National Institute for Health and Care Excellence

Care of the Dying Adult
Scope Consultation Table
01/08/2014-29/08/2014

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
21	SH	Papworth Hospital	1	General	I think that generally as a team at Papworth Hospital that the outline For developing clinical guidelines for care of the dying adult is good.	Thank you for your comment.
22	SH	Papworth Hospital	2	General	It will be useful to have overall guidelines in this area,that can be followed Nationally.	Thank you for your comment.
181	SH	Cochrane Pain, Palliative and Supportive Care Review Group]	4	General	Please note the recent publication of the rapid Cochrane review, 'Impact of morphine, fentanyl, oxycodone or codeine on patient consciousness, appetite and thirst when used to treat cancer pain' (http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD011056.pub2/abstract) .	Thank you for drawing our attention to this. We will forward this reference to the guideline development group for their consideration.
182	SH	Cochrane Pain, Palliative and Supportive Care Review Group]	5	General	We are currently working on the Cochrane review, 'Palliative pharmacological sedation for symptom relief in terminally ill adults', with funding support from NIHR. Deadline for publication is 31 December 2014, in order to inform this guideline. Protocol available here: http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD010206/abstract	Thank you for drawing our attention to this. We will discuss this with the guideline development group to inform their discussions to finalise their review questions.
206	SH	NHS England	7	General	The guidance should definitely seek to include equal emphasis on the less medical aspects of care, the elements in addition to medication, nutrition and hydration that ensure a good case; understanding and implementing what is important to the persona and what good support looks like for them. Many of the issues raised through the Neuberger review highlighted the lack of person-centred care, that people were not treated as individuals in the last few days and hours of life. I do not feel this guidance effectively acknowledges or	Thank you for your comment. The title of this guideline has been amended to reflect that the focus of this piece of NICE guidance will be with the clinical care of the dying adult in the last few days or hours of life. Even though the emphasis in this guideline is on clinical

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					addresses these needs.	aspects, we anticipate that the guideline development group will consider these broader care issues when drafting their recommendations. We have prioritised a review to address communication and shared decision making between health care professionals, the dying person, their families, carers and others important to them in the last days of life to support this. Further NICE guidance on the care of the dying person is planned and additional detail can be found on the NICE website.
251	SH	British Pain Society	1	General	The British Pain Society (BPS) welcomes the proposal for further guidance on this difficult area. In particular, the provision of concise and accessible guidance on the use of medications will be very helpful although it remains doubtful as to how specific these can be given the very wide range of clinical manifestations of dying.	Thank you for your comment. We agree that this is a complex topic. We anticipate that the proposed review on the pharmacological management of symptom control will inform recommendations in this area.
291	SH	Dignity in Dying	1	General	Dignity in Dying is the sister organisation to the charity Compassion in Dying and endorses their response to this consultation.	Thank you for your comment.
294	SH	Nottingham University Hospitals NHS Trust	1	General	No need to change the scope. The draft does not discriminate any one based on age, disability, gender, gender identity, ethnicity, religion and belief, sexual orientation or socio-economic status.	Thank you for your comment.
325	SH	Royal College of Nursing	1	General	This is to inform you that there are no comments to submit on behalf of the Royal College of Nursing to inform on the above clinical guideline consultation. Thank you for the opportunity to participate.	Thank you for your comment.
37	SH	Faculty of Intensive Care	2	GENERAL	Whilst uncertainty about "recognising dying" is acknowledged, there is no reference to reviewing decisions as circumstances change.	Thank you for your comment. Section 4.3.1 a) has been amended to be clear

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Medicine			This is of importance, as we know that even in the extreme example of withdrawing organ support on intensive care, a small proportion of patients survive, and it can be an appropriate decision to reverse "care of the dying patient" and recommence full active management of the patient with an expectation of survival.	that this will cover how uncertainty around recognizing dying is dealt with. This will include reviewing if circumstances change.
249	SH	Royal College of Anaesthetists	5	General	Our lay members have suggested that the issue of living wills should be considered and mentioned in the guideline as these contain a patient's wishes regarding life prolonging medical treatments.	Thank you for raising these points. It is not possible to include this level of detail in the scope and will not be the focus of a specific evidence review. However, we can highlight these issues when the review strategy for included areas is discussed in the guideline meeting and when recommendations are drawn up.
300	SH	Royal College of GPs	1	General	This a thoughtful and helpful scoping exercise, in addition to symptoms around pain, breathlessness etc. it would be helpful to consider problems around urinary incontinence-catheterisation? and faecal incontinence with the distress and loss of dignity which may accompany them. Constipation is often neglected and causes distress. A prescription of an opioid should be accompanied by a laxative or at least considered. Oral care is important particularly where the patient finds taking fluids difficult, management of thrush may be necessary and regular mouth washes, sucking pineapple can be helpful and humanising. (PS)	Thank you for raising these points. We feel that a review of the evidence in these areas will not provide any useful new guidance to support practice, which should already recognise these issues. When considering the pharmacological management of symptoms, the issue of constipation may be addressed as part of the review of evidence around the use of opioids. We will share your comment with the guideline development group.
62	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	1	General	In light of the findings of the 'More Care Less Pathway' review of the Liverpool Care Pathway which highlighted the need for clear unambiguous terminology and clear conversations, and the Publication of the Leadership Alliance for the care of Dying Persons 'One Chance to get it Right' which gives 5 key priorities for the care of the dying person, these NICE guidelines need to **support the 5 key priorities** and at present they do **NOT** do that. In particular	Thank you for your comment. The purpose of this scope is to outline the areas that have been prioritised for a systematic review in order to make evidence-based recommendations. Your comment was considered but we do not feel the terms in this scope are inconsistent with the 5 priorities in 'One

