is particularly important for patients being cared for at home.	models for end of life care, and this will address, out of hours, weekend and 24/7 availability of services.
70	The Patients Association	5	104	The Patients Association believes that sharing information between multi-professional teams is crucial. Patients can often be asked the same questions or for the same information from multiple healthcare professionals. This can be bewildering and unnerving. A lack of communication between services can also cause delays in treatment. Important information and decisions about supportive and palliative care needs must be passed on to the relevant professionals. It may be useful to have one named contact acting as a link for people using supportive and palliative care to help "triage" calls and point people towards relevant advice and support. This could help palliative care system be more proactive.	Thank you for your comment. The revised scope will cover service organisation for care in the last year of life and address planning and coordinating services, including sharing information between multiprofessional teams.
71	The Patients Association	6	131	The Patients Association believes that one of the key questions that needs to be asked is how can patients and their carers understanding of what services are available to them be improved? People using supportive and palliative care (and their carers) need to know where they can go to access this information. Vulnerable groups, particularly the elderly, may have problems directing questions and there is a need for increased	Thank you for your comment. The list of draft key questions has been amended to reflect changes to the scope and will focus on service organisation for end of life care services.

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				communication of information. Equally the system needs to be more proactive in meeting the needs of patients and their carers. In order to learn from failures, this should involve proactive consultation with patients and their carers, as well as bereaved family members. Another key issue for supportive and palliative care is access to other services, such as accessing psychological support, where there is often a prolonged wait. This is not acceptable for physical conditions.	
72	The Patients Association	8	186	The Patients Association welcomes the consideration of patient reported outcomes for searching for and assessing evidence.	Thank you for your comment.
73	The Patients Association	12	255	The Patients Association strongly agrees high-quality, timely and compassionate care should be accessible to all those who need it. There has to be equality of access for everyone, regardless of geographical location.	Thank you for your comment, The context section of the scoping document has been amended to reflect changes to the scope.
362	**The Reiki Guild**	1	19-24	The draft scope mentions "other people delivery end of life care services". This includes people delivering complementary therapy servces – especially in hospices who receive NHS funding but also in the community	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will

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					remain within the published guideline.
363	**The Reiki Guild**		19	Removing complementary therapy guidelines is detrimental to service users, families, carers and the public as the guidelines currently serve as a safeguarding measure.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
364	**The Reiki Guild**	2	27	Charitable services delivering palliative care, especially user groups, hospices, Macmillan care etc use complementary therapies. As a safeguarding measure guidelines on complementary therapy are still needed.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
365	**The Reiki Guild**	4	65 – 89	Orthodox medicine in the NHS does not generally address the psychological, social, religious and spiritual well-being mentioned in the context of a holistic needs assessment. These areas are covered in many complementary therapies. Therefore having guidelines for their safe use is essential to support the 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. We will ensure consistency between the new

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				needs assessment	recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
366	**The Reiki Guild**	4	68	The Pepsi-Cola aide-memoire focuses on holistic care and the type of things that complementary therapies can help address. It seems that these guidelines are about much more than physical care and standard orthodox health care. Having guidelines that cover the provision of services which enables holistic needs assessment is therefore essential.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
367	**The Reiki Guild**	5	108-115	What is the rationale for removing these guidelines? They all seem central to support and palliative care services. Given the focus on a holistic approach, the logic is not clear.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					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 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 /
368	**The Reiki Guild**	6	134-148	If holistic needs' assessments are recommended, it is important to give safe guidelines for the services that actually enable these to happen ie complementary therapies in their full range of approaches.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service

