End of life care – service delivery

Consultation on draft guideline - Stakeholder comments table
26/04/2019 to 07/06/2019

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

Organisation name	**Document**	**Page No**	**Line No**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
ASPCP – Association of Palliative and SUPPORTIVE CREA PHARMACY	Guideline	11	1.12.1	Should be noted that access to out of hours pharmacy is desirable but the need for this is much reduced where arrangements for anticipatory prescribing of end pf life drugs (Opioid, benzodiazepine, Anticholinergic and anti-emetic) are in place and promoted in any area, The experience of specialist pharmacists in the field is that this significantly reduces need of emergency supplies out of hours. This practice is widespread and supported by evidence below. Refs: https://www.pharmaceutical-journal.com/opinion/comment/how-a-just-in-case-approach-can-improve-out-of-hours-palliative-care/10019364.article?firstPass=false NICE NG31 https://www.goldstandardsframework.org.uk/cd-content/uploads/files/Library%2C%20Tools%20%26%20resources/ExamplesOfGoodPracticeResourceGuideJustInCaseBoxe https://www.palliativecarescotland.org.uk/content/publications/14.-Anticipatory-prescribing-for-dying-patients.pdf Cost and drug waste can be cited as barriers but the cost of a typical set of medications in less than £50 - and while medication is returned unused the savings from being able to maintain patients at home as per their wishes and the avoidance of distress as medication is where it is needed at the time it is needed far outweigh this.	Thank you for your comment. The committee agrees there are variations in the provision of out of hours pharmacy across the NHS and that the need will be determined by local needs. This review evaluated the effectiveness of out of hours services provision and did not evaluate the use of anticipatory prescribing. The committee agree this may have an impact on the need for out of hours services and have added text on anticipatory prescribing and its potential impact into the 'other factors the committee took into account' section of Evidence review K.
Association of	Recommendation	4	12	In our collective experience as neurologists, a major barrier to people with life-limiting neurological diseases receiving appropriate	Thank you for your comment.

British Neurologists				health and social support in the community is a poor level of understanding of the severity and impact of these conditions, in social care professionals especially. The implementation of this NICE guidance will require improved education of health and social care professionals.	
Association of British Neurologists	Recommendation	4 And 12	4 And 8	The definition of "people approaching the end of life" as "when they are likely to die within the next 8-12 months", is potentially prejudicial to people with the kind of life-limiting conditions seen in neurological practice (eg; motor neuron disease, rapidly progressive forms of dementia and other neurodegenerative diseases). These conditions are always fatal but patients face a longer period of pre-terminal decline in function and quality of life, typically a couple of years. Such neurological conditions often involve advance care planning with palliative care teams at a relatively early stage, even from diagnosis. Thus, the challenges associated with having a terminal condition are typically present before the 8-12 month time period. Our concern is that such a specific definition of "end of life" will exclude patients with neurological disease from services and support they desperately need.	Thank you for your comment. The committee agrees that the terminology and definitions used in this area can vary. To clarify that this guideline could apply to people that need end of life for more than a year the following sentence has been added to the context and terms used in the guideline sections, 'Although for some conditions care could be provided for months or years.' The NICE guideline on Motor neurone disease: assessment and management has been cross reference to the advance care planning section of the guideline.
Association of British Neurologists	Recommendation	4 and 12	4 and 8	Furthermore, although patients are aware that they have a life-limiting condition from the point of diagnosis, the prognosis in terms of months is governed by many factors and is difficult to specify with precision at that stage. Therefore, this definition fails to capture the challenges involved in the natural history of neurodegenerative diseases and appears to be based on cancer where there may be a more predictable terminal phase before death, once treatment options have been exhausted. Our concern is that such a specific definition of "end of life" is difficult to achieve in neurological diseases, and, as in point 1, will exclude patients with neurological disease from services and support.	Thank you for your comment. The committee agrees that the terminology and definition used in this area can vary. The following sentence has been added to the context and terms used in the guideline sections, 'Although for some conditions care could be provided for months or years.' The NICE guideline on Motor neurone disease: assessment and management has been cross reference to the advance care planning section of the guideline.
Association of British Neurologists	Recommendation for research	14	1	The evidence for timing of palliative care involvement in life-limiting neurological conditions in relation to overall outcomes is lacking. The recommendations should make explicit reference to conditions other than dementia (eg; motor neuron disease, multiple system atrophy, progressive supranuclear palsy, terminal multiple sclerosis).	Thank you for your comment. This additional wording has been added,' for example in patients with progressive organ failure, such as advanced heart failure, or patients with life-limiting neurological disease, such as motor neuron disease or dementia. The NICE guidelines on Motor Neurone disease: assessment and management have been cross referenced in the advance care planning section.
Association of	Recommendation	15	21	In our experience, the failure for people to die in their 'preferred place of death' is intimately linked to unplanned admission to	Thank you for your comment.

British Neurologists	for research			hospital, as well as to delayed discharge. We believe that an important gap in evidence exists about the factors governing unplanned admission in the later phases of terminal disease (specifically for neurological conditions), and that the Committee should consider adding this as a recommendation for research.	The aim of the guideline in recommending ; improving the identification of people approaching the end of their life, assessing and reviewing their needs, supporting carers, ensuring advance care planning is offered, improving communication across services, ensuring co-ordination of care in a multipractitioner team, and providing out of hours care would help to prevent and reduce unplanned admission and support people preferences for where they would like to to be cared for and die.
Barnsley District EOLC Steering Group,	Guideline – Rationale and Impact section	17	4 - 8	The guideline states: “The recommendations are expected to increase the number of people identified. However, this is not likely to have a significant resource impact because early identification will ensure that people approaching the end of their life will receive the appropriate care, and their carers will receive support, which will help to avoid unnecessary hospital admissions.” Comment: We are concerned that this recommendation may imply that resource is not required. As this recommendation will be a challenging change in practice because the are resource implications in primary care and community services including social care which need investment upstream, before any expected savings can be accrued in secondary care by reducing unwanted admissions. In addition, given demographic change and increasing numbers of people with EOLC needs anticipated over coming years is it realistic to expect meeting this need to be cost neutral as it will need increases.	Thank you for your comment. The text has been revised to “The recommendations are expected to increase the number of people identified. The net impact on services is uncertain. Some investment will be required to establish systems to systematically identify patients in some areas. However, this will ensure that people approaching the end of their life will receive the appropriate care, and their carers will receive support, which will help to avoid unnecessary hospital admissions.”
Barnsley District EOLC Steering Group,	Guideline – Rationale and Impact section	24	24 - 28	The guideline states “The recommendations reflect current good practice available in some services, but there is variation nationally. Care that meets the person's identified needs and is delivered by health and social care practitioners with the relevant skills may reduce costs by minimising crises and helping to avoid emergency unplanned care and unnecessary hospital attendances and admissions.” There are initial resource implications in primary care and community services including social care which need investment upstream, before any expected savings can be accrued in secondary care by reducing unwanted admissions.	Thank you for your comment. This text has been added to the end of this paragraph: “However, this will require some investment upstream”.
Barnsley District EOLC Steering Group,	Guideline – Rationale and Impact	General	General	We experience challenges in resourcing improvements in access for patients and families (particularly those with non-cancer diagnoses) due to: Workforce availability and quality of care - capacity in social care in nursing/care home staff who have skills and quality issues due to	Thank you for your comment. The committee are aware that the resource impact of this guideline will be uneven across the country and between sectors. There will need to be investment in some areas.

	section			high turnover, areas with low numbers of GPs and lack of primary care resource in some areas of England. Some of this results in physical and emotional cost to carers at a time where social care is stretched. Improvements with integration between social and healthcare requires resource as well as leadership, as outlined in the NHS 10 year plan. It is not always feasible to have MDT in one location and IT investment and infrastructure is required to move forward with integration. Recent local work to improve coordination of care through developing and implementing an EPaCCs system has required charitable funding in addition to that which has been paid for by NHS. This work faces ongoing challenges, not only with funding for staff time to implement and educate, but also entrenched problems with IT systems interoperability. In our experience we find that the GP contract is a lever we can use to develop this work and the CCG has locally additionally incentivised GP practices to improve EOL ie. Adopt EPaCC's and increase palliative care register percentage numbers .	In several sections of the Rationale and Impact section we have now been more explicit that investment will be required. The GP contract is not within the remit of this guideline, although clearly this could be one mechanism for facilitating implementation of these recommendations.
Basildon and Thurrock University Hospital NHS FT	Guideline	11	11	We support the concept of an out-of-hours advice line and would appreciate more explicit guidance around the hours of operation (should this be 24/7?) to inform service planning and commissioning	Thank you for your comment. The evidence identified did not allow the committee to propose any explicit guidance around the hours of operation and this is discussed in evidence review K in the committee's discussion of the evidence. In addition, the committee noted that the need for out of hours services and their operationalisation will depend on the local services already available and will vary accordingly.
Basildon and Thurrock University Hospital NHS FT	Guideline	11	12	We support the concept of out-of-hours access to pharmacy. Again, we would appreciate more explicit guidance around access hours (eg should this be 24/7 or would 100 hours/ week in line with extended pharmacy hours be sufficient?) to inform service planning and commissioning.	Thank you for your comment. The evidence identified did not allow the committee to propose any explicit guidance around the hours of operation and this is discussed in evidence review K in the committee's discussion of the evidence. In addition, the committee noted that the need for out of hours services and their operationalisation will depend on the local services already available and will vary accordingly.
British Cardiovascular Society	Guideline	6, 7, 11 Sections: 1.5, 1.6 1.11	General	Consideration needs to be given to patients with cardiac implantable electronic devices (CIEDs), specifically implantable cardioverter defibrillators (ICDs). Such devices will invariably need to be deactivated towards the end of life to prevent unwanted and inappropriate therapy (shocks) from the device. This may also form part of an advanced directive from the patient and should be considered if a patient is approaching a generator	Thank you for your comment and information. This is a very specific example for patients with cardiac implantable electronic devices and it is difficult within a NICE guideline to include all examples of considerations that should be taken into account for all patient groups that are considering advance care planning. While the recommendations here are non-

				change. Furthermore, such patients will usually have the device checked (and therefore deactivated) at the implanting centre. Consideration needs to be given to travel for such appointments and also the possibility of deactivation at home. An important issue is the patient who is approaching their end of life who is admitted to a hospital who may not know they have an ICD nor have the facilities/equipment to deactivate the device. They need to know that a magnet can be used to deactivate the device temporarily. A guidance document has been published by BCS, Resuscitation Council UK and others to cover all these aspects of care: "Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death: guidance from the Resuscitation Council (UK), British Cardiovascular Society and National Council for Palliative Care." Heart 2016; 102 (Suppl 7): A1-A17.	specific to a condition all health and social care practitioners should be taking into account each individuals situation and needs as a fundamental principle of providing optimal care.
British Medical Association	Guideline	11	6-13	A significant proportion of end-of-life care occurs out-of-hours, and it is therefore crucial that providers of out-of-hours care are appropriately resourced and supported. We support the guideline's recommendations that all adults approaching the end of life, their carers, and others important to them should have access to 24/7 care and advice, but are concerned that this will be particularly challenging to implement. The support available to those providing care out-of-hours – for example, access to specialist palliative care advice, access to essential medications and access to basic information, such as patient notes – is incredibly variable between areas. This needs to be addressed with some urgency before this recommendation can be properly implemented.	Thank you for your comment. Evidence report K examines in detail the costs associated with providing out of hours services in the economic evidence section and in the committee's discussion on cost effectiveness and resource use. The committee agreed that this is good practice and noted there was variation of provision across the NHS. Where the services are lacking there may be a need for resources to set up out of hours services, the specific service will be according to local need and current provision. However, the impact of out of hours services is likely to reduce the pressure on other services (for example hospital admissions) and provides the support system to help people to live as actively as possible until their death. The resource impact report and template include the provision of out of hours services including health practitioner support and pharmacy services. A model has been produced using input from the guideline committee to support commissioners to identify current services levels and estimate other costs likely to have significant impact locally .This can be accessed at.
British Medical Association	Guideline	4	13-15	We are pleased to see the reference in the draft guidelines to the assessment of a patient's holistic needs, and for subsequent care to address those needs. It was clear from speaking with doctors during our project work, however, that some doctors see the medical treatment and physical aspects of pain and symptom relief as their	Thank you for your comment. There is a definition of holistic needs assessment in the terms used in the guideline section and this is described as an assessment that considers all aspects of a person's wellbeing,

				first priority, with the broader aspects of holistic care as a secondary concern and dependent on time available. This is not to say that those doctors saw this broader role as unimportant, but it does further highlight our concern, outlined above, that the lack of time and increasing pressure on doctors will make this provision difficult to implement. It could also be helpful for the definition of “holistic needs assessment” to include some examples of the types of needs that should be considered.	spiritual, health and social care needs.
British Medical Association	Guideline	6	21-23	It would be helpful for this section to note that policies should ensure that advance care planning is being carried out <u>at an appropriate time</u>. We are aware from our work in this area that one of the problems is that advance care planning is often initiated too late for it to be beneficial.	Thank you for your comment. The section on identifying adults who may be approaching the end of their life, their carers and other people important to them makes it clear that advance care planning should be initiated when people are identified as approaching the end of their life. Developing systems to identify people should support earlier identification and in turn earlier advance care planning.
British Medical Association	Guideline	9-10	25-13	We pleased to see the emphasis on co-ordination between primary and secondary care. Doctors we engaged with during our project work were resounding in their view that where end-of-life care works well, it was because care was effectively co-ordinated. Very often, however, there is an assumption amongst doctors that it is already happening, or that it is the responsibility of another team. We are concerned that this section will be challenging to implement as currently worded – rather than referring to “health and social care practitioners providing end-of-life care coordination”, we believe it would benefit from referring to the “lead health professional” or a “named health professional”. This would ensure there is an identifiable and accountable individual leading on coordination of care.	Thank you for your comment. The committee discussed this when deciding on the terms used to describe health and care practitioners in the providing end of life care coordination and in reviewing current treatment sections of the guideline. The principle around there being one point of call is maintained and sits with the lead health care professional (see the reviewing current treatment section and the definition of lead health care professional in the terms used in the guideline) and within the multidisciplinary team but a named healthcare professional was considered too prescriptive. The committee described that in their experience this can create gaps when the professional named is on a day off or an annual leave. In the end of life care section it is clear that someone should be given information on who the multipractitioner team members are (this should include the lead healthcare professionals in each setting responsible for their care), the roles of the team members and how services are accessed. The bullet points in this recommendation reflect what end of life care coordination should look like, who delivers it will depend on the local services.
British Medical	Guideline	General	General	The British Medical Association (BMA) is an apolitical professional association and independent trade union, representing doctors and	Thank you for your comment.

Association				medical students from all branches of medicine across the UK and supporting them to deliver the highest standards of patient care. Throughout 2015, we undertook a major project seeking views from doctors and members of the public on their experiences, views and perceptions of end-of-life care and some aspects of physician-assisted dying. We published our final report in three volumes: a literature review of existing evidence; a report of the findings of the public dialogue events; and reflections and recommendations for action. All three volumes are available to download from www.bma.org.uk/endoflifecare, and you may find the final volume, which summarises our findings and recommendations, particularly helpful. Many of the findings of the project align with the recommendations in this draft guideline, in particular, the importance of having systems in place to identify patients approaching the end of life; an emphasis on a holistic approach to end-of-life care; and the importance of ensuring co-ordination of care and out-of-hours access. We therefore very much welcome this draft guideline and believe it addresses a number of current shortcomings in the provision of end-of-life care. The remainder of our submission outlines a few more specific concerns in relation to the implementation of the guideline.	
British Medical Association	Guideline	General	General	We are very much supportive of the emphasis the guideline places on provision of information, high-quality communication, and advance care planning. We are concerned, however, that this will be challenging to implement in practice. In speaking to doctors as part of our 2015 project work on end-of-life care, it was clear that one of the biggest challenges to providing high-quality care was the lack of time they had available to them to do so: time to have difficult conversations with patients and their families; time to speak with other doctors and teams involved in patient care; and time to provide emotional support to meet the holistic needs of patients. This has only been exacerbated in the intervening years, with doctors working in increasingly pressurised systems and having to manage large workloads in resource-poor settings. Careful consideration should be given as to how time is allowed to ensure individual patient needs can be met, for example by ensuring that rotas, work patterns, and appointment times take this into account.	Thank you for your comment. The committee agrees the guideline reflects good practice and that there is variation in the implementation and delivery of these standards of care across the NHS. There are areas that may need support and investment to implement some recommendations in the guideline.
British Medical	Guideline	General	General	The guidelines appear to be very much drafted with patients with capacity to make decisions in mind. It could be helpful to consider	Thank you for your comment.

Association				whether the guidelines could also address the specific challenges relating to the care and treatment of patients who lack capacity – similar to the provisions included under Section 1.6, on advance care planning.	There is reference to the Mental Capacity Act 2005 in recommendation 1.6.2 and the NICE guideline on decision-making and mental capacity is cross referenced in recommendation 1.6.3. This guideline provides support for health and social care practitioners to address the specific challenges relating to the care and treatment of patients who lack capacity.
Compassion in Dying	Guideline	General	General	The guidelines seem to cover only adults who have capacity to make treatment and care decisions. We recommend a note should be included about what to do or which guidance document/s would apply if the person approaching the end of life does not have capacity to make treatment and care decisions.	Thank you for your comment. There is reference to the Mental Capacity Act 2005 in recommendation 1.6.2 and the NICE guideline on decision-making and mental capacity is cross referenced in recommendation 1.6.3. This guideline provides support for health and social care practitioners to address the specific challenges relating to the care and treatment of patients who lack capacity.
Compassion in Dying	Guideline	General	General	Compassion in Dying has supported over 44,000 people to plan ahead in line with the Mental Capacity Act and we believe these guidelines would benefit from reflecting the real concerns people have about their end of life care, which are much broader than the place of care. For example, some of the questions we get asked on our free information line include: “I have Lasting Power of Attorney for Health and Welfare for my father, why are the doctors not listening to me?” “How do I make sure I am not given artificial nutrition when I have dementia?” “How can I make sure that the paramedics know I don’t want to be resuscitated?” To help reflect real people’s experiences in the guidance please see our report - “I wish I had known…”- https://compassionindying.org.uk/library/i-wish-i-had-known/ the launch of which was attended by NHS England, the BMA and the RCP. We also strongly recommend referring to recent case law which highlight the importance of advance care planning and legally binding advance decisions in particular: - Briggs v Briggs & Ors [2016] EWCOP 53 - Mr Justice Charles noted that if Mr Briggs had made an advance decision it would have been decisive - Brenda Grant (2017) - Mrs Grant was given life prolonging treatment against her wishes for 22 months following a severe stroke, when the hospital caring for her lost her	Thank you for your comment There is reference to the Mental Capacity Act 2005 in recommendation 1.6.2 and the NICE guideline on decision-making and mental capacity is cross referenced in recommendation 1.6.3. This guideline provides support for health and social care practitioners to address the specific challenges relating to the care and treatment of patients who lack capacity.

				legally binding Advance Decision to Refuse Treatment https://www.hsj.co.uk/end-of-life-care/the-tragic-brenda-grant-case-should-be-a-wake-up-call/7021361.article - NHS Cumbria CCG v Rushton [2018] EWCOP 41 – Hayden J noted that the medical profession must give advanced decisions the utmost care, attention and scrutiny. - Mr Y [2018] UKSC 46 - Judicial approval not needed for withdrawal of life-prolonging treatment from people with a prolonged disorder of consciousness, where family and doctors agree	
Compassion in Dying	Guideline	Pg 4	Line 15	To avoid having to make decisions at a time of crisis, we suggest replacing “ when it is needed” with “in a timely manner”	Thank you for your comment. In this recommendation when needed refers to the support and not the assessment.
Compassion in Dying	Guideline	Pg 4	Line7 and 8	As advance care planning is not only about preferred place of care, we suggest amending this sentence to read”…help people get the treatment that is right for them in their preferred place of care.” Having supported people to plan ahead for over 12 years and to understand the laws and policies around end-of-life decision-making, we know that people are willing to accept the reality that they may need to be moved from home to a different care setting. However, many are not willing to accept CPR or CANH in certain situations. Therefore, discussing advance care planning only in reference to place of care disregards many other aspects of end of life care that are important to people. Moreover, the focus on place of care disregards the fact that socio-economic status, rather than advance care plans, plays a significant role in determining where someone is cared for. Therefore, if honest and meaningful conversations about planning are to take place, they must necessarily cover all aspects of care and not just location.	Thank you for your comment. The committee agrees that this wording may have been misinterpreted and have revised the text ‘to stay in their preferred place of care’ to where they would like to be cared for and die’. Usual place of residence has been revised to place of residence.
Compassion in Dying	Guideline	Pg 5	Line 16	In line with the emphasis being placed by the NHS on social prescribing, and in recognition that healthcare professionals will not be able to provide all the information a person will need and want, please add – “systems to signpost them to additional sources of information including local and national support services and charities”	Thank you for your comment. This wording has been revised.
Compassion in Dying	Guideline	Pg 5	Line 21	Add additional bullets - Processes to provide ongoing training and support to healthcare professionals on building and maintaining communication skills that enhance patient participation	Thank you for your comment. This recommendation is directly about what processes, systems and arrangements should be in place to deliver information and

				- Processes to maintain the knowledge of healthcare professionals about legal developments that impact end-of-life care (e.g. Court of Protection judgments relating to the Mental Capacity Act)	not about the training of healthcare professionals.
Compassion in Dying	Guideline	Pg 5	Line 3	Please add – "…to carry out holistic needs assessments with an understanding that people can make decisions they (practitioners) may consider unwise"	Thank you for your comment. The choice of the person to make decisions about their care is fundamental to good practice and the committee have not added this. Although the wording in recommendations 1.6.1, and1.10.4 (from provide and done to offer) have been edited to reflect this point about choice.
Compassion in Dying	Guideline	Pg 7	Line 5 - 7	This is not an accurate statement about making decisions when a person lacks capacity. We suggest deleting it from this section and including it in a new recommendation which could be titled: "Making decisions when a person has lost capacity" We recommend this states: "If a decision needs to be made for someone who has lost capacity, healthcare professionals first need to find out if a Lasting Power of Attorney for Health and Welfare has been appointed and if yes, decisions will rest with them. Healthcare professionals also need to identify if a valid and applicable Advance Decision to Refuse Treatment exists, and if yes, decisions should be made accordingly. If neither of these two documents exists, then a best interest decision would need to be made which would include taking into account advance statements and views of carers and other people important to the person approaching the end of life." Please see the BMA/RCP guidance for a very useful flowchart on decision-making. While it refers to CANH, the principles apply to making decisions when a person lacks capacity in line with Mental Capacity Act - https://www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration/decision-making-process	Thank you for your comment. This recommendation on advance care planning has been separated into two recommendations to ensure that the issue of advance care planning and decision making and mental capacity are not conflated.
Compassion in Dying	Guideline	Pg 7	Line1	For effective advance care planning to take place it is vital that the tools available for doing so are well understood by both the patients and healthcare professionals. Not being specific about the legal tools available risks denying people the ability to make decisions about their care in a meaningful way. We strongly recommend adding the following bullet point:	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people important to them. The reviews did not evaluate the clinical and cost effectiveness of different assessment tools.

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				"support people to understand the legal options available for planning ahead such as by a completing an Advance Statement, Advance Decision to Refuse Treatment, a Lasting Power of Attorney for Health and Welfare, a DNAR form and/or TEP/RESPECT form" Please see our Freedom of Information report on the lack of uniform commitment to the Mental Capacity Act and the poor care that results as a consequence of that. https://compassionindying.org.uk/library/advance-care-planning-in-general-practice-does-policy-match-reality/	The definition of advance care planning lists possible areas for discussion and includes preferences and wishes for types of care or treatment in the future and discussion of the care available.
Compassion in Dying	Guidelines	Pg 10	Line 10	Please add – "ensure that a clear decision-making process exists, with reference to Lasting Powers of Attorney and Advance Decisions to Refuse Treatment, where the person has lost the capacity to make their own decisions"	Thank you for your comment. There is reference to the Mental Capacity Act 2005 in recommendation 1.6.2 and the NICE guideline on decision-making and mental capacity is cross referenced in recommendation 1.6.3.
Compassion in Dying	Guidelines	Pg 12	Line 12	Please add –Advance care plans may be documented using Advance Decisions to Refuse Treatment (legally binding if valid and applicable), Lasting Powers of Attorney for Health and Welfare, Advance Statements, DNAR forms, TEP/RESPECT forms. As mentioned above, not being specific about the tools available for advance care planning risks denying people the ability to make decisions about their care in a meaningful way.	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address the clinical and cost effectiveness of tools and how health and social care professionals should deliver and assess care needs.
Compassion in Dying	Guidelines	Pg 14	Line 10	We suggest working with the Professional Records Standards Body (PRSB) on this	Thank you for your comment and suggestion.
Compassion in Dying	Guidelines	Pg 16	Line 17	As place of care is only one of many priorities, please amend this sentence to read – "…to help them get the treatment that is right for them in their preferred place of care."	Thank you for your comment. The committee agrees that this wording may have been misinterpreted and have revised the text 'to stay in their preferred place of care' to where they would like to be cared for and die'. Usual place of residence has been revised to place of residence.
Compassion in Dying	Guidelines	Pg 8	Line 10	Please add – "including ambulance trusts" as many now have systems to either hold copies of Advance Decisions and DNAR forms or flag addresses accordingly. See our recent report for more information - *The role of Ambulance Trusts in respecting people's end-of-life wishes (2018)*https://compassionindying.org.uk/library/the-role-of-ambulance-trusts-in-respecting-peoples-end-of-life-wishes/	Thank you for your comment. Ambulance trusts has been added.
Compassion in	Guidelines	Pg 8	Line 23	So as not to ignore other aspects of treatment and care that may be important to the person, please amend the 3rd bullet to read –	Thank you for your comment.

Dying				"support people to get the treatment that is right for them in their preferred place of care, if possible"	The committee agrees that this wording may have been misinterpreted and have revised the text 'to stay in their preferred place of care' to where they would like to be cared for and die'. Usual place of residence has been revised to place of residence.
Compassion in Dying	Guidelines	Pg 9	Line 5	In line with the emphasis being placed on social prescribing, and a recognition that healthcare professionals will not be able to provide all the information a person will need and want, please add a sentence after the bullet points that reads: "For people who need social, financial and legal support, signpost to local and national support services and charities including peer support services"	Thank you for your comment. This text has been added to the bullet point,' and third-sector, local or national support services'.
Cruse Bereavement Care	Guideline	13	1	The guideline should include specific reference to the needs of the carers being part of the holistic assessment undertaken. It should be recognised that support to address the dying person's concerns and problems may include ensuring support is provided for their carers/family/loved ones after the person nearing the end of their life has died. This should be included within the guideline.	Thank you for your comment. The committee considered it was important that the recommendations on the assessment and needs of the carers were given prominence by having specific recommendations. The committee agreed the concerns of the dying person about their carers/family/loved ones should be explored during the holistic needs assessment and the definition of holistic needs assessment in the terms used in the guideline section is clear that this is an assessment that considers all aspects of a person's wellbeing, spiritual, health and social care needs.
Cruse Bereavement Care	Guideline	16	2 – 4	The guideline should include reference to the impact of not dying in their preferred care setting, on the person who is dying and their carers, family and loved ones. The consequences of a person dying in a setting which is inappropriate or not their preferred place of care has an impact upon them and their carers and loved ones. The carers, family and loved ones' distress at the death may be exacerbated by the knowledge that it did not happen as the person who died wished. Where needed, bereavement support or counselling may be needed and should be available.	Thank you for your comment. The committee agrees and additional wording about the impact of a person dying in a setting which is inappropriate or not their preferred place of care has been added into the introduction and committee discussion sections of evidence review M.
Cruse Bereavement Care	Guideline	18	2	We are concerned that as the legislation does not explicitly require assessment of pre and post bereavement support needs for carers, assessment of their needs will not include this vital part of their needs. We would like to see this included in the guideline for assessment of holistic needs.	Thank you for your comment. The committee agreed the concerns of the dying person about their carers, family, or friends should be explored during the holistic needs assessment. However, the committee considered it was important that the recommendations on the assessment and needs of the carers were given prominence by having specific recommendations and are not conflated with the holistic needs assessment of the person approaching the end of their life.

					Although this guideline did not explicitly address bereavement the added recommendation 1.3.1 is clear that people managing and delivering services should consider what practical and emotional support can be provided to carers.
Cruse Bereavement Care	Guideline	19	20-23	We support this recognition and recommendation that assessment of carers' needs should go beyond the statutory requirements. See comment number 2 above.	Thank you for your comment. To note that after taking into account different stakeholder comments an additional recommendation has been added to the supporting carers section reflecting that people managing and delivering services should consider what practical and emotional support can be provided to carers.
Cruse Bereavement Care	Guideline	5	4	The guideline should include reference to assessment of the carer's, family's and loved ones' need for bereavement support or counselling before and after the person they are caring for has died, as part of the holistic assessment of need. Carrying out an assessment in line with the requirements of The Care Act 2014 would not necessary cover this as it does not include reference to the cared for person dying, or the needs of the carer after the cared for person has died. Carrying out an assessment in line with the requirements of The Children & Families Act 2014 may also not cover this as the Act does not refer specifically to bereavement support: it should be covered by section 172C (consideration of young carers' needs assessments (a) whether the young carer has needs for support in relation to the care which he or she provides or intends to provide). However, as it is not explicitly stated in the Acts, it should be covered in this guideline.	Thank you for your comment. The committee considered it was important that the recommendations on the assessment and needs of the carers were given prominence by having specific recommendations. The committee agreed the concerns of the dying person about their carers, family and friends should be explored during the holistic needs assessment and the definition of holistic needs assessment in the terms used in the guideline section is clear that this is an assessment that considers all aspects of a person's wellbeing, spiritual, health and social care needs. An additional recommendation has been added to the supporting carers section reflecting that people managing and delivering services should consider what practical and emotional support can be provided to carers.
Cruse Bereavement Care	Guideline	7	19	Assessment of holistic needs may include their concerns about family, carers and friends coping after they have died and this should be included in the guideline. Knowing their loved ones will receive appropriate support may contribute to the person who is dying have a 'good death'.	Thank you for your comment. The committee agreed the concerns of the dying person about their carers, family, or friends should be explored during the holistic needs assessment. However, the committee considered it was important that the recommendations on the assessment and needs of the carers were given prominence by having specific recommendations and are not conflated with the holistic needs assessment of the person approaching the end of their life. Although this guideline did not explicitly address bereavement the added recommendation 1.3.1 is clear that people managing and delivering services should consider what practical and emotional support can be provided to carers.
Cruse	Guidelin	General	General	Good palliative and end of life care includes giving care and support	Thank you for your comment.

Bereavement Care	e			to families, friends, carers and all those who are important to the dying person. This support must encompass good bereavement and pre-bereavement care, including for children and young people. It must also respond to the needs to those who are affected by death caused by sudden illness or trauma, including suicide (Ambitions for Palliative & End of Life Care 2015). We are concerned that this guideline does not specifically set out the need for bereavement support for carers and other people important to adults who are approaching the end of their life. Whilst the guideline recognises the need to identify and recognise these people and ensure they are supported to help care for the person who is approaching the end of their life, this must include provision of pre and post bereavement support. This support would be of benefit to the person who is approaching the end of their life and their carers & those important to them. There is growing evidence that, where possible, bringing about a 'good death' for the person who is dying also brings benefits for their carers (Kreicbergs et al 2005, McCarthy et al 2010, van der Geeest et al 2014, Jalmsell et al 2010, Wright et al 2008). Supporting carers' preparedness for the death may have benefits for bereavement outcomes (Caserta et al 2017). Around half a million carers are involved in some kind of end of life care provision each year (NCPC 2012, Payne and Morbey 2013) and, given population projections, mortality trends, policy influences and public wishes, the number of people caring for someone at the end of their lives is likely to increase (Payne and Morbey 2013, Calanzani et al 2013). At the point immediately before the death, carers as a group have higher levels of distress than most non-carers as a result of the strain of caring (Schutz et al 2008, Chentsova-Dutton et al 2002). So even if their distress reduces over time, this does not necessarily mean a return to 'normal' (Breen 2012). The needs of someone at the end of life and their carer are intertwined and mutually reinforcing: lack of support for the carer may have negative implications for the patient (Hudson and Payne 2009) and poor care for the patient can affect the carer's grief.	The committee agreed the concerns of the dying person about their carers, family, or friends should be explored during the holistic needs assessment. However, the committee considered it was important that the recommendations on the assessment and needs of the carers were given prominence by having specific recommendations and are not conflated with the holistic needs assessment of the person approaching the end of their life. Although this guideline did not explicitly address bereavement the added recommendation 1.3.1 is clear that people managing and delivering services should consider what practical and emotional support can be provided to carers.
Dementia UK	Equality Impact	Page 1	Section 3.1	Dementia UK welcomes a focus and distinction between the needs of those living with frailty (young or old), ageing, learning disabilities	Thank you for your comment.