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					- The definitions and terminology need to be in line with the 5 priorities for care. - The key principles of recognition, communication, involvement, support and plan / do **need to be consistent** This is important to ensure that all healthcare professionals use the same language, receive consistent education and training in order to support patients and their families as they are dying. Although it is true that there may be aspects of of difficulty with clinical decision making and symptom management in the last few weeks of life and a formal review of evidence may guide the care, in our opinion it would be unwise to include that in this review as it may distract and confuse. This guidance should concentrate on the last days and hours alone, so that the guidance is clear.	Chance to get it Right'. The introductory section has made clear reference to this document.
96	SH	Marie Curie Cancer care	1	General	It is unclear as to why there is currently a separate quality standard on end of life care for adults and then this consultation on care of the dying adult when one guideline would be sufficient. This guideline currently only considers the very end of life. The creation of separate guidelines presumes that there is an easily identifiable point at which an individual no longer needs end of life care and is then considered to be dying. One of the issues with the Liverpool Care Pathway was that it was set up as a different way of thinking when an individual was considered to be in the terminal phase, meaning that it was disjointed from any previous care planning.	Thank you for your comments. NICE quality standards 'are concise sets of prioritised statements designed to drive measurable quality improvements within a particular area of health or care. They are derived from the best available evidence such as NICE guidance and other evidence sources accredited by NICE' (see NICE website for more information). As such, it is anticipated that the quality standard will be reviewed in light of the recommendations from this clinical guideline.
200	SH	NHS England	1	General	On the whole, I think this draft scope addresses the most significant and difficult issues in this area, and will be very helpful for users of this guidance. The timeframe of 'in whom death is expected within a few days' is the right focus for this guideline. However, I would strongly point out that the context for this guideline includes the response published by the Leadership Alliance for the Care of Dying	Thank you for your comment. We acknowledge these important strategies in our introductory sections of the scope document. As we draft the full guidance, we will consider where our evidence reviews support the priorities of care for the dying person,

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					People, of which NICE and NHS England were co-signatories. This response, entitled 'One Chance to Get it Right' is referred to in the rationale for Section 4.3.1 (b) but it needs to be part of the introductory section as the context for this work is laid out, so that it is absolutely clear how the responses fit together. Similarly, there needs to be explicit reference to the Priorities for Care of the Dying Person, which is the framework of care that the Leadership Alliance has set out. These NICE Guidelines will provide detailed evidence-based guidance for specific elements contained within the Priorities for Care but as it cannot provide fully comprehensive guidance, it will not be able to fully replace the Priorities for Care as a framework. So it is important that those who read and use read these Guidelines understand the relationship between the Priorities for Care and these Guidelines, and don't misinterpret them as alternative approaches to care. This applies to those commissioning these services too.	to ensure that the links are clear and explicit.
250	SH	Royal College of Anaesthetists	6	General	Our lay members have expressed concern that the scope of this guideline will not include several elements of the care of the dying adults as seen in the sections 'Issues that will not be covered'. In particular the rationale for some of these issues states: 'This may be addressed in the proposed NICE guideline etc.'. Some of these issues are quite important such as 'Longer term palliative care or end of life care outside of the last few days or hours of life', and our lay members are concerned that there may not be any guidelines at all on these issues, if robust systems are not put in place to ensure that these are covered in other guidelines.	Thank you for your comment. The exact scope of the proposed NICE guideline is yet to be agreed so it is not possible to ensure that all these areas are all covered in this guideline at this stage. However, we would strongly encourage you to contribute to the consultation exercises on these developing guidelines. Further detail will be made available on the NICE website in due course.
269	SH	Helen and Douglas House Hospices	1	General	It will be important that the scope of this work is matched with the imminent NICE work on end of life care in children, and with NICE palliative care guidance, so that we end up with a suite of linked guidance. Inevitably there will be some overlap.	Thank you for your comments. We have been in touch with the group developing the guideline on end of life care in children and will ensure the guidelines are linked appropriately, as you suggest (for example, which ages will be covered by which guideline).
305	SH	RCSLT	1	General	I think this is a worthy project **but my big concern** is that this document is being drawn up before the Palliative Care doc is even drafted.	Thank you for your comments. The care of the dying adult in the last days of life will be separate to other