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					delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
369	**The Reiki Guild**	8	186-190	Have patients' views been sought about the outcomes and benefits of complementary therapy? Cancer Research says that 33% of all people with cancer access complementary therapies as a support, rising to 50% of people with breast cancer. Should NICE consider accessing satisfaction rates from hospices with complementary therapies or input from the complementary therapy services provided at hospitals e.g. UCH in London	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
370	**The Reiki Guild**	12	250-287	Complementary therapies are provided both to patients and their families at all stages of care, e.g. during chemotherapy, for families as part of carer support during treatment, for patients with on-going symptoms. Complementary therapies are also used in palliative care both in the community, in hospitals and in hospices. Complementary therapies provide key tools for holistic assessment and provision. Therefore guidelines are essential to be kept. In the community complementary therapies are provided for people with many different kinds of conditions from mental health, MS, Lupus, dementia to name but four.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
371	**The Reiki Guild**	13	288-294	If there is such a shortage of specialist support for the dying and complementary therapies can provide holistic support at low cost	Thank you for your comment. Following consideration of all stakeholder comments the

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				for this, in times of budget constrictions, complementary therapy services provide a cost-effective way of supporting more people for less money both in the community and in specialist care centres.	guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
372	**The Reiki Guild**	14	315-316	Complementary therapies can fill some of the needs for holistic support for overlooked groups who need palliative care for on-going disease in a cost-effective way. Removing national guidelines makes no sense given the key role they could play in holistic support for overlooked communities. Has research been conducted into these communities to find what their own preferences are for palliative care. Person-centred care demands that the preferences of the patient are taken 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 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
373	**The Reiki Guild**	14	331-335	Complementary therapy services are well-developed at some teaching hospitals. However for a more equitable and consistent service that takes into account patient preference for patients outside large teaching hospitals guidance on complementary therapies which patients may choose as part of their holistic needs to meet their social, psychological, religious and spiritual well-being. Having national guidelines for the provision of complementary therapies is therefore essential to the success	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and

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				and safety of meeting this provision. Complementary therapies are also ideal for on-going support.	palliative care for adults with cancer, they will remain within the published guideline.
300	**The Royal Marsden NHS Foundation Trust**	2	27	Consideration needs to be given as to how this document will influence and shape care in organisations in the charitable sector or nursing homes that are not NHS commissioned. Many patients with supportive and palliative care needs are cared for in these settings. The quality and continuity of care across organisational boundaries in imperative and impacts considerably on NHS patient pathways	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.
301	**The Royal Marsden NHS Foundation Trust**	2	44	Equality considerations need to include people with a mental health diagnosis in the inpatient setting and prisoners	Thank you for your comment. All settings in which National Health services are commissioned and funded are within the remit of NICE guidance and this includes Prisons. 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.
302	**The Royal Marsden NHS Foundation Trust**	3	52	The document is now not just about cancer so the language of 'life limiting condition' is challenging. Those living 'with cancer' might concur with this but those living 'beyond cancer' might not. The same applies to the professionals working alongside people with cancer. Cancer is now classified as a long term condition but that is not really the same and the semantics are important. Line	Thank you for your comment. The revised scope is dealing with service delivery in the last year of life... Please note that the terminology has been updated to state: progressive life limiting.

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				294 does refer to people who have HAD cancer which does imply it is not life limiting	
303	**The Royal Marsden NHS Foundation Trust**	4	65	HNA is mentioned as a method of ascertaining needs or 'what matters to you' as opposed to 'what is the matter with you' in a person centred manner as per the Health Foundation documents in the context of cancer although not end of life. HNA and indeed the other components of the Recovery Package would assist with this in other diseases or long term conditions.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Holistic needs assessment will not be specifically addressed by any review question, but may be considered as part of service delivery models, in accordance with available evidence.
304	**The Royal Marsden NHS Foundation Trust**	4	79	The AHP professions are critical to the delivery of supportive and palliative care service delivery models. The NHS England Improving Rehabilitation Programme 2015 outlined the economic benefits of rehabilitation as • Early and ongoing assessment and intervention to	Thank you for your comment. Thank you for your comment. The revised scope focuses on service delivery in the last 12 months of life and includes a question on the composition multidisciplinary teams and the types of