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	Assessment			and young carers as well as co-morbidities and dementia. It is an important area for further research and service delivery.	The committee agrees and in first research recommendation for note that the evidence for people with a non-cancer diagnosis, for example in patients with progressive organ failure, such as advanced heart failure, or dementia is limited.
Dementia UK	Equality Impact Assessment	Page 1	Section 3.1	Dementia UK welcomes a focus on the needs of young adults at the end of life – for us this also includes consideration of young onset dementia.	Thank you for your comment.
Dementia UK	Recommendations	Page 10	Line 14	We wish to highlight the recommendations that from diagnosis, to offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be, see: ○ Dementia: assessment, management and support for people living with dementia and their carers, NICE guideline [NG97] Published date: June 2018 The impact of behavioural change, delirium and reduced function in the last year or so of life in dementia and family carers' response to this, often making decisions in crisis, as a proxy decision maker rather than a more proactive approach with a good understanding of what is happening and why. This uncertainty for carers and belief sometimes that the 'medical profession ' can solve problems/reach solutions is what often triggers admissions to care. So a multidisciplinary community approach including Admiral Nurses will have an impact on practice. Currently it is episodic care between GP and memory services but there is a huge gap as dementia progresses.	Thank you for your comment. The NICE guideline Dementia: assessment, management and support for people living with dementia and their carers, [NG97] has been cross referenced in the advance care planning section.
Dementia UK	Recommendations	Page 10	Line 14	Emergency Department attendance in the last year of life for people with dementia is common and is increasing. Policy makers must pay attention to a broader range of indicators of poor end-of-life care alongside the place of death, see: Sleeman, K.E., Perera, G., Stewart, R. and Higginson, I.J., 2018. Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data. *Alzheimer's & Dementia*, *14*(1), pp.20-27.	Thank you for your comment.
Dementia UK	Recommendations	Page 11	Line 1	There is evidence on the importance of understanding the patterns of use of emergency and ambulance services (e.g. dementia, co-morbidities, frailty) and we welcome an emphasis and support for the emergency services, see: Voss, S., Brandling, J., Taylor, H., Black, S., Buswell, M., Cheston, R., Cullum, S., Foster, T., Kirby, K., Prothero, L. and Purdy, S., 2018. How do people with dementia use the ambulance service? A	Thank you for your comment.

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				retrospective study in England: the HOMEWARD project. *BMJ open*, *8*(7), p.e022549.	
Dementia UK	Recommendations	Page 13 Page 14	Line 22 Line 7	Dementia UK welcomes further research into early referral and service provision for conditions other than cancer, see: Fox, S., FitzGerald, C., Dening, K.H., Irving, K., Kernohan, W.G., Treloar, A., Oliver, D., Guerin, S. and Timmons, S., 2018. Better palliative care for people with a dementia: summary of interdisciplinary workshop highlighting current gaps and recommendations for future research. *BMC palliative care*, *17*(1), p.9.	Thank you for your comment.
Dementia UK	Recommendations	Page 14	Line 7	Dementia UK welcomes further research into early referral and service provision for conditions other than cancer, see: Amador, S., Sampson, E.L., Goodman, C., Robinson, L. and SEED Research Team, 2019. A systematic review and critical appraisal of quality indicators to assess optimal palliative care for older people with dementia. *Palliative medicine*, *33*(4), pp.415-429.	Thank you for your comment.
Dementia UK	Recommendations	Page 14	Line 7	Dementia UK believes that that the Empowering Better End of Life Dementia Care (EMBED) Programme will be key to building a new model of dementia care for peole living with dementia and their carers, see: https://gtr.ukri.org/projects?ref=ES%2FS010327%2F1	Thank you for your comment and this information.
Dementia UK	Recommendations	Page 4	Line 8	It might be helpful here or later in the recommendations to acknowledge here that choices about preferred place of care or death can change, see: Gerber, K., Hayes, B. and Bryant, C., 2019. 'It all depends!': A qualitative study of preferences for place of care and place of death in terminally ill patients and their family caregivers. *Palliative medicine*, p.0269216319845794.)	Thank you for your comment. This is reflected in the reviewing needs section of the guideline where regular discussions and repeat assessments of holistic needs and reviews of advance care plans are recommended.
Dementia UK	Recommendations	Page 4	Line 8	It would be helpful here or later in the guidance to acknowledge that actual place of death with capacity for meeting patient and family needs may be a better quality indicator than simply 'achieved preferences, see: Higginson, I.J., Daveson, B.A., Morrison, R.S., Yi, D., Meier, D., Smith, M., Ryan, K., McQuillan, R., Johnston, B.M. and Normand, C., 2017. Social and clinical determinants of preferences and their achievement at the end of life: prospective cohort study of older adults receiving palliative care in three countries. *BMC geriatrics*, *17*(1), p.271.	Thank you for your comment. The committee agrees that this wording may have been misinterpreted and have revised the text 'to stay in their preferred place of care' to where they would like to be cared for and die'. Usual place of residence has been revised to place of residence.
Dementia UK	Recommendations	Page 4	Line 8	It would be helpful here or later in the guidance to acknowledge that there are positive and negative caregivers experiences of supporting preferred place of death at home, see: Woodman, C., Baillie, J. and Sivell, S., 2016. The preferences and	Thank you for your comment. This is acknowledged, identified in the evidence and discussed in evidence reviews G (involving carers) and H (carer support

				perspectives of family caregivers towards place of care for their relatives at the end-of-life. A systematic review and thematic synthesis of the qualitative evidence. *BMJ supportive & palliative care*, *6*(4), pp.418-429.	services).
Dementia UK	Recommendations	Page 4	Line 8	We are concerned that there is an assumption here that if needs are identified, that there will be support to help people stay in their preferred place despite evidence that further expansion of services, notably community support and palliative care units is required, see: Higginson, I.J., Daveson, B.A., Morrison, R.S., Yi, D., Meier, D., Smith, M., Ryan, K., McQuillan, R., Johnston, B.M. and Normand, C., 2017. Social and clinical determinants of preferences and their achievement at the end of life: prospective cohort study of older adults receiving palliative care in three countries. *BMC geriatrics*, *17*(1), p.271.	Thank you for your comment. The recommendations reflect the evidence base and best practice in the service delivery of end of life care but the committee recognise there is considerable variation in the provision of end of life care services across the NHS. It is important that these guidelines reinforce best practice from a service delivery perspective and highlight the key areas of variation for implementation.
Dementia UK	Recommendations	Page 4	Line 8	We are concerned here that there is a generalisation about access to palliative and end of life care. Most deaths occur in people over the age of 65 years, yet there is widespread evidence that older people have inequitable access to good palliative and end-of-life care. For people with dementia, there are further barriers to receiving palliative care. Identifying when older people with dementia are reaching the end of their lives is not straightforward, see: Dening, K.H., Scates, C. and Lloyd-Williams, M., 2018. Palliative care in dementia: a fragmented pathway?. *International journal of palliative nursing*, *24*(12), pp.585-596.	Thank you for your comment. The committee recognise the disparity in access to end of life care and developed a research recommendation to address this. See research recommendation 1 where the committee include people with dementia as a group of people where limited research has been done.
Dementia UK	Recommendations	Page 4	Line 8	We want to raise the importance for people living and dying with dementia in discussing and agreeing ceilings of treatment to achieve end of life preferences, and the importance of revisiting these preferences as death approaches, see: Wiggins, N., Droney, J., Mohammed, K., Riley, J. and Sleeman, K.E., 2019. Understanding the factors associated with patients with dementia achieving their preferred place of death: a retrospective cohort study. *Age and ageing*.	Thank you for your comment. The committee agrees these are all important principles of end of life care and are raised throughout the guideline. The NICE guideline on Dementia: assessment, management and support for people living with dementia and their carers [NG97] has been cross referenced in the advance care planning section of this guideline.
Dementia UK	Recommendations	Page 4	Line 8	There is evidence that emergency department attendance in the last year of life for people with dementia is common and is increasing. Policy makers must pay attention to a broader range of indicators of poor end-of-life care alongside the place of death, see: Sleeman, K.E., Perera, G., Stewart, R. and Higginson, I.J., 2018. Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data. *Alzheimer's & Dementia*, *14*(1), pp.20-27.	Thank you for your comment and this information. The committee have added text into the committee discussion sections of evidence review M that notes that people with dementia may be at risk of inappropriate care and avoidable transitions to hospital near the end-of-life.

Dementia UK	Recommendations	Page 4 Page 6	Line 9 Line 2	We feel it is important to acknowledge that carers' needs differ from those of patients and should be assessed separately. Carers require support within two broad areas: 1. as 'co-workers' in supporting patients, to ensure carers have the information, skills and equipment for this role 2. as 'clients' in their own right to preserve their own wellbeing and health, see: Ewing G and Grande GE. Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change. London: Hospice UK, 2018)	Thank you for your comment. The committee agrees and this is reflected in the section on supporting carers. An additional recommendation has been added in this section reflecting that an assessment should take place and what practical and emotional support can be provided. NICE is developing a guideline on social work interventions for adults with complex needs, including, learning disabilities and mental health. This is cross referenced in a footnote for recommendation 1.6.5.
Dementia UK	Recommendations	Page 4 Page 6	Line 9 Line 2	Dementia UK has experience of successfully implementing a competency framework for Admiral Nurses enabling evidence of the benefits of specialist nurse support for families affected by dementia and would be willing to submit its experiences to the NICE shared learning database. See: Carter, C., Bray, J., Read, K., Harrison-Dening, K., Thompson, R. and Brooker, D., 2018. Articulating the unique competencies of admiral nurse practice. *Working with Older People*, *22*(3), pp.139-147.	Thank you for your comment. We will pass this information to our local practice collection team. More information on local practice can be found here.
Dementia UK	Recommendations	Page 4 Page 6	Line 9 Line 2	We suggest it is important to strengthen the importance of assessing and supporting end of life carers. Other examples of assessing carers needs separately to patients include the Carers Support Needs Assessment Tool (CSNAT), see : ○ Alvariza, A., Holm, M., Benkel, I., Norinder, M., Ewing, G., Grande, G., Håkanson, C., Öhlen, J. and Årestedt, K., 2018. A person-centred approach in nursing: Validity and reliability of the Carer Support Needs Assessment Tool. *European Journal of Oncology Nursing*, *35*, pp.1-8. and is seen in the Royal College of Physicians and Marie Curie Daffodil Standards (see https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/daffodil-standards/the-daffodil-standards.aspx).	Thank you for your comment. The committee agrees and this is reflected in the section on supporting carers. An additional recommendation has been added in this section reflecting that an assessment should take place and what practical and emotional support can be provided. The reviews did not evaluate the different tools available for the assessment of carers and the support they need. NICE is developing a guideline on social work interventions for adults with complex needs, including, learning disabilities and mental health. This is cross referenced in a footnote for recommendation 1.6.5.
Dementia UK	Recommendations	Page 6	Line 20	Dementia UK has experience of advance care planning recommendations for people living with dementia and would be willing to submit its experiences to the NICE shared learning database, see: Dening, K.H., Sampson, E.L. and De Vries, K., 2019. Advance care planning in dementia: recommendations for healthcare professionals. *Palliative care*, *12*.	Thank you for your comment. We will pass this information to our local practice collection team. More information on local practice can be found here.
Dementia UK	Recommendation	Page 6	Line 20	We feel it is important to recognise that staff may need support with developing skills in Advance Care Planning and facilitating end of	Thank you for your comment.

	s			life conversations and assessing capacity, see: McGlade C., Daly E., McCarthy J., Cornally N., Weathers E., O'Caoimh R. & William Molloy D. (2017) Challenges in implementing an advance care planning programme in long term care.*Nursing Ethics* 24(1)	The committee agrees that health and social care practitioners caring for adults approaching the end of their life should be supported to have the training and skills to sensitively carry out needs assessments and this is reflected in recommendation 1.2.2. on assessing holistic needs. The committee anticipate this would include reference to assessing capacity in this situation.
Dementia UK	Recommendations	Page 6	Line 20	Dementia UK has experience of collaborative partnerships for people living with dementia and would be willing to submit its experiences to the NICE shared learning database, see: Harrison Dening, K., Crowther, J. and Adnan, S., 2018. An Admiral Nursing and hospice partnership in end-of-life care: Innovative practice. *Dementia*, p.1471301218806427.	Thank you for your comment. We will pass this information to our local practice collection team. More information on local practice can be found here.
Dementia UK	Recommendations	Page 6	Line 5	This is evidence that there should be a greater emphasis and start focussing more on attempts to assess and manage the nature and impact of different co-morbidities in people with dementia and be vigilant to the interacting effects between the co-morbidities. Care service provision and organisation of care should have the ability to deal with multiple conditions in an integrated way targeting the interventions to deal with co-morbidities at the groups most at risk, see: Subramaniam, H., 2019. Comorbidities in dementia: time to focus more on assessing and managing comorbidities. *Age and Ageing*.	Thank you for your comment.
Dementia UK	Recommendations	Page 7 Page 10	Line 19 Line 14	The evidence in dementia points out the significance of transitions between care settings near the end-of-life for people with dementia, see: Leniz L, Higginson IJ, Stewart R, Sleeman KE. May 2019 Understanding which people with dementia are at risk of inappropriate care and avoidable transitions to hospital near the end-of-life: a retrospective cohort study.*Age and Ageing*,	Thank you for your comment. The committee agrees that transitions between care settings is very important and note there is little evidence in this area and have made a research recommendation for evaluating the optimal way of discharging people approaching the end of life from hospital. The committee have added text into the committee discussion sections of evidence review M that notes that people with dementia may be at risk of inappropriate care and avoidable transitions to hospital near the end-of-life.
Dementia UK	What would help users overcome any challenges? (For example,			Dementia UK has experience of successfully implementing an approach aimed at supporting family carers of people living and dying with dementia and would be willing to submit its experiences to the NICE shared learning database, see: o Aldridge, Z., Burns, A. and Harrison Dening, K., 2019. ABC model: A tiered, integrated pathway approach to peri-and post-diagnostic support for families living with dementia (Innovative Practice). Dementia, p.1471301219838086 o Gridley, K., Aspinal, F.J., Parker, G.M., Weatherly, H.L.A.,	Thank you for your comment and suggestions. We will pass this information to our local practice collection team. More information on local practice can be found here.

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	existing practical resources or national initiatives, or examples of good practice.)			Neves De Faria, R.I., Longo, F. and Van Den Berg, B., 2019. Specialist nursing support for unpaid carers of people with dementia:: a mixed-methods feasibility study. Health Services and Delivery Research, pp.1-232.). Dementia UK also has experience of successfully implementing a practice and professional development approach aimed at supporting clinicans in practice, see: o Carter, C., Bray, J. and Read, K., 2019. The Admiral Nurse Competency Framework: Encouraging Engagement and Putting It Into Practice. The Journal of Continuing Education in Nursing, 50(5), pp.205-210) For further information please contact commentator: Dr Sarah Russell RGN Admiral Nurse Practice and Professional Development Facilitator sarah.russell@dementiauk.org	
Dementia UK	Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why			The biggest area for impact would include co-ordination of service planning and delivery across health and social care. Admiral Nursing is the only specialist nursing dementia service in the UK with a specific focus on carers. In addition to providing emotional support and helping people to live positively with the condition, Admiral Nurses seek to join up different parts of the health and social care system so that needs can be addressed in a coordinated way. Dementia UK would be willing to submit its experiences to the NICE shared learning database. See: o Gridley, K., Aspinal, F.J., Parker, G.M., Weatherly, H.L.A., Neves De Faria, R.I., Longo, F. and Van Den Berg, B., 2019. Specialist nursing support for unpaid carers of people with dementia:: a mixed-methods feasibility study. Health Services and Delivery Research, pp.1-232. o Gridley, K., 2018. Understanding the outcomes of specialist nursing: the continuing importance of relationships for carers of people with dementia. International Journal of Integrated Care, 18(s2).	Thank you for your comment and suggestions. We will pass this information to our local practice collection team. More information on local practice can be found here.
Dementia UK	Whole document	General	General	Dementia UK is pleased to contribute to this necessary end of life care guidance and we support its development. Our particular focus is regarding people living and dying with dementia and their family carers. We note previous guidance for Care of Dying Adults in the Last Days of Life [NG31] as well as Dementia: assessment, management and support for people living with dementia and their carers [NG97] and Van der Steen, J.T., Radbruch, L., Hertogh, C.M., de Boer, M.E., Hughes, J.C., Larkin, P., Francke, A.L., Jünger, S., Gove, D., Firth, P. and Koopmans, R.T., 2014. White paper	Thank you for your comment. The NICE guideline on Dementia: assessment, management and support for people living with dementia and their carers [NG97] has been cross referenced in the advance care planning section of this guideline.

				defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliative medicine*, *28*(3), pp.197-209.	
Dementia UK	Whole document	General	General	Dementia UK has experience of successfully implementing the Admiral Nurse approach which supports family carers of people living with dementia and would be willing to submit its experiences to the NICE shared learning database. See: ○ Aldridge, Z., Burns, A. and Harrison Dening, K., 2019. ABC model: A tiered, integrated pathway approach to peri-and post-diagnostic support for families living with dementia (Innovative Practice). *Dementia*, p.1471301219838086 Gridley, K., Aspinal, F.J., Parker, G.M., Weatherly, H.L.A., Neves De Faria, R.I., Longo, F. and Van Den Berg, B., 2019. Specialist nursing support for unpaid carers of people with dementia:: a mixed-methods feasibility study. *Health Services and Delivery Research*, pp.1-232.)	Thank you for your comment. We will pass this information to our local practice collection team. More information on local practice can be found here.
Dementia UK	Whole document	General	General	Admiral Nursing is the only specialist nursing dementia service in the UK with a specific focus on carers. In addition to providing emotional support and helping people to live positively with the condition, Admiral Nurses seek to join up different parts of the health and social care system so that needs can be addressed in a coordinated way. Dementia UK would be willing to submit its experiences to the NICE shared learning database. See: ○ Gridley, K., Aspinal, F.J., Parker, G.M., Weatherly, H.L.A., Neves De Faria, R.I., Longo, F. and Van Den Berg, B., 2019. Specialist nursing support for unpaid carers of people with dementia:: a mixed-methods feasibility study. *Health Services and Delivery Research*, pp.1-232. Gridley, K., 2018. Understanding the outcomes of specialist nursing: the continuing importance of relationships for carers of people with dementia. *International Journal of Integrated Care*, *18*(s2).	Thank you for your comment. We will pass this information to our local practice collection team. More information on local practice can be found here.
Dementia UK	Whole document	General	General	Dementia UK wishes to highlight other groups of people and their carers e.g. prisons, homelessness, travellers as well as learning disability and young onset dementia.	Thank you for your comment. The committee agrees it is important to acknowledge that people have different access needs to services. To highlight the importance of service providers and people delivering services taking into account the needs of people that find it harder to access services direct reference to underserved and vulnerable groups has been added to the recommendation on advance care planning, into the section on providing end of life care co-ordination and in the rational and impact section for identifying adults who may be approaching the end of their life.

					Preferred place of care has been edited to 'where they would like to be cared for and die' to recognise that place can have different meanings for different people.
Dementia UK	Would implementation of any of the draft recommendations have significant cost implications?			Dementia UK believes the economic considerations of informal carers as well as different models of carer support is essential see, o Longo, F., Neves De Faria, R.I., Parker, G.M., Gridley, K., Aspinal, F.J., Van Den Berg, B. and Weatherly, H.L.A., 2019. Investigating the economic case of a service to support carers of people with dementia: a cross-sectional survey-based feasibility study in England. Health and Social Care in the Community.	Thank you for your comment and suggestion. For NICE's reference-case economic analyses, the health impact on informal carers should be considered. Costs borne by people using services and the value of unpaid care may also be Included, if they contribute to outcomes. The paper you have cited indicates that a particular type of support (Admiral nurses) might be cost neutral. However, as this is a cross-sectional study and therefore particularly prone to confounding, as acknowledged by the authors, it is of insufficient quality to include in the review.
Faculty of Intensive Care Medicine			1.11	Up to 1 in 5 adults in the UK may die on an intensive care unit. The difficulty in transferring home and potential harm to the patient of such a transfer should be recognised in this section	Thank you for your comment. The committee agrees that all transfers between care settings can have difficulties and this is reflected in the recommendations on developing systems and policies to support smooth and rapid transfers. Additional text on the difficulty of transferring adults from an intensive care unit to die at home has been added the section 'other factors the committee took into account' in evidence review M.
Faculty of Intensive Care Medicine			1.2.2	Whilst the evidence for clear communications is listed by NICE in their Evidence Review Sections, the number of people reading these will be limited compared to those reading the draft guideline. **It would therefore be useful if the draft guideline contained some information about the reasons as to why the possibility of death often isn't raised.** It might also be useful if the guideline provides information about resources that can improve an individual's ability to communicate such difficult issues	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and recommended the services and skills that could support health and social care practitioners in initiating discussions about death and dying. Text has been added to the rationale and impact section 'Identifying adults who may be approaching the end of their life, their carers and people important to them' recognising there is a reluctance to talk about death and that identifying adults who may be approaching the end of their life supports health and social care practitioners to start discussions about advance care planning. Information about training resources was not evaluated and cannot be included.
Faculty of			General	Relating to death on intensive care: the NICE guidance would	Thank you for your comment.

Intensive Care Medicine				benefit from a brief overview of the fact that increasing numbers of adult patients are dying in such environments (above) and that this is often where a severe acute illness occurs in association with months/years of physical decline and co-morbidity. The following and links to other issues should therefore be recognised: 1. Advance Care planning can assist in avoiding inappropriate treatments including intensive care at the end of a patient's life 2. Uncertainty of prognosis is frequent in the circumstances above, but intensive care teams have a duty to sensitively raise the possibility of death. This is not a denial of life-sustaining treatments but an honesty on the part of intensive care teams	The committee agrees that advance care planning should be take place as soon as possible after someone has been identified as likely to be approaching the end of their life to consider their future care. This includes reviewing current treatment, and discussions about preferences and wishes for types of care or treatment (this may include declining these, treatment escalation and resuscitation plans). The section on advance care planning includes cross reference to the NICE guideline on emergency and acute medical care in over 16s: service delivery and organisation. This guideline addresses advance care planning in clinical areas where a severe acute illness occurs in association with months/years of physical decline and co-morbidity.
Fresenius Medical Care	Guideline	6	8-19	To be able to utilise NICE guidelines more effectively, it would be valuable to reflect complexity and systems thinking by bringing together more circular evidence bringing pathways together rather than linear guidelines (e.g. how NICE guidelines renal replacement therapy and conservative management (NG107), published 3 October 2018 integrates with the end of life care guidelines).	Thank you for your comment. The related NICE guidelines for this topic are identified and included in the NICE pathway for End of life care. The pathway will cross-refer to this guideline in all future relevant guideline updates and publications**.**
Fresenius Medical Care	Guideline	9	11-19	The role of disease-specific private providers could also be included. An example is in the care of Chronic Kidney Disease patients where, through share decision making, the patients/family/healthcare professionals may choose conservative management. Gaps in the role of case managers and psychological support have been identified in the care of renal patients (of which conservative management is a consideration), and these may be services that can also be provided by private providers to support patient end of life care. References: NICE guidelines renal replacement therapy and conservative management (NG107), published 3 October 2018 Mapping the UK Renal Psychosocial Workforce: The First Comprehensive Workforce Survey, Seekles et al., BMC Nephrology 2019 20: 100 Patient Reported Experience of Kidney Care in the UK 2018, published by Kidney Care UK & Renal Association	Thank you for your comment. NICE guidance provides recommendations for the NHS and the definition of service providers in the terms used in this guidance section is,' All organisations (primary, secondary and tertiary) that provide NHS services for people approaching the end of their life.' The role of disease specific specialists in hospitals is referred to in the section on providing end of life coordination.
Hospice	Guidelin	10	7	This point should presumably include the person's wishes, if those	Thank you for your comment.

UK	e			are included in the guideline?	Wishes has been added to this recommendation.
Hospice UK	Guideline	11	8	The guideline should define what is meant by 24/7 in this context. Would the committee consider telephone or digital access to qualify? Or is it only face-to-face?	Thank you for your comment. The evidence identified did not allow the committee to propose any explicit guidance around the hours of operation and this is discussed in evidence review K in the committee's discussion of the evidence. In addition, the committee noted that the need for out of hours services and their operationalisation will depend on the local services already available and will vary accordingly.
Hospice UK	Guideline	12	19	Should the title of this section in fact be 'Family Carers', as it does not include paid or volunteers carers.	Thank you for your comment. The definition also includes friends. The title carers is broader than family carers to acknowledge that carers may not be relatives.
Hospice UK	Guideline	13	16	It is important to define exactly what is meant by 'that provide NHS services'. There is considerable ambiguity about whether charitable hospices are providing NHS services if they are not delivering specific services under an NHS standard contract. It is vital for the guideline to be clear about its scope in this context. Our preference would be for the guideline to apply to all services.	Thank you for your comment. 'That provide NHS services' refers to any organisation that provides services for people that are funded by the NHS. NICE provides national guidance for publically funded health and social care, but we would hope that other organisation would take the opportunity to use the guideline.
Hospice UK	Guideline	15	21	We would strongly favour a focus on the discharge and transfer from *or to* hospital. There are considerable barriers that people face transferring from a community setting to a hospital setting where that is required, and it would be extremely valuable to include this in future research.	Thank you for your comment. The committee agrees that discharge from any setting to another is important to get right and there are specific recommendations in the transferring people between care settings section of the guideline that underpin this. The committee discussed the particular difficulties that surround discharging people from hospitals and the devastating impact a delay can have, with this in mind they wanted to make a clear research recommendation on this area of transfer.
Hospice UK	Guideline	17	4-8	The guideline is making a huge assumption here that increasing the number of people identified will not have a significant resource impact. There is limited evidence on the health economics of end of life care which is in itself a complex mixed economy spanning the public, voluntary and private sectors in health and social care. We do not believe that there is currently sufficient evidence to make the statement that is included here.	Thank you for your comment. The committee have revised this to say: "The recommendations are expected to increase the number of people identified. The net impact on services is uncertain. Some investment will be required to establish systems to systematically identify patients in some areas. However, this will ensure that people approaching the end of their life will receive the appropriate care, and their carers will receive support, which will help to avoid unnecessary hospital admissions."
Hospice UK	Guideline	19	26-28	We question the assumption that the recommendations 'may reduce the number of hospital admissions'. There is insufficient evidence to	Thank you for your comment.

				conclude this at present (and it is interesting that the Committee has already used ‘may’ as a qualifying statement). It is possible that it may result in increased (and perhaps more appropriate) admissions.	This has been revised this to say “The impact on hospital admission is uncertain. Increased support may reduce the number of hospital admissions or it may result in increased (and perhaps more appropriate) admissions.”
Hospice UK	Guideline	20	4	It is disappointing that the guideline only refers to the physical and mental health needs of carers while they are caring for the person, and does not refer to pre and post bereavement support that may be needed.	Thank you for your comment. Although this guideline did not explicitly address bereavement the added recommendation 1.3.1 is clear that people managing and delivering services should consider what practical and emotional support can be provided to carers.
Hospice UK	Guideline	27	1-2	We agree that it is important to better understand how people move around the system at the end of life. We are concerned, however, that this reads as though the Committee is most concerned with ways in which to move people at the very end of life. Early and better planning for appropriate transfers is vital.	Thank you for your comment. The committee agrees that early and better planning is vital and throughout the guideline the recommendations are about facilitating this through identification, advance care planning, holistic needs assessment and co-ordination of care. However, the committee also acknowledge that transfers and transitions between care settings are not always ideal and considered it important that this was directly addressed in the guideline.
Hospice UK	Guideline	28	24-29	We are concerned that the Committee is making an assumption that increasing the number of people cared for in the community necessarily drives cost savings. It is highly likely that it would in fact result in significant cost shunting, both to community and voluntary sector services (who are not always funded by the NHS to provide such services), or to families and communities. It is important that the Committee takes in to account the wider health and care system in making its assessment of impact and costs.	Thank you for your comment. The last sentence of this paragraph has been revised to say: “The committee noted that the net resource impact of caring for people in the community is uncertain. On balance they felt that providing out of hours care was a good use of resources and key to meeting the needs of patients.” In the following paragraph, it was explicit that there could be a reduction in use of hospital services with an increase in demand for services in the community. The resource impact report and template identify recommendations which could have significant resource implications depending on the extent to which current services are already in place. This can be used by commissioners to identify current services levels and estimate other costs likely to have significant impact locally. .This can be accessed at.. The resource impact report and template do not make the assumption that increasing the number of people cared for in the community drives cost savings.
Hospice	Guideline	29	7-8	As mentioned earlier, we are concerned that the Committee has not	Thank you for your comment.