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					What leads up to this point, let's call it "acute dying" i.e. pall & supportive care services will influence the scope and content of this CotDA guideline. I strongly urge that this project is suspended (despite pressure from media following some high profile issues……) until after the palliative care document is at least well drafted. This will also address your question about timing.	proposed guidelines including the intended update of 'Improving supportive and palliative care for adults with cancer'. We are unable to comment on the scheduling of this work. Further detail will be made available on the NICE website in due course.
8	SH	Action on Hearing Loss	2	General	Following on from the pilot project, we have developed good practice recommendations that care services should follow to improve the care of older people with hearing loss: 1. Provide all staff with training in recognising and understanding hearing loss, communication tips, and basic hearing aid maintenance. 2. Provide staff with access to a hearing loss support kit, including a hearing aid maintenance kit, so hearing aids can be maintained and repaired on wards. 3. Improve communication by following communication tips and providing patients who are struggling to hear with a personal listener 4. Record hearing difficulties in care plans and patient notes 5. Make hearing aid storage boxes available to patients 6. Appoint hearing loss champions 7. Implement a hearing loss pathway to help staff support people with hearing loss	Thank you for your comments, the contents of which are noted. A number of groups have been identified as requiring special consideration in relation to the Equalities Act, including sensory and learning disabilities and, as such, where evidence is available in our specific review areas, specific recommendations for these groups may be made if the guideline development group consider it necessary. This group has been added to the Equalities Impact Assessment Form.
7	SH	Action on Hearing Loss	1	General	Action on Hearing Loss is the largest UK charity representing people with hearing loss and tinnitus. Throughout this response we use the term 'people with hearing loss' to refer to people with all levels of hearing loss, including people who are profoundly deaf. We are happy for the details of this response to be made public. Action on Hearing Loss welcomes the opportunity to comment on the 'Care of the dying adult' draft scope. Hearing loss affects over 10 million people in the UK – one in six of the population. As our society ages this number is set to grow and by 2031 there will be more than 14.5 million people with hearing loss in the UK. Hearing loss is the most widespread long-term condition among	Thank you for your comment.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					older people, experienced by almost three quarters (71%) of all people over 70 years. This means that many of the people who are in care in the final stages of dying are likely to have a hearing loss. It is imperative that their care takes into account their communication needs and enables them to communicate with their family and loved ones in the final days of their life. We conducted research in elderly care wards, which found that issues with hearing loss and communication are common. Staff felt that there is a pressing need to improve the identification of hearing loss among older patients to support them while in care. The research found that making small changes, such as having a personal listener available for patients who are struggling to communicate, can have a big impact on patient experience and can enable patients who would otherwise have struggled with conversation to communicate with staff, visitors and other patients. In 2014 we conducted a Nursing Practice pilot project in an Elderly Care Assessment Unit (ECAU) at Heartlands Hospital, Birmingham. Prior to that pilot project, we conducted a baseline assessment surveying 20 staff and 33 patients on the ward. We found that: - More than half (58%) of patients had some difficulty in hearing staff while in hospital - 71% of patients did not fully understand what staff were saying - 43% of patients felt that they were not fully involved in decision-making regarding their care - All staff experienced communication difficulties with patients, possibly due to hearing loss - Several patients on the ECAU had not brought their hearing aids with them to hospital because of concerns that they would be lost or would be an inconvenience As part of our pilot project, we developed a Nursing Practice Toolkit to help staff to support patients with hearing loss. The toolkit is freely available on our website at: www.hearingloss.org.uk/supporting-you/gp-support/nursing-toolkit	