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				support timely planning, improve outcomes and aid transition. • Early intensive rehabilitation leading to decreased length of stay in hospital. • Wider economic benefits including helping people to return and remain in work help the elderly to maintain independence and increase active participation in society (NHS England 2015). AHP's work across acute and community settings and have expertise to lead service delivery. e.g. services led by physiotherapy, dietitians, occupational therapists, speech and language therapists and lymphoedema therapists The Living with and Beyond Cancer Agenda jointly driven by NHS England and Macmillan shows evidence that many cancer survivors have unmet needs at the end of treatment whilst others struggle with consequences of treatment which could be avoided or managed better (Macmillan 2013). It is recognised that a focus on supporting patients to live well for longer is required as cancer is increasingly recognised as a long term condition.	services provided.

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

Consultation on draft scope
Stakeholder comments table 3

31/12/15 to 29/01/16

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				Service delivery models to support the consequences of cancer treatment require multi-professional expertise for their effective management. Some aspects of care may well be considered to be supportive or rehabilitative however comprehensive services also require a broad approach incorporating the medical and nursing aspects as well as traditional rehabilitation services.	
467	**Weston Park Cancer Information and Support Centre**	5	109	The removal of complementary therapy appears a backward step. There are many benefits of integrating orthodox medicine with complementary therapies, which can have a reduction on the drugs bill. Shiatsu for using pressure points for pain, nausea and vomiting etc. Auricular acupuncture for hot flushes, nausea and vomiting, pain etc. As supportive and palliative care services have always used a wide range of approaches, including complementary therapies, it seems arbitrary to exclude complementary therapies. There is research which shows it improves quality of life, is this not he principle 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. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
468	**Weston Park Cancer**	5	110	Removing research seems very odd when we should be proving evidence based practice and research better	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within

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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	Information and Support Centre			options for supportive and palliative care patients. Researching to ensure we are using up to date treatments and support in the correct way.	the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, 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.
469	**Weston Park Cancer Information and Support Centre**	5	112	Removing user involvement when this should be at the heart of the new NHS. What do patients and cares want to see? Patient reported outcomes.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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					Recommendations related to user involvement in planning, delivering and evaluating services can be found in the NICE patient experience guideline. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v. Patient-reported outcomes are among the main outcomes that will be considered when searching for and assessing evidence.
470	**Weston Park Cancer Information and Support Centre**	5	113	Face to face communication, I trust this is covered in the HNA as this should be face to face communication and included up to date and relevant information whilst undertaking a HNA	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Consequently, Holistic needs assessments will not be specifically addressed by any review

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					question, but may be considered as part of service delivery models, in accordance with available evidence. 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.
471	**Weston Park Cancer Information and Support Centre**	6	139	Glad to see HNA and carers as this is much needed. To support and asses the carers who are the hidden hero's and save the NHS huge amount of monies throughout the year need support and information to do the caring role.	Thank you for your comment. Following revisions to the scope, 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.
161	**YogaClicks**	5	109	We have nearly 300 clinical studies on YogaClicks that evidence the use of yoga for over 30 health conditions. There are many studies which show the practice of yoga as beneficial to cancer sufferers. http://www.yogaclicks.com/YogaMeds/index We ask that you do not remove yoga as a palliative care 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. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will