UK	e			taken in to account the needs of different parts of the community. The statement that care could be given at home as an alternative to hospital does not take in to account what ‘home’ means to different people (e.g. people affected by homelessness)	The committee agrees it is important to acknowledge that people have different access needs to services. To highlight the importance of service providers and people delivering services taking into account the needs of people that find it harder to access services direct reference to underserved and vulnerable groups has been added to the recommendation on advance care planning, into the section on providing end of life care co-ordination and in the rational and impact section for identifying adults who may be approaching the end of their life. Preferred place of care has been edited to ‘where they would like to be cared for and die’ to recognise that place can have different meanings for different people.
Hospice UK	Guideline	4	14	While we welcome the commitment to undertaking a holistic needs assessment, it would be helpful to explain how such an assessment should work alongside other assessments, rather than duplicating them. There is a risk that the guideline could otherwise inadvertently result in duplicate or repetitive assessments	Thank you for your comment. The committee hope that with the recommendations on communicating and sharing information between services and providing end of life care co-ordination this would ensure that members of the multi practitioner team work together to undertake and share assessments and to avoid duplication.
Hospice UK	Guideline	5	14	We recommend that the list of suggestions should also include whether the person wants another person to be with them in such decision making conversations.	Thank you for your comment. This recommendation addresses the process and systems for providing information. The committee agrees that this is important and whether the person wants another person to be with them in decision making conversations is highlighted in the following sections of the guideline; reviewing current treatment, advance care planning and providing end of life care coordination.
Hospice UK	Guideline	6	11	We recommend that this point should say “A lead healthcare professional…” rather than “The lead healthcare professional”. It is entirely possible that the person may have a closer relationship with another member of their healthcare team other than their consultant.	Thank you for your comment. The lead healthcare professional is used to be clear that there is one person that has overall clinical responsibility for the delivery of care to a patient. The definition in the terms used in the guideline acknowledges this is usually a senior doctor or senior nurse. The wording of this recommendation has been amended to clarify that the led healthcare professional should ensure that all treatment plans are discussed and is not necessary the person that has the discussions.
Hospice UK	Guideline	6	19	As well as what community support will be available to support them, this list should also include what options there might be for inpatient care, if that is what the person might need or prefer. It is	Thank you for your comment. Community support refers to any support outside of hospital and

				important to recognise that home or the community is not the right place for everybody in every situation, for example where people may be homeless, in prison, or where they may simply make a choice in favour of alternative care.	includes where people may be homeless. The providing end of life coordination section acknowledges that some people may have their care based in secondary or tertiary care and the reviewing needs section states there should be regular discussions and assessments about needs.
Hospice UK	Guideline	6	3	It is important for the guideline to define terms carefully. How is a ‘young carer’ or ‘older carer’ defined?	Thank you for your comment. A young carer is defined as someone aged under 18 years in the terms used in this guideline. The committee discussed the definition of older but agreed that unlike the legal definition of a when someone is considered an adult there is no clear definition or agreement on what older is. In this context it should be considered relative and specific to the individual and their situation.
Hospice UK	Guideline	7	19	This point should stress that a full repeat assessment may not always be required. In some instances, reviewing key questions may be sufficient. This will help to minimise the risk of assessments that are burdensome and repetitive to the person.	Thank you for your comment. The committee agrees that it is important to avoid duplication of care and assessments and have added text into the section on other factors the committee took into account in Evidence review J: Review of Service provision to highlight this is the context of reviews and repeat assessments.
Hospice UK	Guideline	7	5	As well as reminding providers of their duty to put in place arrangements for people losing capacity under the Mental Capacity Act (2005), it would also be helpful to include Powers of Attorney, and Deprivation of Liberty Safeguards , which have been a cause of particular confusion in relation to end of life care in recent years.	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care or the specific advice they might give. The definition of advance care planning in the terms used in this guideline includes a description of what might be in these discussions and includes covering the possibility of future loss of mental capacity and planning for this. This may include discussions about Powers of Attorney, and Deprivation of Liberty Safeguards if appropriate.
Hospice UK	Guideline	8	22	Crises cannot always be prevented. It may be better to say ‘Anticipate and minimise crises’ to reflect that.	Thank you for your comment. The wording has been amended to reflect your comment.
Hospice UK	Guideline	8	23	This point should also reflect the importance of allowing people to change their preferred place of care.	Thank you for your comment. The committee agrees and this is reflected in the section on reviewing needs that recommends regular discussions and repeat assessments when required by the person approaching the end of

					life.
Hospice UK	Guideline	8	6	The use of electronic systems to facilitate the sharing of information is the ideal, but is not always available. We are currently a very long way away from standardised electronic information sharing systems that span all services and sectors, particularly in end of life care services	Thank you for your comment. The committee agrees that good communication and documentation is critical and this is emphasised throughout the guideline. This is in line with the NHS Long Term Plan and NHS Digital's stated aim to develop joined up digital systems in the health service.
Hospice UK	Guideline	General	General	Hospice UK is concerned that the scope of this guideline leaves a residual gap in the NICE guidance for end of life care. This guideline covers adults in the last year of life, and the guideline on caring for adults in the last days of life focuses on the very end of life. This means that there is now a gap in NICE guidance covering those adults who require palliative care support for more than a year prior to their death. We appreciate that this is a comment beyond the scope of this specific consultation, but we believe that it is an important point to note.	Thank you for your comment. The committee agrees that the terminology and definition used in this area can vary. To clarify that this guideline could apply to people that need end of life for more than a year the following sentence has been added to the context and terms used in the guideline sections, 'Although for some conditions care could be provided for months or years.'
Hospice UK	Guideline	General	General	We recommend that the introduction to the guideline should be more explicit early on that the guideline covers adults in the last year of life, and that for the purposes of the guideline, this is taken to mean the last 12 months of life. This important clarification does not currently appear until page 12.	Thank you for your comment. The definition of end of life care and the context section have been moved to the front of the guideline before the recommendations. The committee recognises that the terminology and definitions used in this area can vary. To clarify that this guideline could apply to people that need end of life for more than a year the following sentence has been added to the context and terms used in the guideline sections, 'Although for some conditions care could be provided for months or years.' The following sentence has been added to the context and terms used in the guideline sections, 'Although for some conditions care could be provided for months or years.'
Hospice UK	Guideline	General	General	The guideline states that it intends to ensure that people have access to the end of life care services to meet their individual needs and wishes. While the guideline addresses ways in which to determine a person's needs, there is no advice on how to determine a person's wishes, and how these should be balanced, for example, against needs, available services or resources.	Thank you for your comment. This guideline focuses on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care or what would be included in a policy acknowledging that implementation may according to local needs, service and resources.
Hospice UK	Guideline	General	General	The guideline currently treats all adults as homogenous, and does not reflect diversity, inclusion health issues or issues associated with population level inequalities. This is a serious omission in our view. Hospice UK recently published a report on good practice in meeting	Thank you for your comment. All NICE guidelines are developed in line with the NICE Social value judgements: Principles for the development of NICE guidance.

				the needs of people approaching the end of life who are affected by homelessness, who are from the LGB&T community, or who are Gypsies or Travellers* **Tackling Inequalities in End of Life Care for Minority Groups VCSE Health and Wellbeing Alliance Project Group (2018). Care committed to me. Delivering high quality, personalised palliative and end of life care for Gypsies & Travellers, LGBT people and people experiencing homelessness: a resource for commissioners, service providers and health, care and support staff. London: Hospice UK, on behalf of the Tackling Inequalities in End of Life Care for Minority Groups VCSE Project Group.*	The committee agrees it is important to acknowledge that people have different access needs to services. To highlight the importance of service providers and people delivering services taking into account the needs of people that find it harder to access services direct reference to underserved and vulnerable groups has been added to the recommendation on advance care planning, into the section on providing end of life care co-ordination and in the rational and impact section for identifying adults who may be approaching the end of their life. Preferred place of care has been edited to 'where they would like to be cared for and die' to recognise that place can have different meanings for different people. In the terms used in this guideline this wording has been added to the definition of people important to adults to remind health and social care practitioners about the impact assumptions can have on people accessing care ,' It is important that health and social care practitioners understand that assumptions should not be made when asking about the 'people important to adults' , for example, assuming everyone is in a heterosexual relationship and asking a female patient about her husband. She may have a wife and feel uncomfortable correcting this assumption.'
Hospiscare		General	General	Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. **IT support for communication and multipractitioner working** These projects are complex and take skilled expertise and significant resource. Resources required include – project management skills, IT technical expertise, clinical leader drive and financial commitment to procure, purchase and use effective tech solutions. These need to be driven by healthcare community leaders – who are often already overstretched. Many of us can see the benefits, but do not have the time available in our busy day jobs to make change happen effectively. **Skills required to deliver effective and appropriate ACP** There is a danger that without proper teaching of these skills, ACP might be done poorly with emphasis on "ticking the box" rather than quality of conversations. Releasing staff for sessions and resourcing	Thank you for your comment and suggestions. To note, the wording has been amended in recommendation 1.2.2 on health and social care practitioners having the skills to sensitively carry out holistic needs assessments to people managing services should ensure that health and social care practitioners caring for adults approaching the end of their life have the training and skills to sensitively carry out holistic needs assessments.

				the production and delivery of teaching sessions is already a challenge.	
Hospiscare		General	General	Would implementation of any of the draft recommendations have significant cost implications? Many of these recommendations are extremely relevant and desirable. It is good to have them clearly described. Our organisation already strives to meet most of them. We can see cost implications in a number of areas: 1. Costs associated with delivering education sessions. 2. Costs associated with delivering change. We often send staff to local and regional project and network meetings. Without effective project management, change projects often flounder. Clinicians already have little time to devote to quality activity. There is often a sense that the “wheel is being reinvented” during these projects and meetings. Projects to deliver change need proper management and they need to be properly paid for.	Thank you for your comment and highlighting the areas that have cost implications. The committee agrees the guideline reflects good practice and that there is variation in the delivery of this standard of care across the NHS. There are areas that may need support and investment, such as training costs and, to implement some recommendations in the guideline. However, this will ensure that people approaching the end of their life will receive the appropriate care and their carers will receive support. This potentially will reduce emergency admissions increasing capacity in other areas of the service.
Hospiscare		General	General	What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) Examples of good practice and practical resources would certainly help. Stability in terms of national political drivers would also help. The multiple changes of organisational structures in the past few decades has not been helpful because local leadership structures have changed frequently. We need to ensure that “organisational memory” in local healthcare communities is not wasted.	Thank you for your comment and suggestion. We will pass this information to our local practice collection team. More information on local practice can be found here.
Hospiscare	Guideline	10	22	We often experience difficult delays for those needing admission to the Hospice in recent times. Emergency ambulances are sometimes delayed, with those at the end of their lives being considered lower priority than other patients. Resources to improve this problem are certainly required.	Thank you for your comment. The committee agrees that this is an issue and note in the transferring people between care settings rationale and impact section that effective and timely transfer may impact on resources and the organisation of services.
Hospiscare	Guideline	10	24	Delays and shortages in getting either equipment or packages of care in situ can be significant and we recognise precipitate admissions. Resources to improve this problem are certainly required.	Thank you for your comment. The committee agrees that delays and poor access are an issue to timely transfer and note this in the transferring people between care settings rationale and impact section. The committee acknowledge that providing equipment will enable people to be

					transferred and potentially reduce the length of their hospital stay.
Hospiscare	Guideline	11	12	Certain pharmacies carry extended stocks of medications that might be required to assist with EOL care in our area. They are paid via a LES agreement. They have extended, though not 24 hour access. We have worked with our local OOH provider (DevonDocs) to appropriately stock each GP visiting car with appropriate medications which might be required for those at the EOL. Contact b.baines@hospiscare.co.uk for signposting to project leads.	Thank you for your comment and this example of practice.
Hospiscare	Guideline	12	27	It would be helpful to specify here what are the key elements required in Health Needs Assessments. There are some common tools – eg. IPOS and Distress Thermometer, but we are aware that there are many more informal ways of collecting this information. What are the minimum elements that the NICE team would recommend? It would be helpful to clarify this.	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care or what tools they should use. The committee acknowledge there are validated tools that support this process and have added this to the description of Holistic needs assessment in the terms used in the guideline section.
Hospiscare	Guideline	13	7	We think the change to Multipractitioner Team (rather than Multidisciplinary Team) is a good one. Is there evidence to describe how these teams might work together across boundaries of organisations? Some examples of good practice – eg. using technology, would be appreciated.	Thank you for your comment. The section of the guideline on communicating and sharing information between services recommends the use of an electronic information-sharing system that is accessible between different services and organisations. However, the committee agrees that examples of successful cross boundary working would be useful (and not only those relating to technology) but unfortunately the evidence identified in Evidence review E did not have this detail and the committee were not able to give direct examples of good practice and how this might be achieved.
Hospiscare	Guideline	14	10	Devon has a fairly well-developed EPACCS system and are currently trialling ways to use “BlackPear” software to enable common GP software to link more effectively to the EPACCS database. Contact b.baines@hospiscare.co.uk for signposting to project leads.	Thank you for your comment and suggestion.
Hospiscare	Guideline	21	7	We agree with the recommendations regarding timely and appropriate Advance Care Planning. However, there are significant resource implications here. Many of our patients who specify a wish, would like to die at home or in the Hospice. Resource lack realistically denies them these choices – ie. in our area, there are only 12 specialist Palliative Care beds to cover a population of almost 400,000 and we simply cannot accommodate all those who wish to die at the Hospice. We question whether prioritising the preferred place of death outcome over quality of care in all settings	Thank you for your comment. The committee agrees that a high quality of care should be available in all settings and that there is variation in access to care across the NHS. The committee agrees that advance care plans should be flexible and the section on reviewing needs recommends the importance of having regular and responsive reviews of needs, preferences, including that of a person’s advance care plan.

				is appropriate. Advance Care Plans (like birth plans) need to be very flexible and responsive to changing needs.	
Hospiscare	Guideline	29	29	Although we are aware that the term "Supportive" care has become more popular in the past few years, we are not clear that this is universally recognised and would wish to see evidence to support its use over the term "Palliative Care"	Thank you for your comment. The committee agrees that the terminology used in this area can vary. The commonly used terms describing the provision of end of life care have been added into the context section of the guideline. The committee uses end of life care to describe both palliative and supportive care and includes symptom management.
Hospiscare	Guideline	30	2	We disagree that "Palliative Care" only applies to those receiving care in the "last months of life". Our Specialist Palliative Care service has been running for 37 years and regularly supports patients who have complex needs for many months and sometimes years. We would not wish for perceived prognosis to be a barrier to referral for those with complex needs who are suffering from a progressive, life-threatening condition.	Thank you for your comment. The committee agrees that the terminology and definitions used in this area can vary. To clarify that this guideline could apply to people that need end of life for more than a year the following sentence has been added to the context and terms used in the guideline sections, 'Although for some conditions care could be provided for months or years.'
Hospiscare	Guideline	4	14	Could the guideline describe the elements that are required in a Holistic Needs Assessment? We assume that no one particular tool has been found to be beneficial over any other as we assume the evidence is lacking. It may be helpful to discuss the dimensions of physical, practical/social, emotional/psychological and spiritual care that might need to be incorporated into an HNA.	Thank you for your comment. There is a definition of holistic needs assessment in the terms used in the guideline section and this describes this as an assessment that considers all aspects of a person's wellbeing, spiritual, health and social care needs. The committee did not review the specific tools but acknowledge there are validated tools that support this process and have added this to the description of Holistic needs assessment in the terms used in the guideline section.
Hospiscare	Guideline	8	24	We have endeavoured to teach local Social Care practitioners as part of our training packages at Hospiscare. We had limited success in engaging privately run Domiciliary Care Agencies and Care Homes in our area. The good homes and care agencies engaged, whereas the there was a cohort that were almost impossible to engage with. Is there any way that this could be mandated? Or specifically looked for in CQC inspections?	Thank you for your comment. NICE provides national guidance for publically funded health and social care but we would hope that other organisations providing end of life care would take the opportunity to use the guideline.
Hospiscare	Guideline	8	7	In Devon we have a well-developed EPACCS system, which has been running for many years – using Adastra software - held by the local Out of Hours Service. This generally works well – but the major flaw in the system is that paramedics on the ground cannot view the information. They must rely on ringing in to their base to ask the appropriate senior clinician for details. What steps might be taken to encourage health communities and software developers to ensure that IT systems connect to each other properly?	Thank you for your comment. The committee agrees that good communication and documentation is critical and one way to achieve this is with an electronic information sharing systems that are accessible between different services and organisations. The committee note in the evidence review I : Information sharing that EpaCCs and CANSIC are examples of these systems.

					These systems are in line with the NHS Long Term Plan and NHS Digital's stated aim to develop joined up digital systems in the health service.
Kidney Care UK	Context	29	30	Terminology – please check the terminology used for kidney patients in NICE guideline 107 https://www.nice.org.uk/guidance/ng107 For people with kidney failure. NICE has adopted the term 'conservative management' rather than 'palliative care' for those who stop dialysis and need support until end of life. In the renal community we may also refer to conservative care as 'supportive care'. Neither term is consistent with the terminology used in this guidance.	Thank you for your comment. The committee agrees that the terminology in this area can vary and the commonly used different terms describing the provision of end of life care have been added into the context section of the guideline. This includes reference to conservative care as used in the NICE guideline renal replacement therapy and conservative management
Kidney Care UK	General			Organ donation. Please consider including a recommendation to allow time to discuss organ and tissue donation. This means referring to the NHSBT organ donation guidance and also NICE guidance CG135, and a referral to a specialist organ donation nurses. There is much evidence that says having a conversation about organ donation can make it easier for families to honour the choice of their loved one.	Thank you for your comment. Cross reference to NICE guideline on Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation has been added to the section on Advance care planning.
Kidney Care UK	Rationale and Impact	26	1	Involving carers. Please consider including the importance of communication with carers alongside the co-ordination of care and communication between services. Carers say that they feel left out in key decisions. Also please consider the need to offer support to distressed carers.	Thank you for your comment. The importance of involving and communicating to carers is included directly in the advance care planning, reviewing current treatment, providing multipractitioner care, providing end of life coordination and providing out of hours care sections of the guideline. The communication and sharing information between services is directed at organisations and specific to the operationalisation of care services.
Kidney Care UK	Rationale and Impact	28	1	Out of hours pharmacy Thank you for including this provision; Kidney Care UK has heard from families where the loved one is in pain and unable to receive appropriate pharmaceutical management out of hours.	Thank you for your comment.
Kidney Care UK	Recommendations	5	1	Where there are patients with specific health needs, such as those who have kidney failure who have chosen to withdraw from, or not take up dialysis, we suggest that the guideline makes it clear that practitioners need to be aware of and able to gain specialist advice on their specific needs.	Thank you for your comment. The recommendations throughout the guideline make it clear that members of the multipractitioner team should communicate with each other and this includes with disease-specific specialist care (see the section on providing end of life care coordination).
Kidney Care UK	Recommendations	5	7	Information for patients and families is available from charities like ours and Marie Curie. Kidney Care UK has 2 leaflets – 'Choosing to stop dialysis' and 'Choosing not to have dialysis'. This has been produced at the request of and with involvement with patients and input from UK specialists via the Renal Association. We recommend	Thank you for your comment.

				that links to specialist information should be made available alongside the advice and guidance of the multi-professional teams supporting people and families at the end of life.	
Kidney Care UK	Recommendations	6	1	Young carers. Thank you for including young carers,	Thank you for your comment.
King's College London	Guideline	13	24-26	Our Breathlessness Support Service RCT, OPTCARE Elderly and OPTCARE Neuro evidence the importance of early and integrated services to improve outcomes for adults with progressive non-cancer disease approaching the end of life. References are below and above. - Higginson IJB, C.; Reilly, C. C.; Gao, W.; Gysels, M.; Dzingina, M.; McCrone, P.; Booth, S.; Jolley, C. J.; Moxham, J. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. Lancet Respir Med. 2014 Dec;2(12):979-87. doi: 10.1016/S2213-2600(14)70226-7. Epub 2014 Oct 29. PubMed PMID: 25465642 - Evans CJ, Ison L, Ellis-Smith C, Nicholson C, Costa A, Oluyase AO, Namisango E, Bone AE, Brighton LJ, Yi D, Combes S, Bajwah S, Gao W, Harding R, Ong P, Higginson IJ, Maddocks M. Service Delivery Models to Maximize Quality of Life for Older People at the End of Life: A Rapid Review. Milbank Q. 2019 Mar;97(1):113-175. - Higginson IJ, McCrone P, Hart SR, Burman R, Silber E, Edmonds PM. Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial. J Pain Symptom Manage. 2009 Dec;38(6):816-26. doi: 10.1016/j.jpainsymman.2009.07.002. - Higginson IJ, Costantini M, Silber E, Burman R, Edmonds P. Evaluation of a new model of short-term palliative care for people severely affected with multiple sclerosis: a randomised fast-track trial to test timing of referral and how long the effect is maintained. Postgrad Med J. 2011 Nov;87(1033):769-75. doi: 10.1136/postgradmedj-2011-130290.	Thank you for your comment. Thank you for the references. Evidence review B: Timing of referral to palliative care services examined the best timing of referral (or provision) to palliative care services in people thought to be entering their last year of life. Limited evidence comparing strategies for early or late referral was identified. It was clear that early assessment of a person's needs is important and this is reflected in the guideline recommendations. What was lacking was evidence supporting decision making on when someone with a non-cancer diagnosis should be referred to additional specialist services. To address this gap the committee developed the research recommendation to examine if early review of service provision and referral to additional specialist palliative care services improve outcomes for adults with progressive non-cancer disease thought to be approaching the end of their life. Higginson et al 2014 did not meet the inclusion criteria for this review as it investigates the effectiveness of a particular intervention including palliative care, compared with usual care, rather than the timing of palliative care provision/referral. While Higginson et al 2009 and Higginson et al 2011 compared early versus delayed palliative care referral, they did not meet the inclusion criteria for Evidence Review B as the populations included are not limited to people thought to be entering the last year of life. Evans et al 2019, as a review of existing systematic reviews, does not meet the inclusion criteria for the evidence reviews in the guideline.
King's College	Guideline	14	11	We are concerned that there is an assumption that electronic information sharing systems improve care of people approaching	Thank you for your comment.

London				the end of life. We suggest that a more prescient question would be 'do electronic information sharing systems improve care?'. We would also require a more balanced appraisal of what their potential harms are in balance against the benefits, and how this is/could be effectively measured.	The committee agreed that good communication and documentation is critical to optimal care and finding systems to do this is imperative. The committee note that the implementation of an electronic information sharing system is in line with the NHS Long Term Plan and NHS Digital's stated aim to develop joined up digital systems in the health service. The committee agrees that it is not clear how this can be done effectively and the second research recommendation in the guideline explores the importance of identifying the best system.
King's College London	Guideline	14	20	Leniz et al, (2019) highlights the specific gaps in experimental data in showing the effectiveness of electronic databases and information sharing systems, particularly for understanding patient and carer perspectives. Leniz J, Weil A, Higginson IJ, et al, Electronic palliative care coordination systems (EPaCCS): a systematic review, BMJ Supportive & Palliative Care Published Online First: 08 May 2019. doi: 10.1136/bmjspcare-2018-001689	Thank you for your comment. The committee agrees there are gaps in the evidence identifying which electronic sharing system is effective and have highlighted this in the second research recommendation exploring the importance of identifying the best system. The committee note that the implementation of an electronic information sharing system is in line with the NHS Long Term Plan and NHS Digital's stated aim to develop joined up digital systems in the health service. Thank you for the information on the new reference that has been published since the final evidence search for the guideline.
King's College London	Guideline	14	5	Evidence from Bone et al, (2019) shows that referral to specialist palliative care in non-cancer patients reduces Emergency Department attendance in this population. Anna E Bone, Catherine J Evans, Simon N Etkind, Katherine E Sleeman, Barbara Gomes, Melissa Aldridge, Jeff Keep, Julia Verne, Irene J Higginson, Factors associated with older people's emergency department attendance towards the end of life: a systematic review, *European Journal of Public Health*, Volume 29, Issue 1, February 2019, Pages 67–74, https://doi.org/10.1093/eurpub/cky241	Thank you for your comment The committee do not dispute the benefit of specialist palliative care services but the evidence is not clear when people with a non-cancer diagnosis should be referred to these additional specialist services. Thank you for the reference. Evidence review B: Timing of referral to palliative care services examined the best timing of referral (or provision) to palliative care services in people thought to be entering their last year of life. Limited evidence comparing strategies for early or late referral was identified. It was clear that early assessment of a person's needs is important and this is reflected in the guideline recommendations. What was lacking was evidence supporting decision making on when someone with a non-cancer diagnosis should be referred to additional specialist services. To address this gap the committee developed the research recommendation to examine if early review of service provision and referral to additional specialist

					palliative care services improve outcomes for adults with progressive non-cancer disease thought to be approaching the end of their life.
King's College London	Guideline	14	6	We challenge the assertion that there is no evidence for patients with progressive organ failure and include a Phase II Randomised Controlled Trial from Bajwah et al (2014). Bajwah S, Ross JR, Wells AU, et al Palliative care for patients with advanced fibrotic lung disease: a randomised controlled phase II and feasibility trial of a community case conference intervention Thorax 2015;70:830-839	Thank you for your comment. The benefit of early engagement with end of life care services is not disputed and early identification and engagement is recommended for everyone throughout the guideline. To address the subsequent referral to specialist services the committee developed the research recommendation to highlight the limited evidence in this area for people with non- cancer diagnosis. The committee wanted to highlight that people with a non-cancer diagnosis are under represented in this evidence base and in the evidence addressing subsequent referral to specialist care. The wording has been amended to 'very limited' from 'does not exist' to acknowledge your comment. This reference was excluded from Evidence review B: Timing of referral to palliative care services examined the best timing of referral (or provision) to palliative care services and limited evidence comparing strategies for early or late referral was identified. The evidence review compared late and early referral, Bajwah et al was excluded as the the referral to the case conference was by 4 weeks for both groups and the committee thought this did not reflect late referral.
King's College London	Guideline	16	9	We suggest that uncertainty, and managing uncertainty is always going to be a concern, and therefore this needs to be taken into account alongside identifying the patients who may be approaching the end of life. - Selman LE, Bristowe K, Higginson IJ, Murtagh FEM. The views and experiences of older people with conservatively managed renal failure: a qualitative study of communication, information and decision-making. BMC Nephrol. 2019 Feb 4;20(1):38. doi: 10.1186/s12882-019-1230-4. - Higginson IJ, Rumble C, Shipman C, Koffman J, Sleeman KE, Morgan M, Hopkins P, Noble J, Bernal W, Leonard S, Dampier O, Prentice W, Burman R, Costantini M. The value of uncertainty in critical illness? An ethnographic study of patterns and conflicts in care and decision-making	Thank you for your comment and the information. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care. Evidence Review A included evidence on service models to support the identification of people who may be entering the last year of life. Qualitative studies such as those referenced do not meet the inclusion criteria for this review.

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

				trajectories. BMC Anesthesiol. 2016 Feb 9;16:11. doi: 10.1186/s12871-016-0177-2. - Fan SY, Sung HC, Wang SC. The experience of advance care planning discussion among older residents in a long-term care institution: A qualitative study. J Clin Nurs. 2019 Jun 4. doi: 10.1111/jocn.14936.	
King's College London	Guideline	25	8	Bone et al (2016) conducted a mortality followback study that showed coordination was key to prevent end of life hospital transitions. Bone AE, Gao W, Gomes B, Sleeman KE, Maddocks M, Wright J et al. Factors Associated with Transition from Community Settings to Hospital as Place of Death for Adults Aged 75 and Older: A Population-Based Mortality Follow-Back Survey. Journal of the American Geriatrics Society. 2016 Nov 1;64(11):2210-2217. https://doi.org/10.1111/jgs.14442, https://doi.org/10.1111/jgs.14442, https://doi.org/10.1111/jgs.14442	Thank you for your comment. The committee agrees that co-ordination is key to optimal care and preventing inappropriate transfers to hospital.
King's College London	Guideline	27	23	Wiggins et al (2019) showed that having ceilings of treatment agreed and documented was associated with being more likely to die in preferred place, whether that is in own home, or a care home. Natasha Wiggins, Joanne Droney, Kabir Mohammed, Julia Riley, Katherine E Sleeman, Understanding the factors associated with patients with dementia achieving their preferred place of death: a retrospective cohort study, *Age and Ageing*, Volume 48, Issue 3, May 2019, Pages 433–439, https://doi.org/10.1093/ageing/afz015	Thank you for your comment. In the definition of advance care planning in the terms used in the guideline section, potential discussion about the 'preferences and wishes for types of care or treatment in the future and discussion of the care available' is included and treatment escalation and resuscitation plans have been added to highlight the importance of these conversations for future planning. With regard to Wiggins et al 2019, Evidence Reviews C and M included qualitative and interventional evidence (respectively); prognostic studies such as the one referenced do not meet the inclusion criteria.
King's College London	Guideline	28	4	Sleeman et al (2018) showed care home residence is associated with reduced Emergency Department attendance. Leniz et al (2109) showed care home residence is associated with fewer end of life transitions. Bone et al (2017) showed through place of death projections that there is increasing need for care home beds. - Sleeman KE, Perera G, Stewart R, Higginson IJ. Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data. Alzheimers & Dementia. 2017 Aug	Thank you for your comment and the information. Evidence Review K included studies investigating out of hours services, models and policies to support people stay in their preferred place of care. The references you have provided do not meet the inclusion criteria for the review as they do not compare out of hours services, models and policies to support people in their last year of life to stay in their usual place of residence.

				22. https://doi.org/10.1016/j.jalz.2017.06.2267 - Javiera Leniz, Irene J Higginson, Robert Stewart, Katherine E Sleeman, Understanding which people with dementia are at risk of inappropriate care and avoidable transitions to hospital near the end-of-life: a retrospective cohort study, *Age and Ageing*, , afz052, https://doi.org/10.1093/ageing/afz052 Bone AE, Gomes B, Etkind SN, Verne J, Murtagh FE, Evans CJ et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. Palliative Medicine. 2018 Feb 1;32(2):329-336. 269216317734435. https://doi.org/10.1177/0269216317734435	
King's College London	Guideline	4	14	The initial holistic needs assessment would benefit from incorporation of the Integrated Palliative Care Outcome Scale (IPOS). There is also evidence that early integrated services are also beneficial to patient and family/carer experiences. - Etkind, S. N., B. A. Daveson, W. Kwok, J. Witt, C. Bausewein, I. J. Higginson and F. E. Murtagh (2015). "Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference? A systematic review." J Pain Symptom Manage 49(3): 611-624 Brighton LJ, Miller S, Farquhar M, et al Holistic services for people with advanced disease and chronic breathlessness: a systematic review and meta-analysis Thorax 2019;74:270-281.	Thank you for your comment. The committee did not review the specific health needs assessment tools but acknowledge there are validated tools that support this process and have added this to the description of holistic needs assessment in the terms used in the guideline section. Specifically, Etkind et al 2015, which investigates the impact of using patient-centred outcome measures on processes of care, does not meet the inclusion criteria for the reviews in the guideline given the use of these outcome measures is not a service model in itself. Brighton, Miller and Farquhar et al 2019, as a mixed methods systematic review, included a broad range of primary studies reviewing the effectiveness of interventions and not service models. This did not meet the inclusion criteria for any of the reviews in the guideline.
King's College London	Guideline	5	12, and should be incorporated elsewhere.	There is evidence that early palliative care integrated with services can improve decision making, support for carers and dignity. Evidence from the Breathlessness Support Service Randomised Controlled Trial (RCT) has shown the importance of early integrated breathlessness services to improve dignity and mastery of breathlessness, as well as improved survival rates in some populations. Qualitative papers derived from the trial highlight patient satisfaction with the service, due to its combination of personalised care, education, empowerment, and use of specific interventions. A systematic review and meta-analysis which included 37 articles representing 18 different services definitively showed	Thank you for your comment. The guideline is a service delivery guideline with recommendations for people providing and managing services and does not include the evaluation of the clinical and cost effectiveness of specific end of life care interventions. The committee do not dispute the benefit of palliative care services but the evidence is not clear when people with a non-cancer diagnosis should be referred to these and additional specialist palliative care services acknowledging that not

				benefit over controls, with no additional costs to health and social care services or families, and possible savings (Brighton et al 2019). Delphi and consultation also further explored expert opinion on optimal configurations. In addition a Cochrane review from Gomes et al (2013) also showed that home palliative care increases the likelihood of a home death, which evidence suggests may be through a mechanism of support for communication, decision making and symptom management. - Higginson IJB, C.; Reilly, C. C.; Gao, W.; Gysels, M.; Dzingina, M.; McCrone, P.; Booth, S.; Jolley, C. J.; Moxham, J. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. Lancet Respir Med. 2014 Dec;2(12):979-87. doi: 10.1016/S2213-2600(14)70226-7. Epub 2014 Oct 29. PubMed PMID: 25465642 - Reilly CC, Bausewein C, Pannell C, Moxham J, Jolley CJ, Higginson IJ. Patients' experiences of a new integrated breathlessness support service for patients with refractory breathlessness: Results of a postal survey. Palliat Med. 2016 Mar;30(3):313-22. doi: 10.1177/0269216315600103. Epub 2015 Aug 26. PubMed PMID: 26311570; PubMed Central PMCID: PMC4778380 - Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database of Systematic Reviews 2013, Issue 6. Art. No.: CD007760. DOI: 10.1002/14651858.CD007760.pub2. - Brighton LJ, Tunnard I, Farquhar M, Booth S, Miller S, Yi D, Gao W, Bajwah S, Man WD, Reilly CC, Ogden M, Bailey S, Ewart C, Higginson IJ, Maddocks M. Recommendations for services for people living with chronic breathlessness in advanced disease: Results of a transparent expert consultation. Chron Respir Dis.2019 Jan-Dec;16:1479973118816448. doi: 10.1177/1479973118816448. - Brighton LJ, Gao W, Farquhar M, Booth S, Bajwah S, Man WD, Reilly CC, Yi D, Higginson IJ, Maddocks M. Predicting outcomes following holistic breathlessness services: A pooled analysis of individual patient data. Palliat Med. 2019	everyone will need referral. Evidence review B: Timing of referral to palliative care services examined the best timing of referral (or provision) to palliative care services in people thought to be entering their last year of life. Limited evidence comparing strategies for early or late referral was identified. It was clear that early assessment of a person's needs is important and this is reflected in the guideline recommendations. What was lacking was evidence supporting decision making on when someone with a non-cancer diagnosis should be referred to additional specialist services. To address this gap the committee developed the research recommendation to examine if early review of service provision and referral to additional specialist palliative care services improve outcomes for adults with progressive non-cancer disease thought to be approaching the end of their life. We have considered the list of references you have provided. While they are broadly related to the guideline topics, they were not included in the evidence reviews in the guideline for the reasons set out below. Higginson et al 2014 did not meet the inclusion criteria the reviews in this guideline as it investigates the effectiveness of a particular intervention including palliative care, compared with usual care, rather than the optimal design of end of life care services. Similarly, Gomes et al 2013 did not meet the inclusion criteria the reviews in this guideline as it investigates the effectiveness of home palliative care services compared with usual care (or with a different form of home palliative care), rather than the optimal design of end of life care services. Reilly et al 2016 and Gysels et al 2016 were not included in either of the qualitative reviews conducted for the guideline (Evidence Review C (barriers and facilitators to access and planning of end of life care services) and Evidence Review G (involving carers)) as they did not align with the focus of those reviews. Higginson et al 2014, the trial population also does not meet the inclusion criteria for the guideline.

				Apr;33(4):462-466. doi: 10.1177/0269216319830299. - Brighton LJ, Miller S, Farquhar M, Booth S, Yi D, Gao W, Bajwah S, Man WD, Higginson IJ, Maddocks M. Holistic services for people with advanced disease and chronic breathlessness: a systematic review and meta-analysis. Thorax. 2019 Mar;74(3):270-281. doi: 10.1136/thoraxjnl-2018-211589. - Maddocks M, Lovell N, Booth S, Man WD, Higginson IJ. Palliative care and management of troublesome symptoms for people with chronic obstructive pulmonary disease. Lancet. 2017 Sep 2;390(10098):988-1002. doi: 10.1016/S0140-6736(17)32127-X. - Gysels M, Reilly CC, Jolley CJ, Pannell C, Spoorendonk F, Moxham J, Bausewein C, Higginson IJ. Dignity Through Integrated Symptom Management: Lessons From the Breathlessness Support Service. J Pain Symptom Manage. 2016 Oct;52(4):515-524.doi: 10.1016/j.jpainsymman.2016.04.010. In addition when considering preferences, especially for place of care and treatment, family members views are important, as is least as well as most preferred. - Etkind SN, Bone AE, Lovell N, Higginson IJ, Murtagh FEM. Influences on Care Preferences of Older People with Advanced Illness: A Systematic Review and Thematic Synthesis. J Am Geriatr Soc. 2018 May;66(5):1031-1039. doi: 10.1111/jgs.15272. - Higginson IJ, Daveson BA, Morrison RS, Yi D, Meier D, Smith M, Ryan K, McQuillan R, Johnston BM, Normand C; BuildCARE. Social and clinical determinants of preferences and their achievement at the end of life: prospective cohort study of older adults receiving palliative care in three countries. BMC Geriatr. 2017 Nov 23;17(1):271. doi: 10.1186/s12877-017-0648-4. Etkind SN, Lovell N, Nicholson CJ, Higginson IJ, Murtagh FE. Finding a 'new normal' following acute illness: A qualitative study of influences on frail older people's care preferences. Palliat Med. 2019 Mar;33(3):301-311. doi: 10.1177/0269216318817706.	Brighton, Tunnard and Farquhar et al 2019, as a report of an expert consultation process, and Brighton, Gao and Farquhar et al 2019, as a prognostic review of predictors of breathlessness outcomes, did not meet the inclusion criteria for any of the reviews in this guideline. Brighton, Miller and Farquhar et al 2019 and Etkind et al 2018, as mixed methods systematic reviews, included a broad range of primary studies and did not look directly at service delivery but it did not themselves meet the inclusion criteria for any of the reviews in the guideline. Higginson et al 2017, which looks at the determinants of preferences of place of death, also did not meet the inclusion criteria for any of the reviews in the guideline. Maddocks et al 2017 which looks at the management of symptoms didn't meet the inclusion criteria for any of the review sin the guideline. The population in Etkind 2019, being frail older people with recent acute illness, did not meet the inclusion criteria for the guideline.
King's College London	Guideline	6	21	We are concerned that there is very little evidence on the effectiveness or best way to conduct advance care planning, unless it is part of an overall holistic assessment. There is a lack of evidence that advance care planning improves outcomes for	Thank you for your comment. In the rationale and impact section for advance care planning the committee agrees that the evidence for how to conduct advance

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				patients, and issues regarding ensuring that staff offering it are suitably trained and the timing and methods of introduction. We are very concerned that there is sufficient evidence to recommend Advance Care Planning in the NICE guidance, the reviews that do exist highlight the levels of bias in existing research. Instead ACP should be evaluated in rigorous research, including of its costs, benefits, potential harms, and best approaches to fidelity and safety. Existing studies could be subjected to a new systematic review. - Martin RS, Hayes B, Gregorevic K, Kwang Lim W. The effects of Advance Care Planning Interventions on Nursing Home Residents: A Systematic Review. Journal of the American Medical Directors Association. 2016 April; 17(4):284-293. Doi: 10.1016/j.jamda.2015.12.017 We would add that a major international randomised trial is due to report soon (protocol below plus abstracts presented at meetings), and so it may be timely to conduct a new independent systematic review. - Overbeek A, Korfage IJ, Hammes BJ, van der Heide A, Rietjens JAC. Experiences with and outcomes of Advance Care Planning in bereaved relatives of frail older patients: a mixed methods study. Age Ageing. 2019 Jan 7. doi:10.1093/ageing/afy184. - Overbeek A, Polinder S, Haagsma J, Billekens P, de Nooijer K, Hammes BJ, Muliaditan D, van der Heide A, Rietjens JA, Korfage IJ. Advance Care Planning for frail older adults: Findings on costs in a cluster randomised controlled trial. Palliat Med. 2019 Mar;33(3):291-300. doi: 10.1177/0269216318801751. - Zwakman M, Jabbarian LJ, van Delden J, van der Heide A, Korfage IJ, Pollock K, Rietjens J, Seymour J, Kars MC. Advance care planning: A systematic review about experiences of patients with a life-threatening or life-limiting illness. Palliat Med. 2018 Sep;32(8):1305-1321. doi: 10.1177/0269216318784474. Epub 2018 Jun 29. - Rietjens JA, Korfage IJ, Dunleavy L, Preston NJ, Jabbarian LJ, Christensen CA, de Brito M, Bulli F, Caswell G, Červ B, van Delden J, Deliens L, Gorini G, Groenvold M, Houttekier D, Ingravallo F, Kars MC, Lunder U, Miccinesi G, Mimić A, Paci E, Payne S, Polinder S, Pollock K, Seymour J, Simonič A, Johnsen AT, Verkissen MN, de Vries E,	planning was unclear and that implementation is complex but overall there was some benefit in helping people to stay where they would like to be cared for but not enough to recommend a specific service model. This aligns with the conclusions of the reviews you have referenced (Martin et al 2016; Brinkman-Stoppelenburg et al 2014) which also conclude that advance care planning has beneficial effects despite a need for further research into optimal design of the delivery and intervention. In the terms used in this guideline advance care planning is described as a discussion about future care and support planning between a person and their health and social care providers specifically for people approaching the end of life. This communication between any person receiving care and their health and social care providers is fundamental, the committee agrees on the principle of advance care planning but the committee that the best way to conduct advance care planning is not clear. Thank you for the information on the new references that have been published since the final evidence search for the guideline. To note the main results of the Overbeek et al 2018 study to which you refer (cluster randomised trial of 16 residential care homes) has been included in Evidence Review F (Advance Care Planning) and formed part of the evidence base on which the recommendations were based. The following associated costs paper has been added to Evidence review F : advance care planning but this has only confirmed the view of the committee that ACP could potentially produce modest cost savings to the health system in addition to meeting the preferences of patients. Overbeek A, Polinder S, Haagsma J, Billekens P, de Nooijer K, Hammes BJ, Muliaditan D, van der Heide A, Rietjens JA, Korfage IJ. Advance Care Planning for frail older adults: Findings on costs in a cluster randomised controlled trial. Palliat Med. 2019 Mar;33(3):291-300. doi: 10.1177/0269216318801751. To note Zwakman et al 2018, as a systematic review of qualitative studies on experiences with advance care planning, did not meet the inclusion criteria of the Evidence Review F (Advance Care Planning) as that review was an intervention review, looking for

				Wilcock A, Zwakman M, van der Heide Pl A. Advance care planning--a multi-centre cluster randomised clinical trial: the research protocol of the ACTION study. BMC Cancer. 2016 Apr 8;16:264. doi:10.1186/s12885-016-2298-x. - Korfage IJ, Rietjens JA, Overbeek A, Jabbarian LJ, Billekens P, Hammes BJ, Hansen-van der Meer E, Polinder S, Severijnen J, Swart SJ, Witkamp FE, van der Heide A. A cluster randomized controlled trial on the effects and costs of advance care planning in elderly care: study protocol. BMC Geriatr. 2015 Jul 22;15:87. doi: 10.1186/s12877-015-0087-z. - Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. Palliat Med. 2014 Sep;28(8):1000-25. doi: 10.1177/0269216314526272. Epub 2014 Mar 20. In addition - - Skorstengaard MH, Jensen AB, Andreassen P, Brogaard T, Brendstrup E, Løkke A, Aagaard S, Wiggers H, Neergaard MA. Advance care planning and place of death, hospitalisation and actual place of death in lung, heart and cancer disease: a randomised controlled trial. BMJ Support Palliat Care. 2019 Apr 11. pii: bmjspcare-2018-001677. doi: 10.1136/bmjspcare-2018-001677. - Gleeson A, Noble S, Mann M. Advance care planning for home health staff: a systematic review. BMJ Support Palliat Care. 2019 Feb 26. pii:bmjspcare-2018-001680. doi: 10.1136/bmjspcare-2018-001680. - Krones T, Budilivschi A, Karzig I, Otto T, Valeri F, Biller-Andorno N, Mitchell C, Loupatatzis B. Advance care planning for the severely ill in the hospital: a randomized trial. BMJ Support Palliat Care. 2019 Jan 21. pii: bmjspcare-2017-001489. doi: 10.1136/bmjspcare-2017-001489. In addition, implementation is complex and not yet fully understood. - Combes S, Nicholson CJ, Gillett K, Norton C. Implementing advance care planning with community-dwelling frail elders requires a system-wide approach: An integrative review applying a behaviour change model. Palliat Med. 2019 May 6:269216319845804.	data on effectiveness. Studies which have not yet reported (Korfage et al 2015; Rietjens et al 2016) will be identified in future updates of this guideline. Gleeson et al 2018 reviewed the evidence for advance care planning staff training interventions and was outside the scope of Evidence Review F (advance care planning).
King's College London	Guideline	6	6	While hospital deaths have fallen among people with COPD and other advanced respiratory disease, this has not been the case for people with multiple comorbidities, and therefore services may need	Thank you for your comment. The committee agrees and recognise the importance of raising

				to be targeted to those with multimorbidity, and also social deprivation. - Higginson IJ, Reilly CC, Bajwah S, Maddocks M, Costantini M, Gao W; GUIDE_Care project. Which patients with advanced respiratory disease die in hospital? A 14-year population-based study of trends and associated factors. BMC Med. 2017 Feb 1;15(1):19. doi: 10.1186/s12916-016-0776-2.	awareness of people with multimorbidites and have include cross reference to the NICE guideline on mulitmorbidity in the reviewing current treatment and advance care planning sections of the guideline. To highlight the importance of service providers and people delivering services taking into account the needs of people that find it harder to access services direct reference to underserved and vulnerable groups has been added to the recommendation on advance care planning, into the section on providing end of life care co-ordination and in the rational and impact section for identifying adults who may be approaching the end of their life.
King's College London	Guideline	7	15	We suggest the inclusion of evidence from early integrated palliative care trials when recommending the development of systems enabling adults approaching the end of life to have regular discussions with care team and repeat assessments of holistic need. This includes randomised trials, and systematic reviews. - Higginson IJB, C.; Reilly, C. C.; Gao, W.; Gysels, M.; Dzingina, M.; McCrone, P.; Booth, S.; Jolley, C. J.; Moxham, J. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. Lancet Respir Med. 2014 Dec;2(12):979-87. doi: 10.1016/S2213-2600(14)70226-7. Epub 2014 Oct 29. PubMed PMID: 25465642 - Higginson IJ1, McCrone P, Hart SR, Burman R, Silber E, Edmonds PM. Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial. J Pain Symptom Manage. 2009 Dec;38(6):816-26. doi: 10.1016/j.jpainsymman.2009.07.002. - Evans CJ, Ison L, Ellis-Smith C, Nicholson C, Costa A, Oluyase AO, Namisango E, Bone AE, Brighton LJ, Yi D, Combes S, Bajwah S, Gao W, Harding R, Ong P, Higginson IJ, Maddocks M (2019), Service Delivery Models to Maximize Quality of Life for Older People at the End of Life: A Rapid Review. The Milbank Quarterly, 97: 113-175. doi:10.1111/1468-0009.12373 - Ambroggi M, Biasini C, Toscani I, Orlandi E, Berte R, Mazzari M, Cavanna L. Can early palliative care with anticancer treatment improve overall survival and patient-related outcomes in advanced lung cancer patients? A	Thank you for your comment. The recommendations on reviewing needs (recommendation 1.7.1) were based on two qualitative evidence reviews (Evidence Review C (barriers to end of life services) and Evidence Review G (involving carers)) as well as an intervention review of how such additional need should be identified and the timing and frequency of review (Evidence Review J). Evidence review J was specifically looking for comparative evidence on specific methods/services to review service provision and identify when additional services may be required, as well as the timing/frequency of review of service provision. Evidence from early integrated palliative care trials, which generally compared a palliative care intervention with usual care, did not meet the specific inclusion criteria for this evidence review and were therefore not included in the guideline. Specifically, Higginson et al 2009 and 2014 did not meet the inclusion criteria the reviews in this guideline as it investigates the effectiveness of a particular intervention including palliative care, compared with usual care, rather than the optimal design of end of life care services. Similarly, the trials in Ambroggi et al 2018, Haun et al 2017 and Tassinari et al 2016 were comparing early palliative care with usual care and were not included on that basis. Evans et al 2019, as a review of existing systematic reviews, does not meet the inclusion criteria for the evidence reviews in the guideline but for a future reviews would be used for reference. The population in Aziz et al 2019, being geriatric trauma patients, does not meet the inclusion criteria for this guideline. Brighton et al 2019, as a mixed methods systematic review, included a broad range of primary studies but it did not themselves

				review of the literature. Support Care Cancer. 2018 Sep;26(9):2945-2953. doi:10.1007/s00520-018-4184-3. Epub 2018 Apr 27. Review. Erratum in: Support Care Cancer. 2018 Jun 11;:.. - Haun MW, Estel S, Rücker G, Friederich HC, Villalobos M, Thomas M, Hartmann M. Early palliative care for adults with advanced cancer. Cochrane Database Syst Rev. 2017 Jun 12;6:CD011129. doi: 10.1002/14651858.CD011129.pub2. - Tassinari D, Drudi F, Monterubbianesi MC, Stocchi L, Ferioli I, Marzaloni A, Tamburini E, Sartori S. Early Palliative Care in Advanced Oncologic and Non-Oncologic Chronic Diseases: A Systematic Review of Literature. Rev Recent Clin Trials. 2016;11(1):63-71. - Aziz HA, Lunde J, Barraco R, Como JJ, Cooper Z, Hayward T 3rd, Hwang F, Lottenberg L, Mentzer C, Mosenthal A, Mukherjee K, Nash J, Robinson B, Staudenmayer K, Wright R, Yon J, Crandall M. Evidence-based review of trauma center care and routine palliative care processes for geriatric trauma patients; A collaboration from the American Association for the Surgery of Trauma Patient Assessment Committee, the American Association for the Surgery of Trauma Geriatric Trauma Committee, and the Eastern Association for the Surgery of Trauma Guidelines Committee. J Trauma Acute Care Surg. 2019 Apr;86(4):737-743. doi:10.1097/TA.0000000000002155. - Higginson IJB, C.; Reilly, C. C.; Gao, W.; Gysels, M.; Dzingina, M.; McCrone, P.; Booth, S.; Jolley, C. J.; Moxham, J. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. Lancet Respir Med. 2014 Dec;2(12):979-87. doi: 10.1016/S2213-2600(14)70226-7. Epub 2014 Oct 29. PubMed PMID: 25465642 - Brighton LJ, Miller S, Farquhar M, Booth S, Yi D, Gao W, Bajwah S, Man WD, Higginson IJ, Maddocks M. Holistic services for people with advanced disease and chronic breathlessness: a systematic review and meta-analysis. Thorax. 2019 Mar;74(3):270-281. doi: 10.1136/thoraxjnl-2018-211589.	meet the inclusion criteria for any of the reviews in the guideline
King's	Guidelin	8	11	We would challenge the evidence on this recommendation to have a	Thank you for your comment.

College London	e			printed copy of their advanced care plan available at their usual place of residence, or with them if they are admitted to hospital/hospice, based on Brinkman-Stoppelenburg et al's (2014) systematic review which reviewed the effects of different types of advance care planning in various settings. They concluded that complex advance care planning interventions may be more effective in meeting patient preferences than written documents alone. Brinkman-Stoppelenburg, A., Rietjens, J. A., & van der Heide, A. (2014). The effects of advance care planning on end-of-life care: A systematic review. Palliative Medicine, 28(8), 1000–1025. https://doi.org/10.1177/0269216314526272	The committee agrees, this recommendation takes into account that health and social care practitioners may not always have immediate access to the system where the advance care plan is held. The copy held by the person approaching the end of life is to ensure their advance care plan can be accessed at such times. 'Printed' has been removed to reflect that a copy of the advance care plan could be in different formats and not just on paper. This guideline is a service delivery guideline with recommendations for people providing and managing services and did not evaluate the clinical and cost effectiveness of the different type of clinical interventions. The Brinkman-Stoppelenburg review evaluated the different types ofadvance care planning (such as Do Not Resuscitate orders) and not different models of service delivery. The protocol in appendix A of Evidence review F: Advance Care Planning sets out the inclusion criteria for the review and the clinical effectiveness of different methods of ACP are not relevant for this review.
King's College London	Guideline	8	24	We are concerned that there is no mention of palliative care in the list of care provided from health and social care practitioners with the skills to meet the person's identified needs, despite extensive evidence, as outlined above, of effectiveness and cost effectiveness. In addition to the evidence above, the May et al systematic review - May P, Normand C, Cassel JB, Del Fabbro E, Fine RL, Menz R, Morrison CA, Penrod JD, Robinson C, Morrison RS. Economics of Palliative Care for Hospitalized Adults With Serious Illness: A Meta-analysis. JAMA Intern Med. 2018 Jun 1;178(6):820-829. doi: 10.1001/jamainternmed.2018.0750. This has a total 133 118 patients (range, 1020-82 273), found that when patients were pooled irrespective of diagnosis, there was a statistically significant reduction in costs (-\$3237; 95% CI, -\$3581 to -\$2893; P < .001). In the stratified analyses, there was a reduction in costs for the cancer (-\$4251; 95% CI, -\$4664 to -\$3837; P < .001) and noncancer (-\$2105; 95% CI, -\$2698 to -\$1511; P < .001) subsamples. The reduction in cost was greater in those with 4 or more comorbidities than for those with 2 or fewer. The authors conclude: Increasing palliative care capacity to meet national guidelines may reduce costs for hospitalized adults with serious and complex illnesses.	Thank you for your comment. The committee agrees that the terminology used in this area can differ. The commonly used terms describing the provision of end of life care have been added into the context section of the guideline. The committee uses end of life care to describe both palliative and supportive care and includes symptom management. The list of care describes what may be needed in delivering palliative care recognising this is not an exhaustive list. The committee recognise the difficulties of when to refer to additional specialist palliative care services and particularly for people with non-cancer conditions and have developed a research recommendation to address this (see research recommendation 1).

King's College London	Guideline	General	General	We have general concerns and are puzzled that in this draft guideline, interventions for which there is good evidence are not included, while interventions for which there is very little evidence are recommended. For example, Advance Care Planning, for which there is little strong or even moderate evidence, is recommended. While it is rightly identified that there is very little evidence for EPaCCS, we believe the biggest priority for research should be understanding whether or not these systems are effective. However, specialist palliative care, including early palliative care, has good evidence, and yet is recommended for further research into its effectiveness. We are concerned that the guideline appears to be promoting some interventions without clear evidence, and yet overlooking others which have a stronger evidence base. The process and methods need further review to understand why this is the case. Further details (including relevant evidence) are below.	Thank you for your comment. EPaCCs The committee agreed that good communication and documentation is critical and one way to achieve this is with an electronic information sharing system systems that are accessible between different services and organisations. The committee note in the evidence review I: Information sharing that EpaCCs and CANSIC are examples of these systems. It is recognised that there is variation in the delivery of services across the NHS and there may be additional costs for some services but in other areas they might be already integrated within current care. The systems are in line with the NHS Long Term Plan and NHS Digital's stated aim to develop joined up digital systems in the health service. The committee agrees here are gaps in the evidence and have highlighted this in the second research recommendation exploring the importance of identifying the best system. Specialist palliative care The committee do not dispute the benefit of specialist palliative care services but the evidence is not clear when people with a non-cancer diagnosis should be referred to these additional specialist services acknowledging that not everyone will need referral. Evidence review B: Timing of referral to palliative care services examined the best timing of referral (or provision) to palliative care services and limited evidence comparing strategies for early or late referral was identified. It was clear that early assessment of a person's needs is important and this is reflected in the guideline recommendations. What was lacking was evidence supporting decision making on when someone with a non-cancer diagnosis should be referred to additional specialist services. To address this gap the committee developed the research recommendation to examine if early review of service provision and referral to additional specialist palliative care services improve outcomes for adults with progressive non-cancer disease thought to be approaching the end of their life?
King's College London	Guideline	General	General	1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why Implementing early integrated palliative care will have the biggest impact – see above for the evidence regarding cost benefits and	Thank you for your comment and suggestions. The resource impact report and template identify

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				patients/family benefits 2. Would implementation of any of the draft recommendations have significant cost implications Implementation of some of the proposed interventions which lack evidence has potentially large cost implications and the cost effectiveness is unknown. 3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) NIHR supported research, including the OPTCARE programme of research https://www.kcl.ac.uk/cicelysaunders/research/studies/OPTCare and projects and findings highlighted in the NIHR review – see https://www.dc.nihr.ac.uk/themed-reviews/Better%20endings%20FINAL%20DH%20single%20page.pdf demonstrates examples of best practice initiatives that have been evaluated, many of which should feature more clearly in this guidance.	recommendations which could have significant resource implications depending on the extent to which current services are already in place. This can be used by commissioners to identify current services levels and estimate other costs likely to have significant impact locally. .This can be accessed at.. We will pass this information to our local practice collection team. More information on local practice can be found here.
Leeds Teaching Hospitals	Cost analysis	General	General	This document is very detailed and specific compared to the draft recommendations which are high level. You acknowledged that "They are not intended to provide accurate estimates of the likely costs to commissioners or people planning or providing end-of-life care services of implementing these services in practice." However there is a significant risk they may be interpreted in such a way. Nor is it especially clear if these are additional costs to extend core services. Greater clarity and guidance needs to be provided as how to how these figures should be interpreted and applied in practice. In the NHS England commissioning for palliative care guidance 2016 pg 22 it is clear there is no solid evidence for staffing levels.	Thank you for your comment. The role of the cost analysis has been clarified in Chapter K (1.4.3) and chapter L (1.8.3): "A costing analysis, with a threshold analysis, was conducted to estimate imprecisely the total costs of implementing a number of community services, available out-of-hours and investigate how plausible it is that they could break even. These should not be taken to be a prescription for such services which will vary considerably in order to meet local needs." The costs may be additional costs for some services but in other areas they might be already integrated within current care. To support local planning a resource impact report and local template have been produced using input from the guideline committee members. Based on the recommendations likely to have resource impact, a model has been developed to support commissioners to identify current services levels and estimate

					other costs likely to have significant impact locally. The model uses an integrated care structure, therefore entries can be made for staff requirements and to what extent services are already in place. This can be accessed at…..
Leeds Teaching Hospitals	Guideline	11	8	This needs to be supported by a statement about access to specialist palliative care OOH. Guidance specifies a healthcare professional should be available 24 hours- if specialist palliative care advice is needed they need to be able to access this advice	Thank you for your comment. Evidence review K_Out of hours evaluated out of hours services, to support people in their last year of life to stay in their usual place of residence. Specialist palliative care is catagorised as care that is delivered by specialists and that people have been referred to. This review did not evaluate access to specialist palliative care (for example that delivered in hospices) and focused on the access to care delivered by non specialist services. As such the evidence identified did not allow the committee to include a statement about an access to specialist palliative care out of hours.
Leeds Teaching Hospitals	Guideline	5	4	Should this be a stronger statement - being aware of something does not necessarily translate into action to benefit patients and carers	Thank you for your comment. The wording of this recommendation has been strengthened to, 'health care practitioners should be aware of the requirement of local systems to offer a carer's needs assessment in line with the Care Act 2014 and a young carer's needs assessment in line with the Children and Families Act 2014. '
Leeds Teaching Hospitals	Guideline	General	General	It is not clear from the recommendations what they add to the current guidance / quality statements about end of life care	Thank you for your comment. The recommendations reflect the evidence base and best practice in the service delivery of end of life care but the committee recognise there is considerable variation in the provision of end of life care services across the NHS. It is important that these guidelines reinforce best practice from a service delivery perspective and highlight the key areas of variation for implementation
Leeds Teaching Hospitals	Guideline	General	General	Within the recommendations - there is a mix between recommendations and statements for information, which makes the document less user friendly - e.g page 5, 1.3.1 line 8 and page 7, line 11 1.6.4 & 1.6.3	Thank you for your comment. The statements for information you refer to cross refer to related NICE guidelines and provide the reader with direct links to additional information and support in those sections of the guideline.
Leeds university	Rationale and impact	21	25	You make reference to the availability of advance care planning for different patient groups and refer to the evidence review on barriers to accessing end of life services. I would also add that reticence of	Thank you for your comment. Text has been added to the rationale and impact section

				professionals to engage in difficult conversations (referred to in the evidence review) is particularly true of those patients who have communication needs on top of end of life care planning needs. This was commented on by palliative care professionals in my ongoing qualitative research study.	‘Identifying adults who may be approaching the end of their life, their carers and people important to them’ recognising there is a reluctance to talk about death and that identifying adults who may be approaching the end of their life supports health and social care practitioners to start discussions about advance care planning. Information about training resources was not evaluated and cannot be included.
Leeds university	Recommendation	5	16	The comments about providing information in a way that meets communication needs is appropriate however I would add that referral for specialist communication support should also be considered. There is some evidence that palliative care professionals are not referring for specialist clinical input to support those with speech, language and communication needs	Thank you for your comment. The additional wording has been added to the providing information rational and impact section,’ The committee also acknowledged that peoples' information needs will vary and change over time, *so regular reviews are needed and referral to specialist communication support could be needed*.’
Leeds university	Recommendation	6	21	Similarly, the role for specialist communication support in advance care planning and mental capacity assessment should be considered to enable those who need it to participate in conversations. Please refer to RCSLT’s position statement on supported decision making and mental capacity	Thank you for your comment. The additional wording has been added to the providing information rational and impact section,’ The committee also acknowledged that peoples' information needs will vary and change over time, *so regular reviews are needed and referral to specialist communication support could be needed* .’ This highlights the need to consider and review the information needs of people when appropriate. There is reference to the Mental Capacity Act 2005 in recommendation 1.6.2 and the NICE guideline on decision-making and mental capacity is cross referenced in recommendation 1.6.3
LGBT Foundation	Guideline	10	14	When people are transferred between care settings it is important that information about them is shared. This needs to be done with the consent of the person.	Thank you for your comment. The committee agrees that consent of the person is needed and the wording in the recommendation has been amended throughout the guideline (from provide and done to offer) to reflect this.
LGBT Foundation	Guideline	4	13	Health and social care practitioners carrying out holistic needs assessments need to ensure they are undertaking sexual orientation monitoring and trans status monitoring. It should be ensured that these questions are asked sensitively and appropriately. It must be ensured that professionals are aware of the importance of asking these questions, this will mean they will be able to explain to patients why it is necessary to ask questions around sexual orientation and trans status. For more information and guidance surrounding monitoring see guidance from LGBT Foundation:	Thank you for your comment. The committee agrees and all NICE guidelines are developed in line with the NICE Social value judgements: Principles for the development of NICE guidance. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does

				https://lgbt.foundation/monitoring and NHS Digital's Information Standard: https://www.england.nhs.uk/publication/sexual-orientation-monitoring-full-specification/ In order to make LGBT patients feel included and potentially more willing to share information about their sexuality and/or trans status on monitoring forms it needs there needs to be improved LGBT visibility in services. For example staff carrying out holistic needs assessments could wear a rainbow lanyard and posters from LGBT organisations could be put on the wall. In a 2017 survey carried out by LGBT Foundation 62% of the suggestions made by LGBT people on how services could improve experiences for LGBT patients mentioned increased LGBT visibility (LGBT Foundation. "2017 Primary Care Survey Report").	not address in detail how health and social care professionals should deliver care or what would be included in a training strategy. The committee agrees that it is important that a holistic needs assessment that considers all aspects of a person's wellbeing, spiritual, and health and social care needs. This is set out in the definition in the terms used in this guideline section. This wording has been added to the definition of people important to adults,' It is important that health and social care practitioners understand that assumptions should not be made when asking about the 'people important to adults' , for example, assuming everyone is in a heterosexual relationship and asking a female patient about her husband. She may have a wife and feel uncomfortable correcting this assumption.'
LGBT Foundation	Guideline	4	9	It must be ensured that health and social care practitioners understand that assumptions should not be made when asking about the 'people important to adults'. A Marie Curie report on end of life care for LGBT people found that heteronormative (assuming everyone is straight) assumptions are made by some healthcare professionals. For example asking a female patient about their husband. That patient may have a wife and may feel uncomfortable correcting this question. It's always best to ask open questions such as 'who would you like to be involved in your advanced care plan?' rather than 'would you like your husband to be involved?' (Marie Curie, 2016. *"Hiding who I am" The reality of end of life care for LGBT people*).	Thank you for your comment. This wording has been added to the definition of people important to adults,' It is important that health and social care practitioners understand that assumptions should not be made when asking about the 'people important to adults', for example, assuming everyone is in a heterosexual relationship and asking a female patient about her husband. She may have a wife and feel uncomfortable correcting this assumption.'
LGBT Foundation	Guideline	6	2	It needs to be ensured that those who take into account the support needs of carers are aware of a range of organisations that can offer support- including voluntary and community sector organisations. This is essential so that effective social prescribing can be carried out by those organising support for carers.	Thank you for your comment. The committee agrees and a recommendation has been added to the supporting carers section to ensure that people managing and delivering services should consider what practical and emotional support can be provided to carers.
LGBT Foundation	Guideline	6	20	When carrying out advance care planning people's identities must be taken into account. It must be ensured that questions are not heteronormative e.g. asking men if they want their wife involved. The use of 'people important to the person' that is used in the guidance is a good way of asking open questions that don't make assumptions about a person.	Thank you for your comment. The committee agrees and this wording has been added to the definition of people important to adults,' It is important that health and social care practitioners understand that assumptions should not be made when asking about the 'people important to adults' , for example, assuming everyone is in a heterosexual relationship

					and asking a female patient about her husband. She may have a wife and feel uncomfortable correcting this assumption.'
LGBT Foundation	Guideline	7	11	It must be ensured that lead healthcare professionals have broad knowledge on the person they are supporting. This must include all demographic information about a person. For example someone may benefit from support from an LGBT organisation, however if the healthcare professional does not know that the person identifies as LGBT then they will be unlikely to offer this support. This shows the importance in demographic monitoring (including trans status monitoring and sexual orientation monitoring) in providing person centred care. Following on from this leads should ensure they have good knowledge of the range of support that exists in the area so that they can signpost people to a range of organisations that are appropriate for that person, such as LGBT organisations or faith organisations.	Thank you for your comment. The committee agrees this is important and would hope that the lead healthcare professional is someone that knows they person they are supporting. In addition in the section on out of hours care it is recommended that adults approaching the end of their life, their carers and other people important to them should have access to a healthcare professional available 24 hours a day, 7 days a week, who can access the person's records and advance care plan, and make informed decisions about changes to care.
LGBT Foundation	Guideline	8	1	It is important relevant information is shared between services so that patients do not have to keep explaining themselves over and over. It must be ensured that open conversations are had with patients to ensure that they give consent for this information being shared, including information about their identity, particularly if this information is sensitive and/ or personal.	Thank you for your comment. The committee agrees that communicating and sharing information between services is important to the provision of good care and this Is recommended throughout the guideline, see the sections on communicating and sharing information between services, reviewing treatments and providing end of life care coordination.
LGBT Foundation	Guideline	8	17	It is essential that a range of care is offered. It is essential that health and social care practitioners have good knowledge on a range of services so they can carry out effective social prescribing if necessary. It is also essential that they have good knowledge on the person approaching the end of their life so they can fully take into account all aspects of the person and provide the best person centred care.	Thank you for your comment. The committee agrees this is important and would hope that the members of the team and the lead healthcare professional know the person they are supporting and have knowledge of the services they may need. In addition in the section on out of hours care it is recommended that adults approaching the end of their life, their carers and other people important to them should have access to a healthcare professional available 24 hours a day, 7 days a week, who can access the person's records and advance care plan, and make informed decisions about changes to care.
LGBT Foundation	Guideline	General		Sustained efforts must be made to eradicate discrimination and unequal treatment based on someone's LGBT identity in end of life services. In 2016 Marie Curie published evidence that concluded that, because they anticipated discrimination, people from LGBT	Thank you for your comment. The committee agrees and all NICE guidelines are developed in line with the NICE Social value judgements: Principles for the development of NICE guidance. In the terms used in this guideline this wording has been added to

				communities would access palliative care services later than people who are not from LGBT communities (Marie Curie, 2016. *“Hiding who I am” The reality of end of life care for LGBT people).* Palliative and end of life care improves quality and length of life, reduces emergency admissions to hospital and the likelihood of dying in hospital. They therefore concluded that it is likely therefore that people from LGBT communities have a significantly worse experience of dying than people who are not from LGBT communities. It is also likely that this reluctance to access palliative care means there is increased pressure on informal carers of LGBT people. This Marie Curie report also found: • There is anecdotal evidence to suggest that LGBT patients and their partners and families may not have their religious/ spiritual needs addressed in the same way as other patients. • LGBT people are concerned that their loved ones will not be respected and recognised as next of kin. Furthermore a 2018 Stonewall report found that 13% of LGBT people had experienced unequal treatment from healthcare staff, this includes 32% of trans people and 20% of LGBT disabled people (LGBT in Britain: Health). This demonstrates that more work needs to be done to improve end of life care for LGBT people. A number of steps can be taken to improve care: • Having a zero tolerance policy on discrimination which is displayed in services. • Ensuring there are robust processes for patients to be able to report discrimination and give feedback and ensure patients are aware of these processes. • Seeking out LGBT inclusion and awareness training for all staff. • Monitoring sexual orientation and trans status of all patients. • Ensuring professionals are aware of the different LGBT support organisations in the area so they can signpost	the definition of people important to adults to remind health and social care practitioners about the impact assumptions can have on people accessing care ,’ It is important that health and social care practitioners understand that assumptions should not be made when asking about the ‘people important to adults’ , for example, assuming everyone is in a heterosexual relationship and asking a female patient about her husband. She may have a wife and feel uncomfortable correcting this assumption.’