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					remain within the published guideline.
374	**Yorkshire & the Humber Strategic Clinical Network**	General	General	There is a lack of consensus or ownership of the definitions given for supportive care, palliative care, and specialist palliative care. Comments from across the region included: a. Palliative care clinicians do not recognise palliative care to be limited to the end of life, and find this categorisation unhelpful (and self-fulfilling)p3. b. Supportive care considered to be a subset of palliative care c. The use of the term 'end of life care' is confusing, being conflated with the Liverpool Care Pathway and therefore last hours/days of life (p12 254-5), and elsewhere used in the definition of palliative care. d. Palliative care definition should also state that it starts at diagnosis many younger people diagnosed with a life limiting condition need extensive symptom management but are not	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The 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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				necessarily end of life	
375	**Yorkshire & the Humber Strategic Clinical Network**	3	47 59	Given the proposed scope of the NICE guideline, the implications for AHPs are likely to be considerable and if the members of the multi-professional specialist palliative care team are to be listed then AHPs should be within this list. Does this mean it excludes those receiving care from a voluntary organisation such as a hospice if so it should be included.	1 Thank you for your comment. The scoping document has been amended to reflect changes to the scope and 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. 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.
376	**Yorkshire & the Humber Strategic Clinical Network**	General	General 82	The vital role of the voluntary/charitable sector is overlooked. This may be technically accurate in terms of the reach of NICE guidance, but is not representative of the field of palliative care services. Reference should include teenage /young adult specific services alongside the reference to adult 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.

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					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)..
377	**Yorkshire & the Humber Strategic Clinical Network**	5	88 108-115	Does this exclude those who may wish to have bereavement care who do not have complex bereavement and it should include siblings parents and possibly grandparents There have been numerous comments from across the region regarding the areas to be removed from the published guideline, most notably complementary therapy services. Without explanation for the omission, there have been suspicions, and anxiety expressed, that such services/components intrinsic to palliative care are not valued. At best this has been viewed as a lost opportunity.	Thank you for your comment. Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in End of life care: service delivery and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations on bereavement can be found in the 2004 guideline.
378	**Yorkshire & the Humber Strategic**	General	General	In the document there is no apparent recognition that the palliative care needs of differing groups of people are likely to require differing service models. There are numerous	Thank you for your comment. After the guideline committee have agreed the review questions and protocols and have considered the published evidence they will make

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	Clinical Network	5	102	examples from across the region of services that have developed and evolved for people with a broad spectrum of life-limiting illnesses including MND, renal disease, COPD, heart failure, dementia. 'One size does not fit all'. Many of these services are outpatient-based. Should outcome measurement be included or will this be covered in holistic needs assessment	recommendations. These may well differ for certain groups of people, but we do not wish to pre-judge the evidence at this stage. These are the main outcomes. When the full review protocols are developed additional outcomes may also be included after discussion with the Guideline Committee.
379	**Yorkshire & the Humber Strategic Clinical Network**	6 13	139 onwards 310-316	Specific reference should be made for those conditions where those affected have a learning disability or those who will lose their capacity Chronic pain services are not stated as being within the scope of the guidelines, whilst reference is made to the inclusion of conditions managed by chronic pain services.	Thank you for your comment.. The equalities issues you raise will be discussed 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. Chronic pain services may be identified and reviewed as part of service delivery models, if published evidence is identified.
380	**Yorkshire & the Humber Strategic**	General	General	How patients expectations will be managed is linked firmly with the definitions of palliative and supportive care and specialist palliative care and it is vital that consideration is	Thank you for your comment. ,The wording of the scope has been amended. The terminology to be used in this guideline will be agreed with the guideline committee to ensure that there is

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	Clinical Network	 12		given to this in the report. If the guideline is to look at the support throughout the trajectory of a condition a reference should be made to the support offered to those where the end of life is unpredictable	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.
381	**Yorkshire & the Humber Strategic Clinical Network**	12	277	If we are to include those who at the age of 18 are already diagnosed with a life limiting condition then we would disagree with the statement for many palliative care is most appropriate throughout the progression of their condition and symptom management can be problematic it is not adequate to only deliver supportive care up to the time "end of life" is recognised	Thank you for your comment.. The context section of the scoping document has been amended to reflect changes made to the scope.
382	**Yorkshire & the Humber Strategic Clinical Network**		296	Disagree with the statement in relation to those who care for children and young adults with life limiting conditions they have predominately been looking after non cancer patients , Many of which are now living into adulthood and will need to transition across to the services outlined in the document	Thank you for your comment. The context section of the scoping document has been amended to reflect changes to the scope. Additionally, 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

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					people using health or social care services (NG43)..