				patients if necessary.	
MacIntyre Charity	Guideline	10	2	Their carers and others important to them (add in with consent, if the person chooses)	Thank you for your comment. The committee agrees that consent of the person is needed and the wording in the recommendation has been amended (from provide and done to offer) to reflect this.
MacIntyre Charity	Guideline	11	10	Ensure the person is involved and agrees to changes in care and decisions being made. If the person lacks capacity (which is likely if they are approaching end of life care), then ensure Best Interest Decisions are made and documented accordingly.	Thank you for your comment. The committee agrees that consent of the person is needed and the wording in the recommendation has been amended throughout the guideline (from provide and done to offer) to reflect this. There is reference to the Mental Capacity Act 2005 in recommendation 1.6.2 and the NICE guideline on decision-making and mental capacity is cross referenced in recommendation 1.6.3.
MacIntyre Charity	Guideline	4	6	We should recommending that advance care planning and choices/preferences regarding end of life care are made much sooner. The Recommendation in 1.1 is suggesting that we need to identify adults approaching the end of their life in order to plan ahead, however for many people that are approaching end of life, their capacity is likely to be null and therefore we cannot advance care plan appropriately. Advance Care Planning should be done as early as possible, whilst the person is well and has capacity – not as they are approaching end of life.	Thank you for your comment. The committee agrees that advance care planning should happen as soon as someone is identified as approaching the end of life. Approaching end of life is defined in the terms used and in the context sections of the guideline and this is, 'End of life care includes the care and support given in the final weeks and months of life, and the planning and preparation for this. For some conditions this could be months or years'.
MacIntyre Charity	Guideline	4	9	If possible, the person themselves should identify who is important to be told – not reply on health and social care practitioners or carers.	Thank you for your comment. The committee agrees and consider this is part of the initial discussions with the person approaching the end of their life. The wording of the recommendation is to remind health and social care practitioners that carers and people important to adults should be identified.
MacIntyre Charity	Guideline	6	21	Same as first comment made (Page 4, Line number 6). Advance Care Planning should not be done as a person is approaching the end of their life. There are huge implications for this.	Thank you for your comment. The committee agrees that advance care planning should happen as soon as someone is identified as approaching the end of life. Approaching end of life is defined in the terms used and in the context sections of the guideline and this is, 'End of life care includes the care and support given in the final weeks and months of life, and the planning and preparation for this. For some conditions this could be months or years.'
MacIntyre Charity	Guideline	7	1	A new bullet point should be added: Service providers should develop processes to: Involve the person in advance care planning. We have mentioned others important to them being involved, but not	Thank you for your comment. The first recommendation in the advance care planning section

				stated explicitly that the person themselves should be at the centre of this and be involved throughout (as much as they want to and can)	focuses on the person approaching the end of life.
MacIntyre Charity	Guideline	8	1	The person themselves should be communicated to effectively, in a way that makes sense to them.	Thank you for your comment. The committee agrees and the recommendations in the section on providing information reflect this principle.
MacIntyre Charity	Guideline	General	General	From what I have read so far, it is written as if carers and health professionals will be making decisions – there is no strong voice of the person themselves. This needs to be clearer throughout.	Thank you for your comment. The committee agreed and the wording in recommendations 1.6.1, and1.10.4 (from provide and done to offer) have been edited to reflect this.
Macmillan Cancer Support	Evidence review: Guideline Introduction and Methods	8	25	It is noted that in this document on page 8 under section *2.3.3 Relationships between the guideline and other NICE guidance* the document *End of life care for adults [QS13] (updated: March 2017)* is not listed as a related NICE document – why is this? The final scope for this draft guideline says the quality standard Q13 may be updated, but this does not explain why it is not listed as a related NICE document.	Thank you for your comment. This has been amended.
Macmillan Cancer Support	Guideline	11	11	Suggest amending to ‘24hr access to End of Life Care and Specialist Palliative Care Advice Line’.	Thank you for your comment. The evidence identified did not allow the committee to propose any explicit guidance around the hours of operation and this is discussed in evidence review K in the committee’s discussion of the evidence. In addition, the committee noted that the need for any out of hours services and their operationalisation will depend on the local services already available and will vary accordingly. The term end of life care advice line is broader than a specialist palliative care advice line. A specialist palliative care advice line may be interpreted as only for people that have been referred to

					specialist palliative care and this guideline's population includes people approaching the end of their life outside of that service.
Macmillan Cancer Support	Guideline	4	14	Could be more strongly worded to emphasise that services should not only be able identified needs but should have in place processes and services to meet needs.	Thank you for your comment. The recommendation on health needs assessment states that this is to enable the right support to be provided. This indicates that the process and services should be in place to provide the support.
Macmillan Cancer Support	Guideline	4	7	Suggest amending to 'help people to stay or be transferred to their preferred place (obviously this may not always be possible)'.	Thank you for your comment. Recommendations about Transferring people between care settings are in section 1.11 of the guideline. This recommendation focuses on identifying people to ensure that discussions can take place to ensure their future care is optimal, including planning for transfers.
Macmillan Cancer Support	Guideline	6	1	There is no recommendation around supporting carers needs including bereavement needs, and we would strongly recommend this needs to be explicitly included, especially give there are several references to the importance of carer support. A strong recommendation here and link to the Quality Standard *End of life care for adults [QS13] (updated: March 2017)* – in which bereavement services do form part of the recommendations - would support and enable commissioners to give this important area more priority.	Thank you for your comment. An additional recommendation has been added to the supporting carers section reflecting that people managing and delivering services should consider what practical and emotional support can be provided to carers. Although this guideline did not explicitly address bereavement the added recommendation is clear that people managing and delivering services should consider what practical and emotional support can be provided to carers.
Macmillan Cancer Support	Guideline	6	15	Need to assess the individual's understanding of the treatment plan to ensure informed choice including benefits and burdens of treatments	Thank you for your comment. The committee agrees that any discussion with an individual should include the health or social care practitioner assessing and ensuring that the person has understood and is making an informed choice. This is a fundamental part of communication as a health and social care practitioner and the section on providing information includes cross reference to the NICE guidelines on patient experience in adult NHS services and people's experience in adult social care services to emphasise the importance of good communication.
Macmillan Cancer Support	Guideline	6	22	Suggest amending to say that 'advance care planning is *offered* and carried out where agreed.	Thank you for your comment. The committee agreed and the wording in recommendations 1.6.1, and1.10.4 have been edited to reflect this. The text has been changed in recommendation 1.6.1 from 'carried out' to 'offered to adults' and from 'provide' to 'offer' in recommendation 1.10.4.

Macmillan Cancer Support	Guideline	8	20	Suggest amending to add ‘Provide adults approaching the end of their life, their carers and other people important to them with access to the expertise of highly skilled health and social care practitioners, *including specialist level palliative care*, when needed, to:	Thank you for your comment. The wording, ‘the expertise of highly skilled health and social care practitioners’ is deliberately broad to include all practitioners in all levels of care, adding reference to some services could be interpreted as access to those not mentioned being less important. The wording has not been edited for this reason.
Macmillan Cancer Support	Guideline	8	24	Suggest amending to add ‘Provide care from health and social care practitioners, *including a specialist level palliative care multipractitioner team*, with the skills to meet the person’s *and those identified as important to the person’s* identified needs, which may be:’	Thank you for your comment. The wording,‘the expertise of highly skilled health and social care practitioners’ is deliberately broad to include all practitioners in all levels of care, adding reference to some services could be interpreted as access to those not mentioned being less important. The wording has not been edited for this reason.
Macmillan Cancer Support	Guideline	9	17	Suggest amending to add ‘tertiary care, *including specialist level palliative care*’.	Thank you for your comment. This wording has been revised to,’ hospital services for adults whose treatment is based in secondary or tertiary care, provided by health and social care practitioners based in hospices or disease-specific specialists in hospitals.’ This includes within in the definition specialist level palliative care.
Macmillan Cancer Support	Guideline	9	24	Suggest amending to add ‘community-based care *and vice versa*’	Thank you for your comment. The committee agrees and the wording has been revised to reflect your comment.
Macmillan Cancer Support	Guideline	General	General	It would be helpful to summarise at the beginning how this document relates to and should be reviewed in conjunction with the clinical guideline *Improving Supportive and Palliative Care for Adults with Cancer CSG4 (March 2004)*. Whilst the NICE guideline on Care of Dying Adults is referenced, the above document is not. The project timeline information on the website explains that the original draft scope was to update the *Improving Supportive and Palliative Care for Adults with Cancer CSG4 (March 2004)* but that this was reviewed following scoping consultation and this new guidance developed instead - it would be helpful to explicitly explain this in the introductory section and how the new document relates to the CSG4.	Thank you for your comment. The quality standard will be updated when this guideline is published and there will be a link from the pathway on the NICE website for end of life care to the quality standard.
Macmillan Cancer Support	Guideline	General	General	The most closely related NICE document related to this draft guideline is the Quality Standard *End of life care for adults [QS13] (updated: March 2017)* so it would be helpful to be explicit at the beginning of this document about how the quality standard for End of Life Care and this draft guideline relate to one another and should	Thank you for your comment. The quality standard will be updated when this guideline is published and there will be a link from the pathway on the NICE website for end of life care to the quality standard.

				be used together. The final scope document for this draft guidance states this guideline will also be used to update the NICE quality standard for end of life care and that the quality standard may need to be revised or updated when this guideline is published. Whilst these two documents are very closely related, this draft guideline contains significantly less detail than the quality standard. This detail is crucial to service delivery and we strongly recommend that the two documents remain as co-existing and related documents to be used together and that this link is made explicit in the introduction to this guideline.	
Macmillan Cancer Support	Guideline	General	General	With comment 3 in mind, we suggest it may be helpful throughout the document in each recommendation to reference the corresponding part of the NICE Quality Standard *End of life care for adults [QS13] (updated: March 2017)* as a source of further related information, recommendation and implementation guidance.	Thank you for your comment. The quality standard will be updated when this guideline is published and there will be a link from the pathway on the NICE website for end of life care to the quality standard.
Macmillan Cancer Support	Guideline	General	General	It would be helpful to ensure that there is signposting to the clinical guideline *Improving Supportive and Palliative Care for Adults with Cancer CSG4 (March 2004)* particularly in relation to care plans and ensuring these are updated regularly.	Thank you for your comment. The quality standard will be updated when this guideline is published and there will be a link from the pathway on the NICE website for end of life care to the quality standard.
Macmillan Cancer Support	Guideline	General	General	The document describes the need for policies for things like advance care planning but does not emphasize the importance of the need for learning and development to support the policies to ensure the workforce are competent and confident to meet the policy requirements and deliver the services. Either this needs to be more explicitly referenced in this document or there should be clear signposting to the relevant sections in the NICE Quality Standard *End of life care for adults [QS13] (updated: March 2017).*	Thank you for your comment. The quality standard will be updated when this guideline is published and there will be a link from the pathway on the NICE website for end of life care to the quality standard.
Macmillan Cancer Support	Guideline – Rationale and impact	17	5	We question the assumption that increased identification will not have significant resource impact – early identification of needs will require those needs to be met by services which previously may not have seen that cohort of patients. We agree that the hope is the wider system impact – such as reduced unnecessary hospital admissions should have a positive impact, but on an individual service level there may be increased demands on some elements of the system.	Thank you for your comment. The text has been revised to "The recommendations are expected to increase the number of people identified. The net impact on services is uncertain. Some investment will be required to establish systems to systematically identify patients in some areas. However, this will ensure that people approaching the end of their life will receive the appropriate care, and their carers will receive support, which will help to avoid unnecessary hospital admissions."
Macmillan Cancer	Guideline –	13	16/17	In the context of EOLC hospices should be added to this list and considered as an organisation that provides services for people	Thank you for your comment.

Support	Terms used in this guideline			approaching the end of their life. Page 30, line 10 referenced hospices as one of the services this guideline advises on so hospices should be listed in this section.	This has been added.
Macmillan Cancer Support	Guideline – Transferring people between care settings	11	1-4	Additional recommendation is needed to ensure that there is timely, appropriate written/electronic communication about the adult's care and needs between care settings, when adults at the End of Life are transferred in order to maximise seamless care as much as possible. This will support efficient coordination of care between care settings and minimise distress to the adult at the End of Life	Thank you for your comment. This is addressed in the communicating and sharing information between services section of the guideline and in the cross reference to the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.
Marie Curie	Guideline Recommendation 1.11	10	19	Transferring people between care settings 1. **Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** Due to the complexity of patient needs at the end of life, especially where patients are living with a terminal illness or multiple comorbidities, transport must be able to manage the patient safely during any transfer between settings. For that reason, it is often an emergency ambulance that is used with paramedic crew. In practice, however, this often means that when there is an emergency the crew are pulled away from completing a transfer. The timing of the transfer needs to be coordinated to ensure all necessary equipment and care packages are in place. Transfer can be delayed if everything is not set up in a short timeframe. The availability of equipment varies, and it may be necessary to provide better stocked equipment stores that have easy access and provision of equipment when needed. 2. **Would implementation of any of the draft recommendations have significant cost implications?** As above, there may be some cost implications in ensuring that equipment stores are sufficiently well-stocked to ensure easy access and provision of equipment for patient transfers when required. However, we would expect any additional cost here to be relatively minor.	Thank you for your comments.

				3. **What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice)** As an example, one hospice that Marie Curie works with in London received funding to purchase a palliative care ambulance which has a crew trained in looking after the needs of the palliative care patients. Similarly, Marie Curie has an ambulance that is used in the Leeds area to move patients between the hospital, independent hospices and their homes. These reduce reliance on emergency ambulances to move patients with complex needs or terminal illnesses which require management during transfer – reducing instances of transfers having to be abandoned or rescheduled due to emergency calls taking preference and otherwise reducing demands on emergency ambulance crews.	
Marie Curie	Guideline Recommendation 1.1	4	4	Identifying adults who may be approaching the end of their life, their carers and other people important to them 1. **Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** Identifying patients approaching the end of life can be challenging despite guidance to support health practitioners with this. Research for the Marie Curie Palliative Care Research Department at University College London has found that clinicians are frequently inaccurate when predicting how long those living with terminal illnesses will survive – the accuracy of such predictions ranges from 78% to just 23%[1]. Even where patients are much closer to death, further research by the same team has shown that clinicians' estimates of when patients are likely to die within 72 hours are incorrect in approximately one case in four[2].	Thank you for your comments and suggestions. The committee agrees, identifying people who may be approaching the end of their life is challenging. It is important that people are identified as soon as possible to allow discussions to begin and this is the underlying principle of the guideline set out in recommendation 1.1.1. The definition of End of life care placed at the beginging of the guideline makes it clear that this includes the care and support given in the final weeks and months of life, and the planning and preparation for this. For some conditions this could be months or years. The resource impact report and template identify recommendations which could have significant resource implications depending on the extent to which current services are already in place. Training costs are picked up, however these are highly variable and therefore left for providers and commissioners to estimate these locally in the model.

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[1] White N, Reid F, Harris A, Harries P, Stone P (2016), A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts?

[2] White N, et al. BMJ Supportive & Palliative Care (2019)

				In addition to this challenge, not all patients or carers recognise their own diagnosis as either palliative or terminal. This can be challenging and requires the practitioner to have strong, effective communication skills and time to have effective discussions with patients and their carers about palliative and end of life care planning. Having time to facilitate these conversations in the primary or acute care setting can be extremely difficult – but without them implementing the other areas of these guidelines is likely to be challenging. **2. Would implementation of any of the draft recommendations have significant cost implications?** As per the below, there would be cost implications associated with providing education and training for generalist health professionals with regard to identifying end of life and having constructive conversations with patients and their carers around end of life care planning. **3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice)** Education for generalist health care professionals with regards to triggers for conversations around end of life care; this is important to ensure that clinicians are able to have the effective conversations which are necessary to ensure advance care planning takes place. Increase in both health and social care community resources to support those who have identified home as being preferred place of care and death. Promotion and emphasis of the importance of planning for end of life. This is especially important given the ageing population living with multiple comorbidities; helping to raise awareness among the elderly and the general population of the importance of end of life planning will further support clinicians to have effective conversations about advance care planning.	
Marie Curie	Guideline Recommendation	4	7-8	Too focused on preferred place of care as an easy to measure, surrogate metric. Alternative form of wording: "…to help people live out the end of their life in line with their preferences."	Thank you for your comment. The wording has been amended to,' support people's preferences for where they would like to be cared for and die'.

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Marie Curie	Guideline Recommendation 1.6.2	7	2-4	Suggest making specific reference to tools for advance care planning such as lasting power of attorney, will-writing, advance directions and statements of preference.	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care or the specific advice they might give. The definition of advance care planning in the terms used in this guideline includes a description of what might be included in a discussion and includes resuscitation plans.
Marie Curie	Guideline Recommendation 1.8.3	8	11	Communicating and sharing information between services **1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** Ensuring that patients have access to printed copies of their advance care plan is a positive recommendation; however, it should be noted that in practice many patients lose or mislay such documents – a paper copy should not be the only means of different providers accessing a patient's advance care plan. **3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice)** As noted in Comment 3, encouraging greater availability for online care-planning services like Coordinate my Care will support better communication between services and provide an alternative to a single, patient-held copy of an advance care plan that is easily-accessible to multiple providers involved in that patient's care.	Thank you for your comments. The committee agrees and recommend the use of online information sharing systems that are accessible between different services organisations. The committee note in the evidence review I: Information sharing that EpaCCs and CANSIC are examples of these systems. They note that Coordinate my Care is used in London. This recommendation takes into account that health and social care practitioners may not always have immediate access to the system where the advance care plan is held. The copy held by the person approaching the end of life is to ensure their advance care plan can be accessed at such times. 'Printed' has been removed to reflect that a copy of the advance care plan could be in different formats and not just on paper.
Marie Curie	Guideline Recommendation 1.9	8	17-25	Too focused on care being 'done to' people; approach should include seeing family, friends or other carers as part of the care team through providing education and enabling patients and family to self-care, where appropriate.	Thank you for your comment. This recommendation is an action for people managing services to provide access to the expertise of highly skilled health and social care practitioners and provide is appropriate here. However, the committee agreed there are other recommendations that would benefit from editing and the wording in recommendations 1.6.1, and1.10.4 (from provide and done to offer) have been edited to reflect your comment.
Marie	Guidelin	8	6	Communicating and sharing information between services	Thank you for your comment and suggestions.

Curie	e Recommendation 1.8.2			**1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** The use of electronic clinical records is established in the NHS; however, the use of these varies within the voluntary sector. There are many different programmes in use and the ability to share information between services is usually dependent on the system availability, compatibility and IT structure within an organisation. Using standardised electronic information sharing would be a way forward to address this, but this will involve ensuring it can be used on the various IT platforms in the various organisations involved in the care. To change this could involve organisations having to bring in new systems, and train staff in the system, which will have a cost implication. Adopting this approach will also have implications for the governance of sharing data and the need for data-sharing agreements between organisations and providers to facilitate the transfer of personal, patient data. **2. Would implementation of any of the draft recommendations have significant cost implications?** As above, if adopting standardised electronic information sharing requires providers to bring in new IT systems, this will have cost implications for providers who have to change or upgrade their IT systems to accommodate this. **3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice)** Encouraging greater take-up by patients of services like Coordinate my Care[3], and greater availability of such platforms for providers, would be beneficial. The Marie Curie nursing service in London has been able to link into this service and we have found it effective in	The committee agrees that good communication and documentation is critical and one way to achieve this is with an electronic information sharing systems that are accessible between different services and organisations. The committee note in the evidence review I: Information sharing that EpaCCs and CANSIC are examples of these systems. They note that Coordinate my Care is used in London. It is recognised that there is variation in the delivery of services across the NHS and there may be additional costs for some services but in other areas they might be already integrated within current care. The systems are in line with the NHS Long Term Plan and NHS Digital's stated aim to develop joined up digital systems in the health service. The Resource and Impact report and template include the additional costs associated with the need to develop IT systems allowing appropriate clinicians to access a persons ACP and records.The template can be used to support commissioners to identify current services levels and estimate other costs likely to have significant impact locally. This can be accessed … We will pass this information to our local practice collection team. More information on local practice can be found here.

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[3] www.coordinatemycare.co.uk

				both facilitating information-sharing between providers and better coordination between different providers of patient care. At present Coordinate my Care is only available in London; adopting an approach or service like it more widely will support providers in other parts of the UK to provide better-coordinated care and support more effective information-sharing.	
Marie Curie	Guideline	General	General	Marie Curie supports the proposed guidelines for organising and delivering end of life care services. The draft guideline and recommendations cover each of the key areas which are relevant for delivering quality care at the end of life. Our submission principally aims to answer the following additional questions identified by NICE: 1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. 2. Would implementation of any of the draft recommendations have significant cost implications? 3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) We have no comments on the Equality Impact Assessment.	Thank you for your comments.
Multiple System Atrophy Trust	“	Page 11	Line 8	This is very important, full details of MSA treatment and palliative care teams should be easily available to access with key contacts for co-ordination.	Thank you for your comment.
Multiple System Atrophy Trust	“	Page 5	Line 13	Information about possible care / end of life care should be discussed earlier in neurological disease, including MSA, as communication / capacity issues may affect discussion if left until later	Thank you for your comment. The committee agrees and highlight the importance of early discussion in the recommendations on identification and advance care planning. The NICE guidelines on Motor Neurone disease: assessment and management have been cross referenced in the advance care planning section.
Multiple System Atrophy Trust	“	Page 6	Line 8	Need to be aware of the requirement for some medication that may need to be continued until near to death, and alternative routes of administration considered	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address how health and social care professionals should

					deliver care. Recommendation 1.5.1 cross refers to the NICE guidelines on multimorbidity and medicines optimisation for advice on reducing treatment burden and reviewing medicines and other treatments.
Multiple System Atrophy Trust	“	Page 7	Line 21	This is important as deterioration may be rapid at certain times and quick assessment may be required.	Thank you for your comment.
Multiple System Atrophy Trust	“	Page 8	Line 2	This issue is very important. This is needed as continuing certain medication or avoiding medication that could worsen symptoms will need good sharing of a persons individual and evolving needs.	Thank you for your comment.
Multiple System Atrophy Trust	“	Pages 10-11	Line 19	There is a specific need for care packages to enable people to remain at home in case of sudden deterioration. This may be through NHS Continuing Care Funding but may involve other sources of support. Processes need to be put in place in advance to ensure this can happen rather than attempting to respond to crises.	Thank you for your comment. The committee agrees and throughout the recommendations there is an emphasis on early identification, planning and regular responsive review. The section on providing multipractitioner care is clear that where possible crises should be anticipated, prevented or minimised.
Multiple System Atrophy Trust	“	Pages 6-7		Advance Care Planning may need to be discussed earlier in rapidly progressing conditions. Perhaps consider when there are new interventions or changes or deterioration in condition?	Thank you for your comment. The committee agrees and highlight the importance of early discussion in the recommendations on identification and advance care planning. The section on reviewing needs makes it clear that discussions about care should be driven by the person’s need and not at prescriptive intervals. This is highlighted in the following bullet point in this recommendation (1.7.1) making it clear that repeat assessments and reviews should happen when needed. The NICE guidelines on Motor Neurone disease: assessment and management have been cross referenced in the advance care planning section.
Multiple System Atrophy Trust	“	Pages 8-9	Line 18	Interesting that the terminology has changed from multidisciplinary team care. Why is this? Need to ensure that all practitioners are aware / can obtain knowledge about the specific needs / issues in MSA Studies of neurological MDT were not included in the review – e.g. MND / MS teams. This seems to have been an oversight? E.g. Veronese S, Gallo G, Valle A, et al. Specialist palliative care improves the quality of life in advanced neurodegenerative	Thank you for your comment. Multidisciplinary team care has been traditionally used to describe healthcare professionals across different clinical disciplines, multipractitioner is broader and ensures that social care professionals and practitioners are included in the recommendations.

				disorders: Ne-PAL, a pilot randomized controlled study. BMJ Supp and Pall Care 2017; 7:164-172. – included MSA patients Aridegbe T, Kandler R, Walters SJ et al. The natural history of motor neuron disease: Assessing the impact of specialist care. Amytroph Lat Scler 2013; 14:13-19. Rooney J, Byrne S, Heverin M et al. A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. J Neurol Neurosurg Psychiatry 2015; 86: 496-503. Edmonds P, Hart S, Gao W et al. Palliative care for people severely affected by multiple sclerosis: evaluation of a novel palliative care service. Mult Scler 2010; 16: 627-36.	The committee agrees that practitioner should be aware of the specific needs of people with life-limiting neurological conditions and have included cross reference to the NICE guideline on Motor Neurone disease in the advance care planning care section of the guideline. Evidence review B: Timing of referral to palliative care services examined the best timing of referral (or provision) to palliative care services and limited evidence comparing strategies for early or late referral was identified. Specialist palliative care is catagorised as care that is delivered by specialists and that people have been referred to. This review did not evaluate referral to specialist palliative care (for example that delivered in hospices) and focused on the access to end of life care delivered by non specialist services. The Veronese et al study evaluated specialist referral and as such was not included in the review. Aridegbe, Rooney and Edmonds evaluates the impact of people being cared for in a disease specfifc specialist multidisciplinary clinic and this does not meet the intervention inclusion criteria for the review. The committee noted the limited evidence in this area but acknowledged that referral to end of life care services for people with a cancer diagnosis is better established than for people with non- cancer diagnosis. The committee wanted to highlight that people with a non-cancer diagnosis are under represented in this evidence base and in that addressing subsequent referral to specialist care. The benefit of early engagement with end of life care services is not disputed and early identification and engagement is recommended for everyone throughout the guideline. To address the subsequent referral to specialist services the committee developed the research recommendation to examine if early review of service provision and referral to additional specialist palliative care services improve outcomes for adults with progressive non-cancer disease thought to be approaching the end of their life**.**
Multiple System Atrophy	“	Pages 9-10	Line 12	This emphasises the importance of data sharing with the need to ensure MSA Nurse Specialists and othe condition specialists are involved. Also need to ensure death certificate has correct cause of	Thank you for your comment. The committee agrees that good communication and

Trust				death, in many cases Multiple System Atrophy is not noted even though it has caused the death.	documentation is critical, and this is emphasised throughout the guideline.
Multiple System Atrophy Trust	“ “	Page 4	Line 13	Very Good	Thank you for your comment.
Multiple System Atrophy Trust	Guideline	Page 4	Line4	Identifying adults- End of life care planning and palliative care may need to be considered earlier for people with Multiple System Atrophy along with other similar rapidly progressing conditions. This is because of the risk of loss of communication ability and general capacity loss in advanced disease which lead to inability to make decisions clear. The use of triggers in identifying the end of life phase for neurological patients was not mentioned- the papers may not have been in the remit of the PICO – but could be raised as system that has some evidence End of life care in long term neurological conditions: a framework for implementation. National End of Life Care Programme 2010. https://www.nai.ie/assets/98/E29C88A6-9CA5-06B3-E74D285E3C0695A2_document/End_20life_20care_20long_20term_20neuro_20conditions.pdf Hussain J, Adams D, Allgar V, Campbell C. Triggers in advanced neurological conditions: prediction and management of the terminal phase. BMJ Supp Pall Care 2014; 4: 30-37. Hussain J, Allgar V, Oliver D. Palliative care triggers in progressive neurological conditions: An evaluation using a multi-centre retrospective case record review and principal component analysis. Pall Med 2018 ;32: 716-725. DOI 10.1177/0269216318755884.	Thank you for your comment. The committee agrees and highlight the importance of early discussion in the recommendations on identification and advance care planning. The NICE guidelines on Motor Neurone disease: assessment and management have been cross referenced in the advance care planning section. To clarify that this guideline could apply to people that need end of life for more than a year the following sentence has been added to the context and terms used in the guideline sections, ‘Although for some conditions care could be provided for months or years.’ The following sentence has been added to the context and terms used in the guideline sections, ‘ Although for some conditions care could be provided for months or years.’
NHS England and NHS Improvement			general	It is hard to find fault with this guidance and I believe that in most health and social care settings staff try to deliver this standard of care. There are however significant difficulties and challenges that will impact on its delivery. The primary risk would be in relation to workforce as we lack specialist practitioners in almost all areas and even if a service is commissioned it is not a guarantee that it can be delivered. I am however very supportive of the content of the guideline. (YK)	Thank you for your comment. The committee agrees the guideline reflects good practice and that there is variation in the delivery of this standard of care across the NHS. There are areas of the guideline, such as providing specialist support, that may need some upstream support and investment to implement recommendations in the guideline. However, implementation will ensure that people approaching the end of their life will receive the appropriate care which potentially will reduce emergency admissions and hospital length of stay increasing capacity in other areas of the service.

					The resource impact report and template identify recommendations which could have significant resource implications depending on the extent to which current services are already in place. This can be used by commissioners to identify current services levels and estimate other costs likely to have significant impact locally. This can be accessed at.
NHS England and NHS Improvement			general	People with a learning disability are more likely to die in hospital than at home or in the community. Their end of life care needs are often unrecognised, or if they are they may not be referred for additional support/services. (JOH)	Thank you for your comment. To reflect your comment cross reference to the NICE guideline on the care and support of people growing older with learning disabilities has been added to sections1.4, 1.6. The NICE guideline in development Social work interventions for adults with complex needs, including, learning disabilities and mental health has been cross referenced in section 1.6. The importance of identifying people with learning difficulties has been added to the relevant rationale and impact section
NHS England and NHS Improvement			general	Thought may need to be given to the support required not only for families, but for paid carers and fellow residents/house mates with a learning disability. (JOH)	Thank you for your comment. A carer is defined in the 'terms used in the guideline' as a carer is someone who helps another person, usually a relative, partner or friend, in their day-to-day life. This term does not refer to someone who provides care professionally or through a voluntary organisation. This definition includes fellow residents/house mates with a learning disability and the NICE guidelines on the care and support of people growing older with learning disabilities and on social work interventions for adults with complex needs, including, learning disabilities and mental health (in development) have been cross referenced.
NHS England and NHS Improvement			general	Particular guidance may be helpful to reference how to document DNACPR. A recent letter from the national medical director was sent to remind clinicians that 'learning disabilities' is not a reason for DNACPR (in line with the recent publication of the 3rd LeDeR Report, May 2019). (JOH)	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address how health and social care professionals should deliver care. The definition of advance care planning in 'the terms used in this guideline' highlights that this discussion should include preferences and wishes for types of care or treatment (including declining these) in the future and discussion of the care available. The NICE guideline on the care and support of people growing older with learning disabilities has also been cross referenced in the Advance care planning recommendations.
NHS		11	1	Agreed transfer policy is often in place but may be compromised by	Thank you for your comment.

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

England and NHS Improvement				availability and can have an impact, clarity on developing a policy that will address this and commissioning a service that will be able to deliver within required parameters. (YK)	The committee agrees the guideline reflects good practice and that there is variation in the delivery of this standard of care across the NHS. There are areas that may need support and investment to implement some recommendations in the guideline. In the committee's discussion of the evidence in Review M: Optimal transistion, the committee suggest that commissioning models could address: palliative care ambulances, pharmacy, community nurses, and junior doctors, with a focus on increased speed and urgency of service delivery as potential approaches to support smooth and rapid transfers.
NHS England and NHS Improvement		7	17	Use of regular assessments would benefit from emphasising the need to flex in response to patient need rather than specifying the need for regularity solely. (YK)	Thank you for your comment. The committee agrees that discussions should be driven by the person's need and not at prescriptive intervals. This is highlighted in the following bullet point in this recommendation (1.7.1) making it clear that repeat assessments and reviews should happen when needed.
NHS England and NHS Improvement	Draft Guidance	10	24 (1.11.2)	This section details coordination of care packages and equipment, there is a need that both Health care and social care packages are available and coordinated, though not all people at the end of their life will want social care intervention. Inclusion of a narrative that details a need for arrangements to be agreed with and communicated to patients and carers and who to contact for help support would be helpful, as breakdown in care is often a reason for readmission to hospital / poor end of life experiences. It would also be useful for people being discharged from acute care to have an understanding of potential issues they may incur and how these could be managed Multiagency and multidisciplinary (SC)	Thank you for your comment. The committee agrees that good communication and documentation is critical in all aspects of end of life care and this is emphasised throughout the guideline. Section 1.7 Reviewing needs recommends the need for regular discussions and assessments of needs with the adult approaching the end of their life and section 1.10 Providing end of life care coordination includes recommendations to ensure that people are told who the members of the team responsible for their care are and how services are accessed.
NHS England and NHS Improvement	Draft Guidance	8	2 (1.8.2)	Whilst we support the reasoning for including this, in reality services are a significant way from being able to achieve this, this is most difficult between health and social care providers (SC)	Thank you for your comment. The committee agrees that good communication and documentation is critical, and this is emphasised throughout the guideline. This is in line with the NHS Long Term Plan and NHS Digital's stated aim to develop joined up digital systems in the health service.
NHS England	Draft Guidanc	9	7	This section details 'access to equipment and rehabilitation', we would suggest adding enablement to this sentence (equipment,	Thank you for your comment.

and NHS Improvement	e			enablement and rehabilitation) as patients may not feel able to undertake rehabilitation but should be enabled to be as independent as is possible during their end of life journey. This section (nor does the whole document) detail any reference to nutrition and hydration, another important area to consider when managing people at their end of life. It may be viewed that this is included in symptom management, however we would like to see explicit reference to the provision of advice and support to manage issues in relation to nutrition and hydration. (SC)	Access to equipment and rehabilitation The committee agrees that people should be enabled to be as independent as possible and to be cared for where they would like to be cared for. This is highlighted in recommendation 1.11.2 in reference to care packages and equipment and in recommendation 1.4.2 in reference to decision making. The bullet point you refer to is about enabling people to be independent ensuring they have access to the services they may need, and the committee did not agree that adding enablement would add to the meaning of the recommendation. Nutrition and hydration Nutrition and hydration has been added to the bullet point' disease-specific'.
NHS England and NHS Improvement	Guideline	11	11	Suggest the phrase 'end of life care' is replaced by 'palliative care' as the advice line is often used for symptom management advice not just end of life care (BW)	Thank you for your comment. The committee agrees that the terminology used in this area can vary. The commonly used terms describing the provision of end of life care have been added into the context section of the guideline. The committee uses end of life care to describe both palliative and supportive care and includes symptom management.
NHS England and NHS Improvement	Guideline	11	12	The out of hours pharmacy service may not just have access to medicines – it has to ensure access to medicine. Also, there is a missing piece here about access to prescription in this whole section – which includes advice, decision making, and pharmacy but the missing requirement is access to prescriptions sometimes. (BW)	Thank you for your comment. The first bullet point of this recommendation states there should be access to a healthcare professional 24 hours a day, 7 days a week, who can access the person's records and advance care plan and make informed decisions about changes to care. This includes access to prescription advice and decision making.
NHS England and NHS Improvement	guideline	4	4	It is vital that adequate consultation is held with those who deliver care rather than commission it, to design the system to be used. However it is likely that many areas will have partial or complete systems in place and it would be sensible to utilise good practice and exemplars if available. (YK)	Thank you for your comment. The committee agrees and people managing and delivering services has been added into recommendation 1.1.1.
NHS England and NHS Improvement	guideline	5	1	A skills framework would be helpful here or suggestions for training. It is not unknown for professionals to assume they are skilled in areas due to longevity in the profession but it may not translate into reality. (YK)	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care or what would be included in a training strategy or skills framework.

NHS England and NHS Improvement	Guideline	6	21-23	Advance care planning should be 'offered' to adults who are approaching the end of their life – the current wording could cause unintended consequence of ACP being carried out as a matter of course – the element of choice is key (BW)	Thank you for your comment. The committee agreed and the wording in recommendations 1.6.1, and1.10.4 have been edited to reflect this. The text has been changed in recommendation 1.6.1 from 'carried out' to 'offered to adults' and from 'provide' to 'offer' in recommendation 1.10.4.
NHS England and NHS Improvement	guideline	6	8	This is rather vague but again it is very likely that existing local policies are in place and it would be sensible for these arrangements to identify who holds the "ring" on the care of an individual. It is still common for there to be significant difficulties in cross organisation communication. A shared care record should be proposed as an ideal and if not in place specific guidance on how care will be navigated across organisations. This is of course not specific to reducing treatment burden but across all aspects of end of life care. (YK)	Thank you for your comment. The committee agrees and this is reflected in the recommendations on communicating and sharing information between services with the use of an electronic information-sharing system that is accessible between different services and organisations. The other recommendation in the reviewing current treatment section and those in providing end of life care coordination are clear there should be a lead health care professional that assumes overall responsibility.
NHS England and NHS Improvement	Guideline	7	5-7	This bullet point is not relevant here – it relates to people lacking capacity. Advance care planning cannot be carried out by somebody who lacks capacity, though it is only if and when they lose capacity that advance care planning decisions that have been made previously become applicable. (BW)	Thank you for your comment. This recommendation on advance care planning has been separated into two recommendations to ensure that the issue of advance care planning and decision making and mental capacity are not conflated.
NHS England and NHS Improvement	Guideline	9	14-15	Suggest the phrase 'in their usual place of residence' is replaced with 'in the community' or 'out of hospital' – even if somebody is not in hospital, they are not necessarily in their 'usual place of residence', e,g. those who are in a hospice or who are temporary residents in a care home (BW)	Thank you for your comment. The committee agreed with the point about 'usual' place and removed this word, place of residence can refer to temporary places of care.
NHS England and NHS Improvement	Guidelines	10	6	Need to include the recording of those discussions here in order for the information to be shared and acted upon (LB)	Thank you for your comment. This has been added into recommendation 1.2.1 on assessing holistic needs.
NHS England and NHS Improvement	Guidelines	11	15 and subsequent definition	Concerned about the definition used here and the nuances between personalised care and support planning and Advance Care Planning (ACP). The opening definition mentions ACP as personalised care and support planning, but the subsequent bullet points outlining what is to be included very much focuses on what I would expect to	Thank you for your comment. The terms used in the guideline section has been edited to address your comments.

				see in ACP; far more focussed on the future rather than the present. I strongly feel these guidelines would benefit from including both personalised care and support planning; highlighting this as the foundation of high quality care in general, with ACP as the opportunity to provide a focus on end of life care. It is important to make a distinction as both have a role to play, but I also think that NICE and NHS England and Improvement would benefit from further conversations on this section, just to ensure practitioners and service providers are being given a consistent message going forward in terms of both what we mean and what we expect in this area. (LB)	Advance care planning is defined as in 'One Chance to get it Right' and a sentence clarifying that ACP is one part of personalised care and support planning has been added. A definition of personalised care and support planning has been added to the terms used in this guideline section and the difference between personalised medicine has been clarified.
NHS England and NHS Improvement	Guidelines	5	14-16	This whole section talks about "processes" and "arrangements" but fails to emphasise the importance of conversation, and providing the individual with opportunities to understand the information they have been given. (LB)	Thank you for your comment. The section on providing information includes cross reference to the NICE guidelines on patient experience in adult NHS services, people's experience in adult social care services and on care and support of people growing older with learning disabilities, these guideline provide advice on communication and information.
NHS England and NHS Improvement	Guidelines	5	16	Should reference be made here to the Accessible Information Standard? (LB)	Thank you for your comment. This has been added to the guideline in the providing information rationale and impact section of the guideline.
NHS England and NHS Improvement	Guidelines	5	3	I am concerned that no reference is made in this recommendation about what to do with the information gathered e.g. putting it into a personalised care and support plan that is then used. It does not highlight the importance of recording and sharing this information. In addition, I worry that the emphasis on this as an Assessment makes this feel like a box to be ticked; rather than a series of conversations to be had. (LB)	Thank you for your comment. The revised wording of recommendation 1.2.1 now includes documentation. The sections on communicating and sharing information and reviewing needs address the importance of recording and sharing this information and it being a series of conversations.
NHS England and NHS Improvement	Guidelines	5	8	Should include a link to the NICE Shared Decision Making Guidelines (LB)	Thank you for your comment. This guideline is in development and not due to publish until April 2021.
NHS England and NHS Improvement	Guidelines	7	1	Reference should also be made here to personalised care and support planning in general. (LB)	Thank you for your comment. The terns used in the guideline section has been edited to address your comments.

					Advance care planning is defined as in 'One Chance to get it Right ' and a sentence clarifying that ACP is one part of personalised care and support planning has been added. A definition of personalised care and support planning has been added to the terms used in this guideline section and the difference between personalised medicine has been clarified.
NHS England and NHS Improvement	Guidelines	8	25	What about the needs of carers and/or loved ones? (LB)	Thank you for your comment. This is reflected in the section on supporting carers and additional recommendation has been added in this section reflecting that an assessment should take place and what practical and emotional support can be provided.
NHS England and NHS Improvement	Guidelines	General	General	Concerned that these guidelines provide no overview of the content within which this care is expected to take place, that is, these things need to happen, but not as a series of tasks but as part of conversations, and general personalised care. (LB)	Thank you for your comment. The terms used in the guideline section has been edited to address your comments. Advance care planning is defined as in 'One Chance to get it Right ' and a sentence clarifying that ACP is one part of personalised care and support planning has been added. A definition of personalised care and support planning has been added to the terms used in this guideline section and the difference between personalised medicine has been clarified.
NHS West Hampshire CCG	Guideline	11	8	As commissioners our approach has been to provide specialist support in NHS 111 to reduce the amount of different points of access and to provide a response that has access to the notes of the person. There is no mention of the role of NHS 111 here	Thank you for your comment and this example of practice. The protocol in appendix A of evidence review K includes helplines in the services to be searched for and in appendix B the Medline (Ovid) search terms included NHS 111.However,no evidence was identified evaluating any specific helplines and as such the committee were not confident in recommending any one helpline and made the general recommendation for an out of hours advice line. In addition, the committee noted that the need for out of hours services and their operationalisation will depend on the local services already available and will vary accordingly.
NHS West Hampshire CCG	Guideline	14	11	We are noting the challenges we had with implementing previous digital attempts to capture and define outcomes, (EMACS)	Thank you for your comment. The committee acknowledge there are challenges in implementing an electronic information-sharing system and that it is not clear how this can be done effectively. The second research recommendation in the guideline explores the importance of identifying the best system. The committee also note this is in line with the NHS Long Term Plan and NHS Digital's stated aim to

					develop joined up digital systems in the health service.
NHS West Hampshire CCG	Guideline	15	2 and general	Mention is made of people living alone, more attention is needed in the guideline to that eventuality, much of the guideline assumes carers involved	Thank you for your comment. The committee agrees it is important to acknowledge that many people will be living alone and that access to carers, family or friends is variable. To highlight the importance of service providers and people delivering services taking into account the needs of people that find it harder to access services direct reference to underserved and vulnerable groups has been added to the recommendation on advance care planning, into the section on providing end of life care co-ordination and in the rational and impact section for identifying adults who may be approaching the end of their life.
NHS West Hampshire CCG	Guideline	19	15	The recommendation should mention relief and psychological support as well is the provision of information	Thank you for your comment. An additional recommendation has been added to the supporting carers section reflecting that people managing and delivering services should consider what practical and emotional support can be provided to carers.
NHS West Hampshire CCG	Guideline	4	4 and 9	We are concerned that there is no definition provided for approaching end of life which may not help practitioners in targeting their efforts	Thank you for your comment. Approaching end of life is defined in the terms used and in the context sections of the guideline.
NHS West Hampshire CCG	Guideline	5	12	There is no reference to the quality of the conversation, (eg open, sensitive)	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care. The section on providing information includes cross reference to the NICE guidelines on patient experience in adult NHS services, people's experience in adult social care services and on care and support of people growing older with learning disabilities, these guideline provide advice on communication and information.
NHS West Hampshire CCG	Guideline	General	General	Whilst the guideline is helpful in supporting basic standards it is mechanistic in approach and makes no mention of the cultural shifts required in the workforce and amongst agencies to bring about a different kind of conversation with adults approaching end of life.	Thank you for your comment. This guideline focuses on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care or what would be included in teaching strategies acknowledging that implementation may according to

					local needs, service and resources.
North East Essex Health and Wellbeing Alliance		8	20	Our patient representative group wanted to express support for the concept of highly skilled health and social care professionals being available including overnight, to offer personal care. They feel that decommissioning of experienced specialist services and replacement with generic social care at the end of life has caused a deterioration in personal care.	Thank you for your supportive comment.
North East Essex Health and Wellbeing Alliance	Guideline	11	11	We support an end of life singlepoint of access. We have had such a service in our area for 5 years and it has been transformative in the support offered to people at the end of life. We have an embedded rapid response nursing service which also supports people either within a care home or their own home in the event of a crisis.	Thank you for your comment and example of good practice. We will pass this information to our local practice collection team. More information on local practice can be found here.
North East Essex Health and Wellbeing Alliance	Guideline	6	20	We think that advance care planning should also have a system wide population approach rather than at service level. The Voices survey in 2011 found that care home residents were the least likely group to have been given the opportunity to express a preference as to where they would like to die. This type of inequity is likely to continue if advance care planning is only offered within services. Care home residents are unable to access primary care services unsupported.	Thank you for your comment. NICE provides national guidance for publically funded health and social care but we would hope that other organisations providing end of life care would take the opportunity to use the guideline.
Northwest Boroughs Healthcare NHS Foundation Trust	Guideline	6		1.5.3 Talks about reviewing treatments, optimising care, improving quality of life and organising appointments. Could we recommend that this section should include Anticipatory Clinical management plans to sit alongside that of an Advance Care Plan.	Thank you for your comment. The recommendation states that the lead healthcare professional should discuss all existing treatment plans, this includes Anticipatory Clinical management plans.
Northwest Boroughs Healthcare NHS Foundation Trust	Guideline	General	General	Throughout the guidance it refers extensively to the importance of Advance Care Planning and having Preferred place of care and Preferred place of death as an outcome measure. What the guidance does not say is that Advance Care Planning is a voluntary process and is something that should be offered to patients and not as suggested in the recommendation 1.6.1 ***“Advance Care planning is carried out”***. Could we recommend that they add ACP is voluntary and that H & SCP should ***offered*** patients the opportunity to have an Advance	Thank you for your comment. The committee agreed and the wording in recommendations 1.6.1, and1.10.4 have been edited to reflect this. The text has been changed in recommendation 1.6.1 from ‘carried out to’offered to adults’ and from ‘provide’ to ‘offer’ in recommendation 1.10.4

				Care Plan. Everything else looks ok and ties in nicely with the new Palliative and End of Life care QOF points that GP's can now get for their Palliative and EOLC patients.	
Public Health Agency	Guideline	whole		The Northern Ireland Palliative Care in Partnership Programme welcomes the development of End of life care – service delivery. If endorsed by Northern Ireland's Department of Health, there will be a requirement to note the relevant acts for Northern Ireland.	Thank you for your comment.
Resuscitation Council (UK)	Guideline	10 11	14–26 1–4	The guidance misses an opportunity to promote good practice by emphasising the importance of a robust system to ensure that those (organisations, professionals or volunteers) involved in transferring a person from one setting to another receive clear communication and documentation to enable them to respond appropriately should the person's condition change abruptly during transfer. There have been clear examples of inappropriate responses causing people avoidable harm or distress in such circumstances, where communication and/or documentation and/or local policy has failed to provide person-centred care.	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care or what would be included in a policy acknowledging that this may according to local needs. The committee agrees that good communication and documentation is critical, and this is emphasised throughout the guideline. In the transferring people between care settings section the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs is cross referenced for more detailed advice on transitions between care settings.
Resuscitation Council (UK)	Guideline	10	8–9	Where the guidance states ' Ensure that care is coordinated across and between the multipractitioner teams and between care settings', please consider adding: "One way to achieve this is the use of universally recognised processes and documentation, as – for example – in the ReSPECT process (www.respectprocess.org.uk)." ReSPECT has been developed as an evidence-based approach. Please see (accessible via the above link): • Fritz Z, Slowther A-M, Perkins GD. Resuscitation policy should focus on the patient, not the decision. BMJ 2017; 356. j813. doi: https://doi.org/10.1136/bmj.j813 and • Pitcher D, Fritz Z, Wang M, Spiller JA. Emergency care and resuscitation plans. BMJ 2017; 356. J876. doi: https://doi.org/10.1136/bmj.j876	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address or look for the evidence in how health and social care professionals should deliver care and in this case what tools are clinically and cost effective for multipractitioner teams to use.
Resuscitation Council	Guideline	General		This is very non-specific guidance. We are aware that there is not a strong evidence base in this area and agree with the recommendation that more research is needed. The failure to	Thank you for your comment. The committee disagree this is a non-specific guideline. The

(UK)				reference examples of recognised good practice means that this guideline appears to lack authority, and may not have the desired impact.	recommendations reflect the evidence base and best practice in the service delivery of end of life care and the committee recognise there is considerable variation in the provision of end of life care services across the NHS. It is important that these guidelines reinforce best practice from a service delivery perspective and highlight the key areas of variation for implementation. We will pass this information to our local practice collection team. More information on local practice can be found here.
Royal College of General Practitioners	Guideline	10	10	Avoid language 'take place' rather 'discussions are offered and supported'. Language must avoid people being forced to have these conversations if they don't want to nor regularly offered because they are dictated.	Thank you for your comment. The committee agreed and the wording in recommendations 1.6.1, and1.10.4 (from provide and done to offer) have been edited to reflect this.
Royal College of General Practitioners	Guideline	3	General	This should mention a public health population based approach to improving care delivery. This should also reference a section on care after death and bereavement support	Thank you for your comment. The guideline is a service delivery guideline with recommendations for people providing and managing services. Although this guideline did not explicitly address bereavement the added recommendation 1.3.1 is clear that people managing and delivering services should consider what practical and emotional support can be provided to carers.
Royal College of General Practitioners	Guideline	30	General	There are differences and challenges between making service improvements in acute and primary care. Ideally this could be highlighted and expanded.	Thank you for your comment. The committee agrees that there are many differences and challenges throughout the guideline that could be expanded on and making service improvements in acute and primary care is one of them. The context section is a concise summary and where appropriate differences and challenges specific to the topic are explored in the separate review chapters.
Royal College of General Practitioners	Guideline	4	7/8	Suggest rephrasing 'to help people stay in their preferred place of care' to read 'to support people's preferences of where they would like to be cared for and die'.	Thank you for your comment. The wording has been amended to,' support people's preferences for where they would like to be cared for and die'.
Royal College of General Practition	Guideline	4	9	'Health and social care practitioners should identify carers'. Suggest adding identify and offer/sign-post to support.	Thank you for your comment. In the supporting carers section an recommendation has been added to direct people managing and delivering services should

ers					consider what practical and emotional support can be provided to carers.
Royal College of General Practitioners	Guideline	5	General	‘Providing information’ – there should be a sentence that ensures people are not just provided with information to tick a box. Information giving should be only IF someone wants to receive information and not bureaucratic. Systems should not be about information overload and ensuring the patient/carer is not bombarded so that a provider can fulfil their ‘system approach’.	Thank you for your comment. This section addresses the process and systems for providing information. The committee agrees that how information is provided is important and should not be bureaucratic. The section on providing information includes cross reference to the NICE guidelines on patient experience in adult NHS services, people's experience in adult social care services and on care and support of people growing older with learning disabilities, these guideline provide advice on communication and information.
Royal College of General Practitioners	Guideline	6	11	If there are multiple lead clinicians such as in hospital with a number of outpatients this could overwhelm and duplicate/conflict – so suggest rephrasing to ensure this is avoided. ‘where possible, have the conversation once’ approach.	Thank you for your comment. The committee agrees and this addressed in the sections on communicating and sharing information between the services and providing end of life care coordination. The aim of the recommendations is to avoid the duplication of assessments and discussions.
Royal College of General Practitioners	Guideline	6	19	What does community approach mean here? Medical or Demedical i.e. peer support groups and voluntary sector. Worth also mentioned integrated – social care, welfare/benefits etc.	Thank you for your comment. Community support refers to any support outside of hospital that is provided by NHS services and includes where people may be homeless. The section on providing multipractitioner care includes a support reference to peer support groups and voluntary sector through signposting.
Royal College of General Practitioners	Guideline	6	21	This does not allow for people who do not want advance care planning, the committee should amend the wording of the recommendation to acknowledge this	Thank you for your comment. The committee agreed and the wording in recommendations 1.6.1, and1.10.4 have been edited to reflect this. The text has been changed in recommendation 1.6.1 from ‘carried out’ to ‘offered to adults’ and from ‘provide’ to ‘offer’ in recommendation 1.10.4.
Royal College of General Practitioners	Guideline	7	1	We suggest emphasising consent prior to involving carers and other people in advance care planning by rephrasing this e.g. ‘if the person approaching the end of their life consents, support carers and other people important to the person to be involved in advance care planning’	Thank you for your comment. The wording of the recommendation is clear that consent is required and the wording has not been changed.
Royal College of General	Guideline	7	16	Replace ‘have’ with ‘be offered’. Otherwise this becomes quite a dictatorial read and the emphasis should be on IF the patient wants the offer and for this to happen they need to ask permission first.	Thank you for your comment. The committee agreed and the wording in recommendations 1.6.1,

Practitioners				Otherwise there's a risk that a blanket approach from a provider will be rolled out.	and 1.10.4 have been edited to reflect this. The text has been changed in recommendation 1.6.1 from 'carried out' to 'offered to adults' and from 'provide' to 'offer' in recommendation 1.10.4
Royal College of General Practitioners	Guideline	7	General	ACPs – consideration to how systems interface across provider and locality boundaries'	Thank you for your comment. The committee agrees that communicating and sharing information between services is important to the provision of good care and this section in the guideline recommends the use of an electronic information-sharing systems that are accessible between different services and organisations.
Royal College of General Practitioners	Guideline	9	8	Offer advice /sign-posting to enable self-management	Thank you for your comment. The list of skills and approaches to delivering a person's identified needs are examples. The committee recognise there are many other examples that could be included and the list or examples are not intended to be exhaustive.
Royal College of General Practitioners	Guideline	9	9	Add pastoral with spiritual	Thank you for your comment. Pastoral has been added.
Royal College of General Practitioners	Guideline	General	General	The RCGP has developed the Daffodil Standards for Quality Improvement at Service Level for General Practice. https://www.rcgp.org.uk/daffodilstandards	Thank you for your comment and information.
Royal College of Nursing	General	General	General	The Royal College of Nursing (RCN) welcomes this draft NICE guidance for end of fife care – service delivery.	Thank you for your comment.
Royal College of Nursing	Guideline	General	General	The guidance is welcome as it strengthens the current guidance and is more focussed on the individual and their carers. However, there is no mention of advanced decisions to refuse treatment or some form of treatment escalation plan, which includes a DNACPR discussion as part of the process of End of Life Care planning. This is often done at the last minute as an afterthought rather than being introduced sensitively over a period of time as part of the care planning. There is also not enough emphasise on sufficient competent staff to	Thank you for your comment. In the definition of advance care planning in the 'terms used in this guideline' possible discussion areas are listed and includes reference to preferences and wishes for types of care or treatment in the future and discussion of the care available. In the section on providing multipractitioner care access to highly skilled health and social is recommended.

				ensure that the support and care is appropriate whatever the care setting.	
Royal College of Nursing	Guideline	Question 1	Question 1	*Q1 Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.* The need to ensure a robust carers assessment as part of the process as well as ensuring that people who are approaching the end of their life, including those with frailty have access to advanced care planning discussions and palliative care. This in reality especially in some care settings will be a challenge to implement for care staff, particularly nursing staff as the numbers of registered nurses in many settings would not be sufficient to undertake this. If there are to be suitably skilled staff to undertake both the assessment and the care delivery this has implications for training and education as well as numbers and will have cost implications.	Thank you for your comment and suggestion. The report and template identify recommendations which could have significant resource implications depending on the extent to which current services are already in place. Training costs are picked up, however these are highly variable and therefore left for providers and commissioners to estimate these locally in the model.
Royal College of Nursing	Guideline	Question 2	Question 2	*Q2 Would implementation of any of the draft recommendations have significant cost implications?* There will be cost implications for providers in many settings especially care homes where they have very little available money to invest in either training or additional staff. Providing suitably trained palliative care staff available to provide advice 24/7 including pharmacy support will have costs attached for some areas where this is not currently available.	Thank you for your comment and suggestion. Evidence report K examines in detail the costs associated with providing out of hours services in the economic evidence section and in the committee's discussion on cost effectiveness and resource use. The committee agreed that this is good practice and noted there was variation of provision across the NHS. Where the services are lacking there may be a need for resources to set up out of hours services, the specific service will be according to local need and current provision. However, the impact of out of hours services is likely to reduce the pressure on other services (for example hospital admissions) and provides the support system to help people to live as actively as possible until their death. The resource impact report and template identify recommendations which could have significant resource implications depending on the extent to which current services are already in place. This can be used by commissioners to identify current services levels and estimate other costs likely to have significant impact locally. .This can be accessed at..
Royal College of Nursing	Guideline	Question 3	Question 3	*Q3 What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice* More shared education for the whole team, offering care homes free places on training or in reaching to provide it. Using the resources and examples of good practice available on the NHS End of Life webpages and the Ambitions for End of Life and Palliative Care as	Thank you for your comment and suggestion. We will pass this information to our local practice collection team. More information on local practice can be found here.

				well as those of the larger charities such as Macmillan and Hospice UK, Compassion in Dying, RCN and medical Royal colleges.	
Royal College of Physicians (RCP)				The RCP is grateful for the opportunity to respond to the above consultation. In doing so we would like to endorse the responses submitted by the Association Of British Neurologists (ABN) and The British Cardiovascular Society (BCS). We have also liaised with our JSC for Palliative Medicine, the Society for Acute Medicine, and our Medical Specialties Board, and would like to make the following comments.	Thank you for your comment and for your contribution to the consultation process.
Royal College of Physicians (RCP)				Our experts note that there is very little in the NICE guidance about addressing inequalities in care in last year of life. This is disappointing, because it is i) one of the most important challenges in delivering better palliative and end of life care in last year, and ii) was highlighted quite specifically in the NHS Long Term Plan. Two of the major inequalities to consider are: 1. In relation to cancer versus non cancer conditions - we know that odds of receiving palliative care are less if you have non-cancer conditions, and we know also that even if you get into palliative care with non-cancer diagnoses, you will receive much less; for evidence see the paper by Matthew Allsop and Mike Bennett in 2018 on length of time in palliative care - median about 50 days if cancer, about half that if non-cancer. See slide 7 and 8 in the attached Powerpoint for details. 2. In relation to socio-economic position - we know that quality of healthcare in last year of life is less/poorer (in context of palliative needs) in people with lower socioeconomic position - see paper just published in PLOS Medicine which reviews all of the published evidence on this (209 papers - on how socioeconomic position is measured in last year of life and how it relates to quality of health care in last year) - https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1002782 It is also disappointing to see no recommendations in relation to costs in this document - there are a few comments about reducing hospital admission costs, and also something specific in relation to	Thank you for your comment. <u>Cancer and non cancer conditions</u> While the recommendations in the guidelines are relevant to all adults approaching the end of their life the committee recognised there is disparity in the access of services to people with non-cancer conditions. The scope section on current practice acknowledges that supportive and palliative care are less established for some diagnostic groups, for example, dementia, Parkinson's disease and frail elderly people with palliative care needs and evidence on non-cancer conditions was searched for in all the evidence reviews. Cross reference to the NICE guidelines on Dementia, Motor Neurone disease and Multimorbidity have been added to the guideline. Very little evidence that met the protocol for Evidence review B: Timing of referral to palliative care services (see Appendix A) was identified,and the committee were unable to make evidence-based recommendations that focused on non-cancer conditions. The guideline review question, 'what is the best timing of referral to (or provision of) palliative care services in people thought to be entering their last year of life?' compared different referral timings on outcomes set out in the protocol. Allsop et al is a retrospective cohort study evaluating patient and organisational factors that influence the duration of hospice-based palliative care and did not meet the inclusion criteria set out in the review protocol. The provision of care to people with non-cancer conditions is the direct focus of two of the research recommendations developed by the committee:

				out of hours care: 'evidence for providing a dedicated out-of-hours end of life care 24 advice line and an out-of-hours pharmacy service showed that the costs of providing these services could be balanced by the savings – incurred by a relatively small reduction in emergency admissions and length of stay of admissions, and an increase in the number of people remaining in the community.' But the much bigger issue is this: numbers of deaths are projected to increase markedly to 2040, and the need for palliative and end of life care will increase with this, alongside more complexity of care needs as multi-morbidities increase. Slides are attached from a presentation from Prof Fliss Murtagh at this year's Association of Palliative Medicine conference (see slides 4, 5, 6). It will be very difficult to implement these NICE guidelines - and deliver personalised care with advance care planning etc - if there is no increase in healthcare resources to enable the providers of palliative and end of life care to do this.	1.Does early review of service provision and referral to additional specialist palliative care services improve outcomes for adults with progressive non-cancer disease thought to be approaching the end of their life? 3.What are the benefits of planned, regular community-based reviews compared with as-required review of non-cancer patients approaching the end of their life? <u>Socio-economic position</u> To highlight the importance of service providers and people delivering services, taking into account the needs of people that find it harder to access services, direct reference to underserved and vulnerable groups has been added to the recommendation on advance care planning, into the section on providing end of life care co-ordination and in the rational and impact section for identifying adults who may be approaching the end of their life.Thank you for the reference. <u>Costs</u> NICE guidelines do not make recommendations directly related to costs but every review question examines the associated costs and cost effectiveness and this is reported in detail in each evidence report. It is recognised that there is variation in the delivery of services across the NHS and there may be additional costs for some services but in other areas they might be already integrated within current care. The resource impact report and template identify recommendations which could have significant resource implications depending on the extent to which current services are already in place. This can be used by commissioners to identify current services levels and estimate other costs likely to have significant impact locally. .This can be accessed at.
Royal College of Physicians (RCP)				Our experts would like to see stronger recommendations on advanced care planning (ACP) as there are far too many people out there in the last year of life who haven't has done any. These patients can end up with care that is not ideal e.g. being 'blue lighted' into hospital when they could have had a more peaceful, dignified death if their wishes had been discussed and recorded.	Thank you for your comment. The committee agrees that people approaching the end of life should be offered advance care planning (ACP) and this reflected in the wording of the recommendation. Sections 9.1and 9.2 in Developing NICE guidelines: the manual outline how NICE reflects the strength of the recommendation in the wording. 'Must' is only used in a recommendation where there is a legal duty or a very serious consequence of not following the recommendation.
Royal			Q3	What would help users overcome any challenges? (For example,	Thank you for your comment and suggestion on good practice.

College of Speech and Language Therapists				existing practical resources or national initiatives, or examples of good practice.) RCSLT Clinical guidance on End of Life care (soon to be published).	We will pass this information to our local practice collection team. More information on local practice can be found here.
Royal College of Speech and Language Therapists	Draft guideline	General comments	General comments	The RCSLT feels that some of the earlier sections of this guidance are little less informative, only starting to have some detail and be of value from point 1.8 onwards. The previous sections 1.1 to 1.7 are very high level and really don't say much. There could be value added by providing some further information in some sections. For example: 1.1 Identifying - says 'develop systems' but what does that mean in practice? Also no mention of challenges in identifying someone as at an 'end of life' stage 1.2 holistic needs assessment mentioned, but not what this could involve (medical, nursing, psychological, spiritual) 1.3 decision making - no mention of mental capacity 1.5 treatment and 1.7 reviewing needs - no mention of MDT Also, we consider that users of this guidance may find it more useful for definitions to be given earlier, e.g. what is meant be 'end of life' comes much later in document (page 12), but would benefit from being said at the beginning.	Thank you for your comment. It is important that recommendations are straightforward and easy to understand. To add more detail and explanation the recommendations are linked to the rationale and impact sections, this in turn links to the evidence reviews that describe the evidence and the committee decision making in more detail. Develop systems The rationale and impact section linked to recommendation 1.1 gives some examples of systems (for example, the Gold Standards Framework, Amber Care Bundle, Supportive and Palliative Care Indicators Tool (SPICT)). Holistic needs assessment This is described in the 'terms used in this guideline' and hyperlinked to in the recommendation. Decision making There is reference to the Mental Capacity Act 2005 in recommendation 1.6.2 and the NICE guideline on decision-making and mental capacity is cross referenced in recommendation 1.6.3 No mention of MDT Sections 1.9 providing multipractitoner care and 1.10 providing end of life care coordination make it clear that reviewing current treatment and reviewing needs is the context of multipractitoner care. Format of document The definition of end of life care and the context section have been moved to the front of the guideline before the recommendations.
Royal Free	Evidence review	10	28	I agree that inappropriate attempts at resuscitation are important outcomes to avoid, but some guidance as to how to define these	Thank you for your comment.

London NHS Foundation Trust	A			would be useful; the Resuscitation Council has some appropriate comments on this.	The committee agrees this is important and identified inappropriate attempts at resuscitation as an outcome to be extracted from the published studies identified in the searches. For this purpose, the committee defined inappropriate attempts at resuscitation as that defined and measured by the authors of included studies. The committee noted that throughout the evidence reviews this outcome was rarely reported.
Royal Free London NHS Foundation Trust	Evidence review A	10	30	This paragraph seems to directly contradict the paragraph above as many of the outcomes are identified as both critically important and to have no evidence.	Thank you for your comment. This section of the evidence review describes the outcomes the committee decided were important to identify in the evidence (this is also set out in full in the protocol in appendix A). The second paragraph states that although this outcome was looked for in the identified study it wasn’t reported.
Royal Free London NHS Foundation Trust	Guideline	21	20	The committee are suggesting better communication and processes to communicate with carers. It would be helpful to consider the resource for this. This is a) educational resource b) time in clinical practice to meet carers at times that they can make (this may not be Mon-Fri 9-5) and also Sampson’s paper shows that carers could not be contacted / did not feel it was their role to advance care plan. Much time is taken up with sourcing the appropriate person to liaise with and to freeing staff for family meetings. Also it is not just about information giving, but listening and negotiating. Please see Ruth Parry’s work on end of life talk….maybe though another literature review is required re educational strategies to achieve conversations with patients and carers? Also it is about managing strong emotions and families that can have complicated communication patterns. There is no advice regarding this.	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care or what would be included in a training strategy.
Royal Free London NHS Foundation Trust	Guideline	4	4	We agree that early identification is important, however, since there is no evidence for one system over another some guidance on whether we should employ existing systems or seek to refine/improve/design them would be helpful.	Thank you for your comment. The evidence review did not evaluate the effectiveness of the different systems but have noted in the rationale and impact section there are different systems and listed some examples of these. The decision about what system to use would be based on local requirements and needs.
Royal Free	Guideline	8	Section 1.8	It takes time to write a mutually agreed electronic record (record writing for co –ordinate my care (London region) takes nearly one	Thank you for your comment.

London NHS Foundation Trust				hour / patient). GPs are being rewarded financially within the new contract for creating records but for other teams this time is not resourced.	The committee agrees that good communication and documentation is critical and one way to achieve this is with an electronic information sharing systems that are accessible between different services and organisations. The committee note in the evidence review I: Information sharing that EpaCCs and CANSIC are examples of these systems. They note that Coordinate my Care is used in London. It is recognised that there is variation in the delivery of services across the NHS and there may be additional costs for some services but in other areas they might be already integrated within current care. The systems are in line with the NHS Long Term Plan and NHS Digital's stated aim to develop joined up digital systems in the health service.
Royal Free London NHS Foundation Trust	Guidelines	10	Section 1.11	Please see the work by Lowson *Lowson E, Hanratty B, Holmes L, Addington-Hall J, Grande G, Payne S, et al. From "conductor'to 'second fiddle': Older adult care recipients" perspectives on transitions in family caring at hospital admission. International Journal of Nursing Studies. Elsevier; 2013;50(9):1197–205.* And Hanratty Hanratty B, Holmes L, Lowson E, Grande G, Addington-Hall J, Payne S, et al. Older Adults' Experiences of *Transitions Between Care Settings at the End of Life in England: A Qualitative Interview Study. Journal of Pain and Symptom Management. Journal of Pain & …; 2012 Jul;44(1):74–83.*	Thank you for your comment and references. Hanratty et al is included in Evidence review C_Barriers to accessing end of life care services. Evidence review C explored the and facilitators barriers to the initial access to end of life care services and also experiences on discharge from hospital.The Lowson et al explored the impact of admission to hospital on established family caring relationships and didnnot meet the inclusion criteria for the review.
Society of Homeopaths	Guideline	General	General	The Society of Homeopaths is the UK's largest professional organisation registering homeopaths, with 1300+ members. Homeopaths practise in accordance with a strict Code of Ethics and Practice, hold professional insurance, and pass academic and clinical assessment before being admitted to the Register. The Society's register is accredited by the Professional Standards Authority (PSA).	Thank you for your comment.
Society of Homeopaths	Guideline	General	General	Reason for submitting We have made several presentations to NICE as they have considered their guidance on end of life, supportive and palliative care. In 2016 we responded to the proposed removal of complementary and alternative medicine (CAM). In 2017 we made a comprehensive presentation demonstrating how homeopathic treatment is well placed to support patients at the end of their lives, is valued by them, and is clinically and cost-effective. We also showed that there is a significant trend for homeopaths to provide	Thank you for your comment. This guideline focuses on the delivery of services for people approaching the end of life and for their carers or people and does not address the clinical and cost effectiveness of treatments or how health and social care professionals should deliver aspects of care acknowledging that implementation of what is available in a service may according to local needs, service and resources.

				palliative care to patients at the end of their lives (https://homeopathy-soh.org/resources/nice-consultation-into-palliative-and-end-of-life-care-2017 available to non-members on request). Despite this, we note that there is now no mention of integrated care using CAM in the proposed NICE guidance on end of life care. We think this is a serious omission and call upon NICE to reconsider. By not advising on the provision of CAM, such services will become exclusive to those able to pay for them privately and patient choice within the NHS removed. Homeopaths make a valuable contribution at end of life in hospices, NHS settings and privately. In order to allow patients to access the therapies that they value and choose for themselves within a variety of health and social care settings, homeopathy needs to be recommended in NICE guidelines.	
Society of Homeopaths	Guideline	General	General	Concordance with NICE guidance The Nice guideline “aims to ensure that people have access to end of life services according to their needs and wishes, considers all aspects of a person's wellbeing and health and social care needs and ensures that the person's concerns and problems are identified so that support can be provided to address them”. Treatment by homeopaths provides this cost-effective and valued model, providing the compassionate and individualised care which has also been highlighted as a key requirement in a number of national reports, guidelines and policy documents (e.g https://icamhub.com/wp-content/uploads/2019/01/PGIH-Report-Download.pdf).	Thank you for your comment. This guideline focuses on the delivery of services for people approaching the end of life and for their carers or people and does not address the clinical and cost effectiveness of treatments or how health and social care professionals should deliver aspects of care acknowledging that implementation of what is available in a service may according to local needs, service and resources.
Society of Homeopaths	Guideline	General	General	Compassionate and Individualised Care Care by homeopaths is tailored to the individual and delivered with compassion taking the whole person into account. Individualisation is a core principle whereby homeopathic medicines are prescribed according to patient specific (as opposed to disease specific) symptomatology. Homeopathic treatment involves an in-depth consultation with a practitioner where information about the patient’s physical, general, mental and emotional symptoms is gathered. It is according to this information that an appropriate homeopathic remedy is prescribed. There is some similarity between consultations carried out by homeopaths, and psychological interventions, such as the amount	Thank you for your comment and information.

				of time given to patients, practitioners' empathy, and patients' disclosure of problems. Care plans and decisions are made in accordance with the patient's needs and wishes, and are reviewed and revised regularly.	
Society of Homeopaths	Guideline	General	General	Cost-effective care Most health economic studies associate homeopathy with reducing direct, indirect and intangible healthcare costs whilst increasing Quality of Life and reducing disease severity (eg Witt et al., 2005 & 2008). For example, a complementary therapies service at Whipps Cross University Hospital (Barts Health Trust) for patients with cancer and palliative care found that patients using homeopathy had 21.5% global improvements in their symptoms and wellbeing, and that treatment costs were "substantially lower than average costs of other treatments in the NHS" (Briscoe, 2014).	Thank you for your comment. This guideline focuses on the delivery of services for people approaching the end of life and for their carers or people and does not address the clinical and cost effectiveness of treatments or how health and social care professionals should deliver aspects of care acknowledging that implementation of what is available in a service may according to local needs, service and resources.
Society of Homeopaths	Guideline	General	General	Valued by patients Qualitative research demonstrates high satisfaction with complementary therapies (including homeopathy) among patients receiving treatment funded within the NHS. Practitioners are perceived as being caring. Patients value the development of a therapeutic relationship within which they are encouraged to take an active part in looking after their health. Positive experiences of complementary therapy use are contrasted with either a failure of orthodox medicine or a dislike of the orthodox treatments available to them. Very few negative aspects were reported (Luff, 2000). Surveys also suggest high satisfaction with treatment by homeopaths (e.g Van Wassenhoven et al, 2014; Spence et al., 2005). 75% of patients at the Bristol NHS homeopathic hospital rated a homeopathic approach to symptom control as helpful or very helpful for their symptoms (Thompson, 2002). At the Cavendish Centre for Cancer Care in Sheffield, 88% reported improvement in their main concern using homeopathy (Peace, 2002). At the Penny Brohn Cancer Care centre patients reported significant improvements in their main concerns, which tend to be psychological and emotional, well-being, physical, and treatment side effects (Seers et al. 2009).	Thank you for your comment. This guideline focuses on the delivery of services for people approaching the end of life and for their carers or people and does not address the clinical and cost effectiveness of treatments or how health and social care professionals should deliver aspects of care acknowledging that implementation of what is available in a service may according to local needs, service and resources.
Society of Homeopaths	Guideline	General	General	Managing side-effects The concerns regarding the side effects and aggressiveness of conventional treatment tend to be the predominant reasons why patients turn to treatment by homeopaths. For example, many patients use homeopathy to help manage the side-effects of surgery, radiotherapy and chemotherapy. Homeopathic and	Thank you for your comment. This guideline focuses on the delivery of services for people approaching the end of life and for their carers or people and does not address the clinical and cost effectiveness of treatments or how health and social care professionals should deliver aspects of

				conventional approaches can be used alongside one another to give the most appropriate care to each individual patient. Seven reviews of the evidence of the safety of homeopathy indicate that homeopathic medicines may cause mild to moderate transient side-effects, but not strong or persisting side-effects (Bornhöft et al., 2006, Dantas & Rampes, 2000, ECCH, 2009, Grabia & Ernst, 2003, Woodward, 2005). No interactions with conventional drugs have been reported.	care acknowledging that implementation of what is available in a service may according to local needs, service and resources.
Society of Homeopaths	Guideline	General	General	Conclusion Provision of homeopathy is valued by patients and is clinically helpful, providing a unique take on palliation of the multi-morbidity and chronic disease which tend to characterise end of life. As an individually tailored therapy it is well placed to support a person-centred approach to management of symptoms. Such a holistic approach is appropriate, cost-effective, and valued by patients. It provides a unique role in management of the side effects of conventional drugs, and increasing autonomy at this vulnerable juncture. Please reinstate the provision of CAM in the NICE end of life guidelines. Provision of homeopathy within the NHS at end of life can offer cost effective provision, greater patient choice and higher quality of life care at this vulnerable juncture, valuing patient's wishes, addressing their discomforts and providing them with autonomy.	Thank you for your comment. This guideline focuses on the delivery of services for people approaching the end of life and for their carers or people and does not address the clinical and cost effectiveness of treatments or how health and social care professionals should deliver aspects of care acknowledging that implementation of what is available in a service may according to local needs, service and resources.
Society of Homeopaths	Guideline	General	General	References Bornhöft, G., Wolf, U., von Ammon, K., Righetti, M., Maxion-Bergemann, S., Baumgartner, S., Thurneysen, A, Matthiessen, P.F.(2006). Effectiveness, safety and cost-effectiveness of homeopathy in general practice – Summarized health technology assessment. Forsch Komplementärmed; 13(suppl 2):19-29. Briscoe, J; Browne, N. (2014). Evaluating an NHS complementary therapies service. BMJ supportive & palliative care Volume: 4 Issue: 1 Pages: 106 Dantas, F., Rampes, H. (2000). Do homeopathic medicines provoke adverse effects? A systematic review. Br Homeopat J; 89(Suppl 1):35-38. European Central Council of Homeopaths (ECCH). (2009). The safety of homeopathy. An ECCH Report. http://www.homeopathy-	Thank you for your comment and references. The guideline is a service delivery guideline with recommendations for people providing and managing services and does not include the evaluation of the clinical and cost effectiveness of specific end of life care interventions, including homeopathy.

				ecch.org/images/stories/pdf/the%20safety%20of%20homeopathy%202009.pdf Fibert, P. (2017). Inquiry into palliative and end of life care - https://homeopathy-soh.org/resources/nice-consultation-into-palliative-and-end-of-life-care-2017 – available to non-members on request Grabia, S., Ernst, E. (2003). Homeopathic aggravations: a systematic review of randomised, placebo-controlled clinical trials. Homeopathy; 92:92–8. Peace, G., Manasse, A. (2002). The Cavendish Centre for integrated cancer care: assessment of patients' needs and responses. Complementary Therapies in Medicine: 10, 1, 33–41 Seers H.E., Gale N., Paterson C., Cooke H.J., Tuffrey V., Polley M.J. Individualised and complex experiences of integrative cancer support care: combining qualitative and quantitative data. Supportive Care in Cancer 2009; 17(9): 1159-1167. (In collaboration with Penny Brohn Cancer Care.) Spence, D.S., Thompson, E.A., Barron, S.J. (2005). Homeopathic treatment for chronic disease: A 6-year, university-hospital outpatient observational study. J Altern Complement Med; 11(5):793-798. Thompson, EA; Reilly, D. (2002). The homeopathic approach to symptom control in the cancer patient: a prospective observational study. PALLIATIVE MEDICINE Volume: 16 Issue: 3 Pages: 227-233 Van Wassenhoven, M., Goossens, M., Anelli, M. (2014). Homeopathy and health related Quality of Life: a patient satisfaction survey in six European countries and Brazil. Homeopathy, 103, 250e256 Woodward, K.N. (2005). The potential impact of the use of homeopathic and herbal remedies on monitoring the safety of prescription products. Hum Exp Toxicol; 24:219-233. Witt, C. et al. (2005). Outcome and costs of homoeopathic and conventional treatment strategies: a comparative cohort study in patients with chronic diseases. Complementary therapies in Medicine. 13 (2): 79-86. doi: dx.doi.org/10.1016/j.ctim.2005.03.005. Witt, C. et al. (2008). How healthy are chronically ill patients after eight years of homeopathic treatment? – Results from a long term	

				observational study. BMC Public Health. 8 (413): n.d. doi: 10.1186/1471-2458-8-413.	
Tees, Esk and Wear Valleys NHS Foundation Trust	Guideline	4	2.1.1	There is a risk that multiple systems could be developed by stating people "managing services" using different criteria for identification. For a consistent joined up process it would be better if there was a unified system in place with a responsible host e.g. primary care, which is accessible to all and provides alerts when accessing other services.	Thank you for your comment. The committee agrees this would be ideal but recognise that there are already systems in pace in some areas and systems are developed according to local need.
The Brain Tumour Charity	Guideline	11	5	The guideline states *'Adults approaching the end of their life, their carers and other people important to them should have access to: a healthcare professional available 24 hours a day, 7 days a week, who can access the person's records and advance care plan, and make informed decisions about changes to care'*. We are concerned about the feasibility of this recommendation based on the current provision of workforce in the social care sector. The King's Fund reports one in 11 social care posts are vacant, claiming a '*need to invest in and support the social care workforce'.* Not only this, but there is a reported plus 100,000 staff shortage in NHS Trusts, equating to 1 in 11 posts. The provision of a healthcare professional during end of life care for brain tumour patients is pertinent for the brain tumour community. In our report, *'Losing Myself',* those respondents who have been given a terminal prognosis, 42% of them said they were not comfortable talking to those around them about dying. The range and unpredictability of the effects of a brain tumour, compared to other cancers, make the progression towards death and the circumstances of dying a particularly acute source of anxiety It is important having a healthcare professional available to a patient during their end of life pathway could provide needed information and assurance, as well as emotional support, at a time when patients do not feel comfortable expressing their worries and fears to their loved ones. Given this statement, The Charity would welcome further exploration and research into whether it is feasible for NICE to recommend adults approaching the end of their life will have access to a healthcare professional 24 hours a day, 7 days a week. As well as the point above, in order to provide the service described,	Thank you for your comment. Every review question in a NICE guideline examines the associated costs and cost effectiveness of an intervention and this is reported in the rational and impact section linked to the recommendation and in each evidence report. Evidence report K examines in detail the costs associated with providing out of hours services in the economic evidence section and in the committee's discussion on cost effectiveness and resource use. The committee agreed that this is good practice and noted there was variation of provision across the NHS. Where the services are lacking there may be a need for resources to set up out of hours services, the specific service will be according to local need and current provision. However, the impact of out of hours services is likely to reduce the pressure on other services (for example hospital admissions) and provides the support system to help people to live as actively as possible until their death. The resource impact report discusses where there is likely to be the greatest need for specialist support for people approaching the end of their life. This need has been identified across recommendations 1.9, 1.10 and 1.12 regarding the provision of mutipractitioner care, care co-ordination and out of hours care. A model has been produced using input from the guideline committee and takes into account the workforce needed to support services services covering a population of 500,000. Commissioners and providers can use the model to identify services needed to meet the end of life care needs of their population and allocate resources where possible.This can be accessed at.. Contact details

				it is paramount to ensure patients/carers are actually told who this healthcare professional is and how they may be contacted. Often, patients have access to a healthcare professional responsible for coordinating their care but do not know who they are/ their contact details.	Recommendation 1.10.4 in the providing end of life co-ordination reflects this and states that people should be given information about who their multipractitioner team members are and how services are accessed.
The Brain Tumour Charity	Guideline	12	5	NICE should make sure 'preferences' has an explicit consideration to include things such as tissue or organ donation.	Thank you for your comment. Cross reference to NICE guideline on Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation has been added to the section on Advance care planning.
The Brain Tumour Charity	Guideline	14	11	We would welcome further exploration into the cost implications of executing this service. Will explicit money be made available to install new, compatible systems across health and social care networks?	Thank you for your comment. The committee acknowledge there are challenges in implementing an electronic information-sharing system and also note this is in line with the NHS Long Term Plan and NHS Digital's stated aim to develop joined up digital systems in the health service. The resource impact report and template identify the need to develop information systems allowing clinicians to access a person's advance care plan and records over a longer timeframe than the last admission to hospital. There is allowance in the resource impact mode for non-recurring set up costs of IT systems.
The Brain Tumour Charity	Guideline	18	16	We would welcome NICE to make better clarifications around the concepts of palliative and end-of-life care. All too often these two concepts are conflated and misunderstandings about what they constitute appear to be common. In order to avoid confusion, it may be useful for NICE to explicitly state the difference between these two concepts in their final draft guideline.	Thank you for your comment. The committee agrees that the terminology used in this area can vary. The commonly used terms describing the provision of end of life care have been added into the context section of the guideline. The committee uses end of life care to describe both palliative and supportive care and includes symptom management.
The Brain Tumour Charity	Guideline	4	13	It is stated '*If it is thought an adult is approaching the end of their life, carry out an initial holistic needs assessment to enable the right to support to be provided when it is needed'* within the draft guideline. Two issues arise here, one practical and one economic. Firstly, statistics from the Department for Work and Pensions (DWP) show that 95% of people accessing benefits via benefit rules regarding terminal illness have terminal cancer. This means patients with unpredictable terminal conditions, such as lung and motor	Thank you for your comment. The committee agrees that the terminology and definitions used in this area can vary. To clarify that this guideline could apply to people that need end of life for more than a year the following sentence has been added to the context and terms used in the guideline sections, 'Although for some conditions care could be provided for months or years.'

				neurone disease, may miss out on a holistic needs assessment since their conditions do not explicitly determine a terminal diagnosis. It would be appropriate to provide a wider terminal illness definition as some conditions may be determine more than one year's life left to live, yet there may exist a strong chance the patient may die before this from their condition. Secondly, the Department for Work and Pensions, in terms of the provision of benefits, determines someone terminally ill if they have six or less months to live. Alternatively, NICE regard a terminal illness as someone who has less than 12 months left to live. A holistic needs assessment, as determined by NICE, is *'An assessment that considers all aspects of a person's wellbeing and health and social care needs. Undertaking a holistic needs assessment ensures that the person's concerns and problems are identified so that support can be provided to address them'*. From this, however, it must be noted that when carrying out a holistic needs assessment, a portion of those determined terminally ill will not be eligible for benefits. As such, patients will fail to be given appropriate information about social care provision upon reviewing their needs via the holistic needs assessment. This is a particularly pertinent point since those diagnosed with a terminal illness (as determined through NICE's definition) will likely not be able to work due to their condition, exacerbating their need for financial help.	
The Brain Tumour Charity	Guideline	4	13	We believe that, ideally, a Holistic Needs Assessment should be conducted as soon as possible after diagnosis for life-limiting conditions, such as brain tumours. That way, a sufficient patient pathway is in place before the person comes to a point of end-of-life. We think this should be regularly reviewed and updated whether the patient is considered to be terminal/ likely to die within 12 months.	Thank you for your comment. The committee agrees and this is the underlying principle in recommendation 1.1.1 about identifying people as soon as possible. Cross reference to the NICE guidelines on Dementia, Motor Neurone disease and Multimorbidity have been added to the guideline and to clarify that providing end of life care can mean years for some conditions has been added into the terms used in the guideline and in context section of the guideline.
The Brain Tumour Charity	Guideline	4	4	The draft recommendation states '*people managing services should develop systems to identify adults who are likely to be approaching the end of their life. This will enable health and social care practitioners to start discussions about advance care planning and provide the support needed to help people stay in their preferred place of care'.* We have heard anecdotal evidence from our community that the	Thank you for your comment. The committee agrees and in the first research recommendation note that there is limited evidence in this area for people with non-cancer disease and further research is important.

				importance of early conversations and early referral of palliative and end-of-life care improves a patient's experience with their disease. The Charity would welcome a further exploration into the evidence, if any, of the importance of early conversations with a patient around their end-of-life care preferences in improving patients' experience, as well as the benefit of linking early conversations over end of life and early referral to end of life specialists.	
The Brain Tumour Charity	Guideline	5	1	There needs to be further clarification on what kind of training will be given to health and social care practitioners to enable them to have the skills to sensitively carry out holistic needs assessments. We know from talking with healthcare professionals in the brain tumour field that they often find having end-of-life care conversations difficult and welcomed more appropriate training. As well as this, if Holistic Needs Assessments are given routinely for life-limiting conditions, then this will hopefully take some of the difficulty or pressure off starting the conversation in the first place.	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care or what would be included in a training strategy. The committee acknowledge there are validated tools that support this process and have added this to the description of Holistic needs assessment in the terms used in the guideline section.
The Brain Tumour Charity	Guideline	5	12	'Patient activation may be relevant here for further exploration. Though it is often used for people managing long-term conditions, it may still be relevant for end-of-life care. Patient activation can lead to better outcomes, a better experience of care, healthier behaviours and fewer episodes of emergency care that leads to lower overall costs for the NHS. As well as this, according to the King's Fund, when patients are fully informed about their options and outcomes, they choose fewer treatments, reducing the gap between what they want and what doctors think they want.	Thank you for your comment. The committee agrees and have included 'enable' in the recommendation to reflect your comment.
The Brain Tumour Charity	Guideline	6	8	It is worth noting that patients have a right to choose no treatments at all and that this is difficult for healthcare professionals to accept. We would welcome further exploration on whether it would be suitable to provide training on these types of decisions by patients for healthcare professionals.	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care or what would be included in training strategies acknowledging that this may according to local needs.
The Brain Tumour Charity	Guideline	9	2	The guideline states '*Adults approaching the end of their life should have care that is coordinated between health and social practitioners within and across different services and organisations, to ensure good communication and a shared understanding of the person's needs and care'.* We believe it an important need to have a named healthcare	Thank you for your comment. The committee discussed this when deciding on the terms used to describe health and care practitioners in the providing end of life care coordination and in reviewing current treatment sections of the guideline. The principle around there being one point of call is maintained and sits with the lead health care professional (see the

				professional responsible for this to ensure services can effectively implement this recommendation, as well as a back-up healthcare professional, or process in place, to deal with the service when this person is away.	reviewing current treatment section and the definition of lead health care professional in the terms used in the guideline) and within the multidisciplinary team but a named healthcare professional was considered too prescriptive. The committee described that in their experience this can create gaps when the professional named is on a day off or an annual leave. In the end of life care section, it is clear that someone should be given information on who the multipractitioner team members are (this should include the lead healthcare professionals in each setting responsible for their care), the roles of the team members and how services are accessed.
The Brain Tumour Charity	Guideline	9	22	Healthcare professionals should also outline to patients what to expect in the dying process to health with preventing and minimising crises. Patients knowing the natural physical changes in end-of-life and how to manage them reduces the worry that these changes are a medical emergency, which in turn requires more drastic intervention. Some physical changes can be distressing if patients are not aware that this may be a normal part of the dying process. However, it must be noted that some patients may not want to know this.	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care. The section on multipractitioner care makes it clear that health and social care practitioners should have the skills to provide care for adults approaching the end of their life who need support.
The Brain Tumour Charity	Guideline	9	6	There needs to be a system in place if electronic information-sharing systems are not compatible, which is sometimes the case across healthcare and other establishments. We welcome further exploration on NICE about how they plan to circumvent this in the event described above.	Thank you for your comment. The committee agreed that good communication and documentation is critical to optimal care and finding systems to do this is imperative, this is emphasised throughout the guideline.The committee acknowledges that there are different IT systems and it is important that they are compatible. The implementation of an electronic information sharing system is in line with the NHS Long Term Plan and NHS Digital's stated aim to develop joined up digital systems in the health service. The Resource Impact report and template include the additional costs associated with the need to develop IT systems allowing appropriate clinicians to access a person's ACP and records. The template can be used to support commissioners to identify current service levels and estimate other costs likely to have significant impact locally. This can be accessed.
The Brain Tumour Charity	Guideline	General	General	Statistics, provided by AgeUK, find that the fourth top fear in life for people is dying in hospital (59%). As well as this, AgeUK found that most people are unlikely to die in their preferred place of death,	Thank you for your comment. The committee agrees that this wording may have been

				regardless of where they live in England. Although 66% of people on average express a wish to die at home, the majority of people, unfortunately, die in hospital. Similarly, in our report, *'Losing Myself'*, around 20% of brain tumour respondents were given a terminal prognosis, with 55% of those given a terminal diagnosis not given a choice of end of life options. T The guideline states multi-practitioner care should '*provide adults approaching the end of their life, their carers and other people important to them with access to the expertise of highly skilled health and social care practitioners, when needed, to… support people to stay in their preferred place of care, if possible.'* Whilst we welcome NICE's recognition of patients' desire to stay in their preferred place of care, we think it is important to do the utmost to fulfil a patient's desire to die at their preferred place of choice (usually at home). NICE should look into exploring systems to make this achievable for as many patients as possible and we would welcome further research exploration into this issue.	misinterpreted and have revised the text 'to stay in their preferred place of care' to where they would like to be cared for and die'. Usual place of residence has been revised to place of residence.
The Brain Tumour Charity	Guideline	General	General	We would welcome further exploration by NICE into transparent decision-making, especially in cases of best practice. We have heard healthcare professionals should be advised to write down where their clinical decisions derive from, as nowadays patients are questioning decisions much more, especially since there is such a wide-range of information available to the patient over the internet.	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver or document care or what would be included in a policy acknowledging that this may according to local needs.
The Gold Standards Framework Centre	Guideline	14-15		**Enabling generalist services** and provision is recognised as vital- most people are under the care of generalist providers not just specialist pall care Only 4% people die in hospices and in our experience Specialist pall care teams in hosiptals , important as they are, only see about 12% of patients who might be in the last year of life (according to the cLarke figure of a 30% hospital patients being in last year of life. More details available if interested	Thank you for your comment and information.
The Gold Standards Framework Centre	Guideline	28	18	**Coordination through integrated care** eg In and Out of Hours Services - The committee agreed that an out-of-hours end of life care advice line could help to provide this support – there are notably excellent examples such as the Airedale Gold Line http://www.airedale-trust.nhs.uk/services/the-gold-line/ built upon use of GSF in the community and hospitals, and similar models in	Thank you for your comment and this example of practice.

				other areas – see examples http://www.goldstandardsframework.org.uk/cross-boundary-care-training	
The Gold Standards Framework Centre	Guideline	5 1.23 and 6 1.4	4 2	**Carers-** Reference to carers needs assessments apply here I understand but might be better included in Section 1.4 on supporting carers, so keeps together as 1.41 is fairly weak otherwise. Could refer to CNAT, NATC or other tools **Care Homes Residents**' **relatives** In the case of families of residents in care homes, they are not included here as 'carers' but usually known as relatives. In Sect 1.4 page 6 on carers, there should be some additional notes on the important role of CH staff to support relatives of residents in care homes, eg supporting them in transition of relatives, care of dying etc **Bereavement.** In addition there should be more on supporting carers/ families in bereavement eg for GP practices these families are often still their patients and are often supported by primary care team (See GSF Primary Care Going for Gold training) and many hospitals have a bereavement service, send a card of condolences and signpost to other support.	Thank you for your comment. The section on supporting carers has been moved and now follows the recommendation on carer's needs assessment. An additional recommendation has been added to the supporting carers section reflecting that people managing and delivering services should consider what practical and emotional support can be provided to carers. Although this guideline did not explicitly address bereavement the added recommendation is clear that people managing and delivering services should consider what practical and emotional support can be provided to carers.
The Gold Standards Framework Centre	Guideline	General all And future research/ evidence		**For maximal effectiveness the use of RTCs to evidence here is less of value and experiential benefits from people on the ground must be included eg use of the patient voice , GPs hospitals care homes staff etc rather than RTCs** **Our experience with thousands of accredited teams should be included within this in greater detail , and future research help support the evidence of benefits of practice on the ground** **Coordination of care can** be improved using cross boundary care approaches such as GSF which is well evidenced http://www.goldstandardsframework.org.uk/evidence and particularly in primary care where it was mainstreamed through QOF at basic level since 2004 – see BMJ papers http://www.goldstandardsframework.org.uk/cd-content/uploads/files/End%20Life%20J-2016-Clifford-.pdf and http://www.goldstandardsframework.org.uk/cd-content/uploads/files/Primary%20Care/98806%20GSF%20Frontrunners%204pp(1).pdf http://www.goldstandardsframework.org.uk/cd-content/uploads/files/Evidence%204%20%20%20GSF%20Improves%20coordination%20of%20care%20in%20different%20settings%20Sept%202016.pdf	Thank you for your comment and suggestions. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people important to them. The reviews did not evaluate the clinical and cost effectiveness of different assessment tools.

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

The Gold Standards Framework Centre	Guideline And in ACP document	Page 7 1.6 and definition page 11	1 15	**Advance Care Planning** . There should be an additional section on transference/ translation of preferences into practice , what is known internationally as ‘ goal concordant care’ ie expressing preferences is one thing but translating them into practice is another . This is not just related to preferred place of care which is one factor but not always te most important. There is much work on this from USA , and some literature on outco9mes measures of ACP as discussed at the recent Advance Care Planning International conference that I am a member of https://www.eiseverywhere.com/ehome/acp-i2019/748102/ In addition the definition of ACP coud be importoved on page 11 ie using the Sudore international consensus definition of ACP ie ***‘Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.’*** *International Consensus Definition of Advance Care Planning (Sudore et al 2017).* *See* http://www.goldstandardsframework.org.uk/advance-care-planning In the given definition of ACP listed here , I would suggest that it is important to include more on 3 elements which the international ACP group find useful – reference ACP in GSF website and Australian Government ACOP department led by Karen Detering https://www.advancecareplanning.org.au/ • What’s important to you (goals values preferences) • What do you want to happen/ not want to happen (treatment and care preferences , could include TEP DNAR etc) • Who will speak for you (proxy spokesperson, LPOA etc) The latter is thought to be very important in most ACPI countries promoting ACP- not just LPOA	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people important to them. The reviews did not evaluate the clinical and cost effectiveness of intervention and the most effective way for health and social care practitioners to deliver care. The committee have revised their definition of advance care planning and are happy that It is reflective of advance care planning.

				For a summary of ACP in End of Life care and an up to date list of references , evidence, cost effectiveness etc , please see recently updated OUP Book Advance Care Planning in End of Life Care , (I was lead Co-editor) which ives numerous examples of research evidence of effectiveness from across the world See ghttps://global.oup.com/academic/product/advance-care-planning-in-end-of-life-care-9780198802136?cc=gb&lang=en& I could provide the references , more details and guidance on this important area if wanted	
The Gold Standards Framework Centre	Guideline	Page 9 1.12 17 1.10	8	**IMPORTANT OMISSION OF SOCIAL CARE PROVIDERS** Please note that there is little reference to the important contribution of care homes (where about 25% people die) and for the 23% who die at home the importance of domiciliary care providers . both groups care n=b trained to improve care for people in the last year of life. We run training programmes in bioth these areas having trained over 3000 care homes http://www.goldstandardsframework.org.uk/care-homes-training-programme and 1000 dom care staff http://www.goldstandardsframework.org.uk/domiciliary-care-training-programme the evidenmce is that care can improv with appropriate training and upskilling . It might be tat NICE did not wish to include these but in describing care this is a vital omission to redress Suggest should include *Care homes and domiciliary care providers trained in end of life care provision contribute to integrated cross boundary care and reduction of hospital admissions*	Thank you for your comment. The beginning of the guideline sets out who it is for: Commissioners, planners and coordinators of health and social services, Providers of health and social care and Health and social care practitioners. The recommendations directly refer to health and social care practitioners throughout the guideline, in turn people providing and managing services refers to social care providers and care homes are also directly referred to.
The Gold Standards Framework Centre	Identification			The GSF Proactive identification Guidance / PIG is well used across the world and evidence based through multiple wide ranging international studies http://www.goldstandardsframework.org.uk/cd-content/uploads/files/1%20%20vs%204%20%20Evidence%20that%20use%20of%20GSF%20Improves%20identification.pdf	Thank you for your comment.
University of Cambridge				The CSNAT intervention has achieved impact on policy and practice in end of life care both nationally and internationally. • The CSNAT Intervention was recognised by the award of the first Practice-Changing Research Study Prize by the NIHR & Charities Consortium for Hospice and Community Research in April 2018 • In February 2019 the UK Royal College of General Practitioners' (RCGP) and Marie Curie published the Daffodil Standards for end-of-life care. Standard 3: Carer	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people important to them. Evidence review H evaluated the clinical and cost effectiveness of carer support services and evidence review G explored the barriers and facilitators to the involvement of carers in planning and decision making. The reviews did not evaluate the different tools available for the assessment of carers and the

				Support identifies the CSNAT Intervention for assessment of carers’ needs and links to the CSNAT Toolkit. • Training on the CSNAT Intervention has been delivered by the CSNAT team to 457 practitioners from hospice, hospital, community and primary care teams in workshops hosted throughout the UK. • The CSNAT Intervention is a central component of the Carers’ Strategy at St Christopher’s, the flagship London hospice, which has identified implementation steps for the intervention and outcomes to be achieved • Outside the UK, 61 organisations from 14 countries hold licences to use the CSNAT in Australia, Austria, Canada, China, Denmark, Germany, Gibraltar, Hong Kong, Ireland, New Zealand, Norway, Sweden, Taiwan ROC, USA. The tool has been translated into 13 different languages • The CSNAT is the only tool that has been recommended for assessment of family carers in end of life care in the State of Victoria, Australia in a report to the Department of Health on Clinical tools to assist with specialist palliative care provision. (40 of the licences held outside the UK are in Australia) • In 2017, a Norwegian Government Committee recommended implementation of the CSNAT within patient pathways and the CSNAT team was approached to provide training. Thus the CSNAT Intervention is an example of an evidence based initiative with a fully developed set of Toolkit resources to support practitioner training and organisational implementation of the intervention to support carers in practice	support they need.
University of Cambridge	Guideline	General	General	**1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** We would suggest that the most challenging areas of the guideline are the areas related to carers: there is a considerable change in practice required in palliative care and end of life care (EOLC) in hospices, hospital, primary and community settings to provide better support for carers. This requires consideration of issues not just at the individual (practitioner) level but also at organisational level to ensure practitioners have the necessary support from their organisation including training about carer support needs assessment, an agreed assessment process and crucially support	Thank you for your comment and your suggestions.

				with workload capacity for assessing and supporting carers[1]. The Hospice UK report[1] makes clear the extent of the challenge of supporting carers in EOLC: the key message from the stakeholder consultation was the lack of consistency in how carers are identified, assessed and supported in current practice. The report identifies that achieving consistency and therefore equity for carers is made especially difficult because we are yet to resolve the key question of where carers 'fit' within EOLC service provision: whose responsibility are they? While palliative and EOLC has a strong ethos of being there for the family, not just the patient, this does translate consistently into practice. The question of whether carers are to be viewed as true clients of EOLC services must be resolved if their identification, assessment and support is to become legitimised and routine. We would suggest that a more precise guideline by NICE (addressing the issues we raise below) would go a considerable way towards addressing this challenge. Furthermore, in so doing, these areas of the guideline related to carers could achieve the biggest impact on EOL practice. Where carers are supported, as the current guideline itself already notes, patients are more likely to achieve their preferred place of care and may reduce hospital admissions. [1] Ewing G and Grande GE. Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change. London: Hospice UK, 2018; https://www.hospiceuk.org/docs/default-source/What-We-Offer/Care-Support-Programmes/Research/carers-report---10-recommendations-for-achieving-organisational-change_final.pdf?sfvrsn=0t,	
University of Cambridge	Guideline	General	General	**3 What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)** The challenge of supporting carers in everyday practice in a timely and responsive way could be addressed by use of The Carer Support Needs Assessment Tool (CSNAT) Intervention, which already has an accompanying Toolkit for practitioner training and implementation. The Toolkit was developed to address issues of implementation of person-centred carer assessment and support, at individual (practitioner) level but also at organisational level through	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people important to them. Evidence review H evaluated the clinical and cost effectiveness of carer support services and evidence review G explored the barriers and facilitators to the involvement of carers in planning and decision making. The reviews did not evaluate the different tools available for the assessment of carers and the support they need. The references you have included evaluate the development and the clinical effectiveness of the CSNAT and not

				two different learning units. The CSNAT intervention derives from a programme of research undertaken by the Universities of Manchester and Cambridge to resolve how to achieve comprehensive, person-centred EOLC support for carers within routine practice. The CSNAT was developed and validated with carers, encompasses assessment of carers' physical, practical, social, financial, psychological and spiritual support needs that policy indicates should be addressed during EOL care[1], has good face, content and criterion validity[2]and is comprehensive[2] yet concise to facilitate its use in routine practice. The CSNAT is used within a clearly delineated process (the CSNAT Intervention) in routine practice to achieve a person-centred approach[3]. Two cluster trials of the person-centred CSNAT Intervention demonstrated improved outcomes for carers: a significant reduction in caregiver strain in current carers[4] and significantly lower levels of early grief and better psychological and physical health for carers in bereavement[5]. The research programme has included a series of studies to understand factors affecting implementation in practice, including both initial adoption and sustaining the intervention in practice.[7,8] Lessons learned have been developed into an online CSNAT Approach Training and Implementation Toolkit to support practitioners and organisations to implement the intervention in routine practice (http://csnat.org/training/). 1. Ewing G, Grande GE. Development of a Carer Support Needs Assessment Tool (CSNAT) for end of life care practice at home: a qualitative study. Palliat Med 2013; 27: 244-256. 2. Ewing G, Brundle C, Payne S, Grande G. The Carer Support Needs Assessment Tool (CSNAT) for Use in Palliative and End-of-life Care at Home: A Validation Study. J Pain Symptom Manage 2013: 46: 395-405. 3. Grande GE, Austin L, Ewing G, O'Leary N, Roberts C. Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. BMJ Supportive & Palliative Care 2017: 7 (3): 326-334. doi: 10.1136/bmjspcare-2014-000829. Epub 2015 Dec 30. 4. Aoun SM, Grande G, Howting D, Deas K, Toye C, Troeung L,	the delivery of services to support carers.

				Stajduhar K, Ewing G. The Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial. *PLoS One* 2015; 10(4):e0123012. 5. Ewing G, Austin L and Grande G. The role of the Carer Support Needs Assessment Tool (CSNAT) in palliative home care: qualitative study of practitioners' perspectives of its impact and mechanisms of action. Palliat Med. 2016 Apr; 30(4):392-400. 6. Austin L, Ewing G, Grande G (2017) Factors influencing practitioner adoption of carer-led assessment in palliative homecare: A qualitative study of the use of the Carer Support Needs Assessment Tool (CSNAT). PLoS ONE 12(6): e0179287. https://doi.org/10.1371/journal. pone.0179287 7. Diffin J, Ewing G, Grande G. The influence of context and practitioner attitudes on implementation of person-centred assessment and support for family carers within palliative care. Worldviews on Evidence-Based Nursing 2018; 15:5, 377–385. 8. Diffin J, Ewing G, Grande G. Facilitating successful implementation of a person-centred intervention to support family carers within palliative care: a qualitative study of the Carer Support Needs Assessment Tool (CSNAT) intervention. BMC Palliative Care 2018: 17; 129. https://rdcu.be/bd2EQ	
University of Cambridge	Guideline	General	General	The CSNAT intervention has achieved impact on policy and practice in end of life care both nationally and internationally. • The CSNAT Intervention was recognised by the award of the first Practice-Changing Research Study Prize by the NIHR & Charities Consortium for Hospice and Community Research in April 2018 • In February 2019 the UK Royal College of General Practitioners' (RCGP) and Marie Curie published the Daffodil Standards for end-of-life care. Standard 3: Carer Support identifies the CSNAT Intervention for assessment of carers' needs and links to the CSNAT Toolkit. • Training on the CSNAT Intervention has been delivered by the CSNAT team to 457 practitioners from hospice, hospital, community and primary care teams in workshops hosted throughout the UK. • The CSNAT Intervention is a central component of the Carers' Strategy at St Christopher's, the flagship London hospice, which has identified implementation steps for the intervention and outcomes to be achieved	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people important to them. Evidence review H evaluated the clinical and cost effectiveness of carer support services and evidence review G explored the barriers and facilitators to the involvement of carers in planning and decision making. The reviews did not evaluate the different tools available for the assessment of carers and the support they need.

				• Outside the UK, 61 organisations from 14 countries hold licences to use the CSNAT in Australia, Austria, Canada, China, Denmark, Germany, Gibraltar, Hong Kong, Ireland, New Zealand, Norway, Sweden, Taiwan ROC, USA. The tool has been translated into 13 different languages • The CSNAT is the only tool that has been recommended for assessment of family carers in end of life care in the State of Victoria, Australia in a report to the Department of Health on Clinical tools to assist with specialist palliative care provision. (40 of the licences held outside the UK are in Australia) • In 2017, a Norwegian Government Committee recommended implementation of the CSNAT within patient pathways and the CSNAT team was approached to provide training. Thus the CSNAT Intervention is an example of an evidence based initiative with a fully developed set of Toolkit resources to support practitioner training and organisational implementation of the intervention to support carers in practice	
University of Cambridge	Guideline 1.2	5 18	1-3 1-2	We wish to raise a further, separate but related concern about Guideline 1.2 on assessing holistic needs. The Guideline says practitioners 'should have the skills to sensitively carry out holistic needs assessment' and later the recommendation reminds *practitioners* that carers should be offered an assessment. We are concerned that the Guideline places sole responsibility for carer assessment on the individual practitioner, without any consideration of the organisational input that is needed to ensure practitioners have the support to carry out assessments in routine practice. We again refer the Committee again to Ewing G and Grande GE. Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change. London: Hospice UK, 2018;	Thank you for your comment. The recommendation on holistic needs assessment refers to people approaching the end of their life. The needs assessment for carers is addressed in recommendation 1.2.3 and in the section 1.3 supporting carers. The wording of recommendation 1.2.3 has been revised to in response to stakeholder comments to focus on the legal requirement, 'health care practitioners should be aware of the requirement local systems to offer a carer's needs assessment in line with the Care Act 2014 and a young carer's needs assessment in line with the Children and Families Act 2014. '. In the section on supporting carers a recommendation has been added that states that ,' people managing and delivering services should consider what practical and emotional support can be provided to carers.' This includes organisational responsibility. NICE is developing a guideline on social work interventions for adults with complex needs, including, learning disabilities and mental health. This is cross referenced in a footnote for

					recommendation 1.6.5.
University of Cambridge	Guideline 1.2	5 17 18	4-5 26-28 1-2	We are concerned that Assessing holistic needs of carers (Guideline 1.2) currently only refers to practitioners being 'aware of the local systems to offer a carer's needs assessment in line with the Care Act 2014'. Further, in the explanation on page 18, the recommendation 'reminds' practitioners that carers should be offered an assessment 'in line with legislation'. In the explanation on page 17 stating why the committee made the recommendation, it is noted that assessment of carers' needs is important to ensure they are supported to help care for the person approaching the end of their life which in effect focuses on the carer as key co-workers in supporting the patient. But the committee also notes that these assessments are often overlooked. The recommendation is of concern for two interlinked reasons: (1) It focuses squarely on assessment under the Care Act 2014, but such statutory assessment does not address the support carers require to be prepared and confident in caring for the patient (2) By focusing on referral to statutory assessment, healthcare practitioners are likely to miss the immediate opportunities to address carers' support needs as co- workers that they as healthcare staff are uniquely and solely able to address. (1) The recommendation makes the assumption that the Care Act assessment will provide sufficient support to help care for the patient. However, carers have a dual role in end of life care with support needs in both of their roles: as 'co-workers' who need support to enable them to care for the patient and as 'clients' in their own right with support needs in terms of their own health and well-being (for details of the support needs in both co-worker and client roles, see Ewing G, Grande GE. Development of a Carer Support Needs Assessment Tool (CSNAT) for end of life care practice at home: a qualitative study. Palliat Med 2013; 27: 244-256.). The statutory carer assessment addresses carers' support needs that arise from their 'client' role, such as need for a break from caring. In an end of life care context, carers also have support needs as 'co-workers' to enable them to care for the patient, such as support in managing symptom and medicines, in understanding the patient's illness and with knowing what to expect in the future. These type of support needs require input from healthcare professionals, not from local authority assessors (see commentary on this in the Executive Summary in:	Thank you for your comment. The recommendation on holistic needs assessment refers to people approaching the end of their life. The needs assessment for carers is addressed in recommendation 1.2.3 and in the section 1.3 supporting carers. The wording of recommendation 1.2.3 has been revised to in response to stakeholder comments to focus on the legal requirement, 'health care practitioners should be aware of the requirement local systems to offer a carer's needs assessment in line with the Care Act 2014 and a young carer's needs assessment in line with the Children and Families Act 2014.' In the section on supporting carers a recommendation has been added that states that ,' people managing and delivering services should consider what practical and emotional support can be provided to carers and review this when needed.' The recommendation on supporting carers has been moved below the assessing the holistic needs section to keep the recommendations on carers together. NICE is developing a guideline on social work interventions for adults with complex needs, including, learning disabilities and mental health. This is cross referenced in a footnote for recommendation 1.6.5.

				Ewing G and Grande GE. Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change. London: Hospice UK, 2018. As the guideline stands, referral to the Care Act 2014 needs assessment will not provide carers with support in many aspects of their vital role of supporting patient. This is a concern given clear research evidence that a large proportion of 'inappropriate/ avoidable' terminal admissions to hospital are family initiated (Gott M, Frey R, Robinson J, Boyd M, O'Callaghan A, Richards N, et al. The nature of, and reasons for, 'inappropriate' hospitalisations among patients with palliative care needs: a qualitative exploration of the views of generalist palliative care providers. Palliat Med. 2013;27(8):747–56; Reyniers T, Deliens L, Pasman HR, Vander Stichele R, Sijnave B, Houttekier D, et al. Appropriateness and avoidability of terminal hospital admissions: results of a survey among family physicians. Palliat Med. 2017;31(5):456–64.) (2) Many carers in an end of life care context never achieve any form of assessment, statutory assessment or otherwise, often because the patients they are supporting present in the later stages and there is insufficient time and opportunity for such an assessment to be put in place. Should carers come to the attention of healthcare practitioners as front line staff and it be evident they are in need of support, there may be a significant missed opportunity to provide much needed, immediate support if the only response is to refer carers for a statutory assessment. Healthcare staff may miss crucial support needs that require healthcare advice and input that they are uniquely placed to address. Again these relate to the support carers need to be confident and competent in their role co-workers. In conclusion, holistic carer assessment cannot be limited to statutory assessment. Healthcare practitioners as frontline staff need to have clearer guidance regarding identifying and assessing carers. Firstly, to enable them to rapidly identify and address carers' support needs (as co-workers) where healthcare rather than social care input is required. Secondly, to ensure speedier and consistent referral to statutory assessment in cases where some of the carers' needs can be met by support offered through statutory assessment.	
University	Guidelin	6	2	We are concerned that there is separation of assessing holistic	Thank you for your comment.

of Cambridge	e 1.4	19	16-24	needs of carers (Guideline 1.2) from Supporting carers (Guideline 1.4). The process of supporting individual carers needs to be the outcome of an assessment process. Without an assessment process, carers will be signposted to generic support provision that is directed by health and social care professionals, rather than person-centred provision (advocated in the Ambitions for Palliative and End of Life Care for carers as well as patients). Support may therefore fail to match carers' needs. The Committee did not find the evidence identified one particular way of supporting carers but the evidence did show that carers have better outcomes when supported. We feel this reflects the nature of the interventions considered, which are often standardised, rather than tailored to the individual, and may indeed not suit all carers. However, while the evidence review (H) on Carer Support Services considers a range of interventions, it does not include comprehensive person-centred assessment as an intervention. An assessment process is an intervention in itself, as well as the supportive input that is the outcome of the assessment process. Unlike the other interventions considered in the review which reach only a small number of carers or may be suitable only for certain carers, a formalised assessment and support process embedded in routine practice has the potential for much wider reach and impact on all carers, provided it follows on from consistent identification of carers in end of life care (which is part of the first Guideline 1.1). We note that the Committee agreed that health and social care practitioners should go beyond the strict statutory requirement for carers' assessment, but the Committee does not state how this is to be accomplished. Without more explicit guidance, this recommendation is much less likely to be taken up in practice. There is now a considerable body of evidence on the Carer Support Needs Assessment Tool (CSNAT) Intervention (a comprehensive, person centred approach for assessment and support for family carers) to merit its consideration as recommended evidence-based practice in end-of-life-care that would assist practitioners in doing this. For further information about the CSNAT Intervention see response to Q3 above: What would help users overcome any challenges? (eg, existing practical resources or national initiatives, or examples of	The recommendation on supporting carers has been moved below the assessing the holistic needs section to keep the recommendations on carers together. The wording of recommendation 1.2.3 has been revised to in response to stakeholder comments to focus on the legal requirement, 'health care practitioners should be aware of the requirement local systems to offer a carer's needs assessment in line with the Care Act 2014 and a young carer's needs assessment in line with the Children and Families Act 2014. '. In the section on supporting carers a recommendation has been added that states that ,' people managing and delivering services should consider what practical and emotional support can be provided to carers and review this when needed.' This includes organisational responsibility. NICE is developing a guideline on social work interventions for adults with complex needs, including, learning disabilities and mental health. This is cross referenced in a footnote for recommendation 1.6.5. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people important to them. Evidence review H evaluated the clinical and cost effectiveness of carer support services and evidence review G explored the barriers and facilitators to the involvement of carers in planning and decision making. The reviews did not evaluate the different tools available for the assessment of carers and the support they need. We will pass this information to our local practice collection team. More information on local practice can be found here.

				good practice).	
University of Cambridge	Guideline 1.7	7 22	14-21 11-29	The recommendation on Reviewing needs is confined to reviewing only patients' needs. In an EOLC context, as patients' needs change, so will those of the carer. Further, carers' needs can change independently of the patients they are supporting. Repeating assessments is only mentioned for patients despite evidence of changing needs of carers. The research we have undertaken on supporting carers indicates that the review process is an integral part of a comprehensive, person-centred approach to carer assessment and support. This is evidenced in Ewing G, Austin L and Grande G. The role of the Carer Support Needs Assessment Tool (CSNAT) in palliative home care: qualitative study of practitioners' perspectives of its impact and mechanisms of action. Palliat Med. 2016 Apr; 30(4):392-400; and Ewing G, Austin L, Diffin J, Grande G (2015). Developing a person-centred approach to carer assessment and support. British Journal of Community Nursing; 20(12): 580-584.	Thank you for your comment. In the section on supporting carers a recommendation has been added that states that ,' people managing and delivering services should consider what practical and emotional support can be provided to carers and review this when needed.' NICE is developing a guideline on social work interventions for adults with complex needs, including, learning disabilities and mental health. This is cross referenced in a footnote for recommendation 1.6.5.
University of Cambridge	Recommendations for research	13	General	As a research team we were concerned to see no recommendations for research on carers at end of life given carers' central role in patient care. One of the recommended areas of research (for patients) is discharge and transfer from hospital – a topic of central importance but also one in which it is key to include the situation of family carers and supporting them in the process of discharge to home. A major factor in patients being cared for at home, and dying there is the availability of family support, and breakdown of caregiving at home is an important reason for (re-)admission of patients to hospital. Therefore, further research on discharge and transfer from hospital should extend beyond a patient focus to consider carers. The CSNAT research team has conducted initial exploratory qualitative research on how to support carers at discharge from hospital (see Ewing G, Austin L, Jones D, Grande G. Who cares for the carers at hospital discharge at the end-of-life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach. Palliat Med. 2018 Vol. 32(5) 939–949). A follow up feasibility study of implementing such support in practice	Thank you for your comment. The committee agrees that research on carers is important, for each evidence review outcomes on carers were included and searched for. The committee anticipate that the impact on carers would be measured in research on the discharge and transfer from hospital. To reinforce this the impact of suboptimal transfer on the person approaching the end of life and their carers has been added to the section 'why this is important' in the discharge and transfer from hospital. The impact of a person dying in a setting which is inappropriate or not their preferred place of care on their carers has been added into the introduction and committee discussion sections of evidence review M.

				has just been completed: the findings can be shared with the Committee upon request to Professor Gunn Grande, University of Manchester.	
University of East Anglia	Guideline	5	1-3	It is correct that health and social care practitioners caring for adults approaching the end of their life should have the skills to sensitively carry out holistic needs assessments, however if this is to be done in a person-centred way then it requires patients to be able to tell practitioners what their needs are. There is good evidence that patients with progressive long term conditions find this difficult (they don't know what needs they should tell practitioners about, they are worried about the practitioners time pressures and they are acutely aware that there are things that the practitioner needs to get on with in the consultation – the practitioner's agenda). An intervention has been developed to enable patients with long term progressive conditions to identify, express and address their support needs with practitioners – the Support Needs Approach for Patients (SNAP): • https://thesnap.org.uk/ • https://www.mariecurie.org.uk/blog/new-research-to-help-people-with-copd/170275 SNAP is a 5-stage intervention underpinned by the evidence-based validated SNAP tool: • Gardener AC, Ewing G, Farquhar M. Enabling patients with advanced Chronic Obstructive Pulmonary Disease to identify and express their support needs to health care professionals: a qualitative study to develop a tool. Palliative Medicine 2019;33(6):663-675 • https://journals.sagepub.com/doi/full/10.1177/0269216319833559?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%3dpubmed • https://spcare.bmj.com/content/8/3/367.2.citation-tools SNAP has been included in the RCGP and Marie Curie Daffodil Standards (under Standard 5: Assessment of unique needs of the patient): • https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/daffodil-standards.aspx SNAP was also included in the British Lung Foundation's Taskforce for Lung Health. A National Five Year Plan for Lung Health. December 2018: • Available at: https://www.blf.org.uk/taskforce/plan [SNAP	Thank you for your comment. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address in detail how health and social care professionals should deliver care or what would be included in a training strategy. The committee acknowledge there are validated tools that support this process and have added this to the description of holistic needs assessment in the terms used in the guideline section.

				cited on page 95] - Online version includes link to SNAP website: https://www.blf.org.uk/taskforce/plan/end-of-life/choice	
University of Manchester	Guideline	General	General	1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. Investment in support for carers (a) as a key resource and co-worker and (b) to ameliorate negative impacts from caregiving is likely to support patient care and reduce psychological morbidity among carers both during care and in bereavement. (a) Whilst formal care services can provide only time limited input, carers provide comprehensive and continuous support for people towards the end of life. Carers of people with cancer can provide an average 70 hours of care per week in the patient's last three months of life [1]. Formal care services will struggle to meet growing demands for care in the face of projected increases in population ageing and number of deaths. To help sustain patient care, present and future, an important component is support of carers as co-workers and a key resource to help them feel informed, prepared and upskilled for this role. (b) Carers suffer considerable adverse effects from caregiving, e.g. 83% or carers of people with cancer suffer clinically significant psychological morbidity during the patient's last three months of life, compared to 15% of the general population [2]. This substantial impact may be ameliorated by ensuring that carers feel supported and prepared for caregiving. A main challenge for practice in ensuring consistent support for carers is to resolve where carers fit within end of life care provision. Consistent carer support needs to be underpinned by clear remits, procedures and structures embedded in practice. Otherwise carer support will remain an occasional add-on where time and resources permit. Carer support will therefore not only require change at practitioner level but at organisation level to ensure the training, workload capacity, structures and processes for assessing and supporting carers. 2. What would help users overcome any challenges? Dr Ewing's submission for the University of Cambridge outlines how challenges can be met by assessment, support and implementation principles illustrated by the Carer Support Needs Assessment Tool (CSNAT) intervention.	Thank you for your comment and suggestions. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people important to them. Evidence review H evaluated the clinical and cost effectiveness of carer support services and evidence review G explored the barriers and facilitators to the involvement of carers in planning and decision making. The reviews did not evaluate the different tools available for the assessment of carers and the support they need. NICE is developing a guideline on social work interventions for adults with complex needs, including, learning disabilities and mental health. This is cross referenced in a footnote for recommendation 1.6.5.

				[1]Rowland et al (2017). The contributions of family care-giving at end-of-life: a national post-bereavement census survey of cancer carers' hours of care and expenditures. Palliative Medicine; 31(4): 346-355. https://doi.org/10.1177/0269216317690479 [2]Grande G et al (2018). Psychological morbidity and general health among family caregivers during end of life cancer care: a retrospective census survey. Palliative Medicine; 32 (10): 1605-1614. DOI: 10.1177/0269216318793286	
University of Manchester	Guideline 1.2	5 17 18	4-5 26-28 1-2	We are concerned that the focus on the Care Act 2014 is likely (1) to cause important aspects of carers' needs to be missed, and (2) underplay healthcare services importance both in addressing carer needs not covered by statutory assessment and in providing the first and sometimes only opportunity to assess carer needs overall in end of life care. Statutory assessment focuses on support to protect and preserve carers' own wellbeing (as 'clients') including help with respite, finance and work related matters. However, key support needs for carers relate to the information, know-how and skills they require to care for their family member/ friend (as 'co-workers'). These support needs require healthcare practitioner knowledge and input in terms of information, education (being shown how to), and signposting to meet carer concerns e.g. regarding how to manage symptoms and medicines or being prepared for the next change in the patient's condition. Holistic assessment for carers therefore also needs to cover these 'co-worker' aspects. Healthcare practitioners as frontline staff are probably best placed to identify carers of patients at end of life, and to provide a first, and possibly only, assessment of need. This can both facilitate rapid addressing of carer support needs that require healthcare input, and consistent, timely referral to statutory assessment for support needs that require social care input. Healthcare practitioners therefore need clearer guidelines regarding how to identify and assess carers and there needs to be organisational support for practitioners to be able to do so.	Thank you for your comment. The wording of recommendation 1.2.3 has been revised to in response to stakeholder comments to focus on the legal requirement, 'health care practitioners should be aware of the requirement local systems to offer a carer's needs assessment in line with the Care Act 2014 and a young carer's needs assessment in line with the Children and Families Act 2014. The recommendation on supporting carers has been moved below the assessing the holistic needs section to keep the recommendations on carers together. In the section on supporting carers a recommendation has been added that states that ,' In the section on supporting carers a recommendation has been added that states that ,' people managing and delivering services should consider what practical and emotional support can be provided to carers and review this when needed.' This includes organisational responsibility. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people important to them. Evidence review H evaluated the clinical and cost effectiveness of carer support services and evidence review G explored the barriers and facilitators to the involvement of carers in planning and decision making. The reviews did not evaluate the different tools available for the assessment of carers and the support they need. NICE is developing a guideline on social work interventions for adults with complex needs, including, learning disabilities and mental health. This is cross referenced in a footnote for

					recommendation 1.6.5.
University of Manchester	Guideline 1.4	6 19	2 16-24	We are concerned that there is separation of assessing holistic needs of carers (Guideline 1.2) from Supporting carers (1.4). Guideline 1.4 importantly notes that practitioners should go beyond statutory requirements for carers' assessments and that carer support is beneficial. However, we cannot support carers effectively without combining this recommendation with clearer guidelines for holistic, person-centred assessment of carers' support needs. Without stipulating a clear assessment process we cannot match supportive input to what individual carers need. We will remain unable to identify the best way of supporting a given carer, continue to offer support based on healthcare and social care perceptions of what carers should need, and on provision of standardised interventions that may fit some carers, but be of little benefit to others. Assessment in itself can be beneficial in validating and recognising carers, but also ensures tailored input. Carers differ considerably in the support they need, 'one size does not fit all', and therefore individualised support based on assessment is necessary to support them meaningfully and effectively. Again, there needs to be clearer guidelines as to how person-centred assessment of carers is to be achieved in practice both for practitioners and organisations.	Thank you for your comment. The recommendation on supporting carers has been moved below the assessing the holistic needs section to keep the recommendations on carers together. The wording of recommendation 1.2.3 has been revised to in response to stakeholder comments to focus on the legal requirement, 'health care practitioners should be aware of the requirement local systems to offer a carer's needs assessment in line with the Care Act 2014 and a young carer's needs assessment in line with the Children and Families Act 2014. '. In the section on supporting carers a recommendation has been added that states that ,' people managing and delivering services should consider what practical and emotional support can be provided to carers and review this when needed.' This includes organisational responsibility. NICE is developing a guideline on social work interventions for adults with complex needs, including, learning disabilities and mental health. This is cross referenced in a footnote for recommendation 1.6.5. This guideline focused on the delivery of services for people approaching the end of life and for their carers or people important to them. Evidence review H evaluated the clinical and cost effectiveness of carer support services and evidence review G explored the barriers and facilitators to the involvement of carers in planning and decision making. The reviews did not evaluate the different tools available for the assessment of carers and the support they need.
University of Manchester	Methods [H] Evidence Review: Carer	6	6 Table 1 "Study design"	We are concerned that the inclusion criteria mean that the review has included small scale before-after studies as valid evidence, but appears to have excluded large scale cluster trials of interventions [e.g. refs 8, 9, 105]. This is a particular concern as cluster trials often are the only viable option for robust testing of interventions in palliative care, because allocation of individual patients/carers to	Thank you for your comment. Cluster randomised trials are not excluded from the review. The studies you reference evaluate and report on the CSNATand this guideline focused on the delivery of services for people approaching the end of life and for their carers or people and does not address the clinical and cost effectiveness or people's

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

	Support Services			interventions is more contentious than allocation of clusters (sites, wards, services) to deliver an intervention or standard care. Because of the particular vulnerability of the client group, ethical concerns often mean that practitioners and services who deliver the interventions to be tested, see it as unacceptable to allocate individual dying patients and their carers to intervention and control arms, and thus giving an intervention perceived as beneficial to one person and excluding another. In contrast, cluster trials are perceived as more acceptable because it is fairly common in healthcare delivery that one site offers interventions that other sites do not offer. Further, cluster trials offer a better means of testing how well an intervention actually performs in real life service delivery settings.	experience of interventions or tools.