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
157	SH	Willowbrook Hospice	20	General	Regarding the aspects of difficulty with clinical decision-making and symptom management in the last few weeks of life: Some issues here include decisions about introduction of anticipatory prescribing, decisions around communication strategies at a time of advancing ill health and use of health services	Thank you for drawing our attention to this.
222	SH	Association for Palliative Medicine	16	general	Need throughout to make clear that decision making is made with patients and their families as much as possible	Thank you for your comment. We anticipate that this will be an overarching theme across all clinical topics in this guideline.
245	SH	Royal College of Anaesthetists	1	General	Our clinical members thought that this is a helpful and well-worded document. However they felt that the guideline would benefit from the addition of several aspects in the care of the dying adult, specifically: • Mention of withdrawal of life sustaining treatment, DNAR completion or organ donation after cardiac death. • There should be reference in the document to the development of a strategy to address conflict between carers/healthcare professionals and patients/family in deciding the most appropriate care for the patients. Many of the problems with the Liverpool Care Pathway arose where families had unrealistic or inappropriate demands and expectations, often insisting on full active treatment, such as surgical interventions, renal dialysis or mechanical respiratory support. This is particularly the case in the non-cancer domains and specifically where patients are severely demented and develop life threatening illnesses acutely. Our members strongly feel that this issue should be addressed if this guideline is to avoid the pitfalls seen in the LCP.	Thank you for your comment, the contents of which have been noted. It will be beyond the scope of this guideline to make specific recommendations about withdrawing or withholding elements of care outside of the proposed review areas. We recognise the particular challenges in intensive care medicine around care of the dying adult. However, we feel that a specific review of evidence of withdrawing or withholding treatment in this setting would not add value to clinicians' practice, which should be tailored to each individual cared for. The review questions and protocols will be discussed and finalised by the guideline development group. We understand the issues of conflict between clinicians and patients/families is important, including in an intensive care setting. Your comment will be passed on for them to discuss around the review area of shared decision making and

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						communication between health care professionals, the dying person, their families, carers and others important to them.
244	SH	Macmillan	21	General	This document raises the question again about how we evaluate 'quality of End of Life care' – hopefully getting the answers to these questions right will help things to be better – but there is also a question about supporting patients and carers in the right way..we can provide lots of 'just in case' medication but if you are lying in a wet bed because you have not got anyone to change your sheets, your care is not 'good quality'- so a question about level of care needed may be important. There is an argument that if you feel safe with your family around you the feeling of needing to be at home to die may not be so important. This may also be important to look at economically – good care at home is not cheap! I would also like to emphasise the need for developing communication skills in all healthcare professionals in order to have these difficult conversations appropriately- not only learning what and how to say things but developing the sensitivity to know when to stop!	Thank you for your comments. The content of which is noted. The focus of this guideline is on the clinical care of the dying adult in the last few days of life and will not comment on service delivery. We are aware that NICE intend to commission an update of 'Improving supportive and palliative care for adults with cancer'. It is anticipated that the remit of this guideline will be extended to all people at the end of life, no longer specific to cancer. Further details will be made available in due course on the NICE website. We are unable to confirm the focus of this work but would encourage stakeholders to submit comments at the public consultation stage to ensure that their views are heard. The issue you raise will not be covered within this guideline. We recognise the need for good communication in this area and would anticipate that recommendations made within this guideline can be used to inform medical education programmes at all levels, however, medical training is outside of the remit of this guidance.
109	SH	Royal Devon and Exeter NHS Foundation	2	General	Many of the areas you are choosing to examine in the palliative care guidance should be integral to this guidance as general physicians and nurses provide the vast majority of end of life care. The separation risks important features of good compassionate care being seen as a specialist skill and poorly	Thank you for your comment. We are aware that NICE intend to commission an update of 'Improving supportive and palliative care for adults with cancer'. It

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Trust			implemented in routine care.	is anticipated that the remit of this guideline will be extended to all people at the end of life, no longer specific to cancer. Further details will be made available in due course on the NICE website. We are unable to confirm the focus of this work, or whether it will be guidance for palliative care teams or clinicians in general, but would encourage stakeholders to submit comments at the public consultation stage to ensure that their views are heard. We would anticipate that our guidance would inform the development of the proposed service delivery guidance.
129	SH	College of Occupational Therapists	13	General	Good use of mention of the multi-disciplinary team	Thank you for your comment. We have now amended this term to multi-professional.
306	SH	RCSLT	2	General	Recognition that a multidisciplinary team is more than doctors and nurses. RCSLT has to fight to get us in here. We're crucial for expertise in swallow issues and communication. E.g. acute team needs some easily identifiable place to check if SLT has been involved for either/both issues.	Thank you for your comment. We have amended the scope and replaced multi-disciplinary with multi-professional to reflect this.
307	SH	RCSLT	3	General	This is an important area driven by the urgent need to optimise patient care at the end of life and the need to minimise carer distress. I wonder whether this project should be conducted in tandem with the palliative care guideline that is referred to. RCSLT need to highlight that even when patients are dying, communication is an issue for some and SLTs should be available to provide assessment and advice - and if required, be an integral part of the process of assessing for mental capacity (under the Mental Capacity Act) With such an emphasis on artificial hydration and nutrition, RCSLT should be	Thank you for your comment. The care of the dying adult in the last days of life will be separate to other proposed guidelines including the intended update of 'Improving supportive and palliative care for adults with cancer'. We expect that this guideline will feed into other guidelines in this clinical area.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					clear that SLTs provide support to both patients and families to minimise disease burden in relation to swallowing and that we have a crucial role in direct intervention and education of caregivers. This does not mean nil by mouth, but rather a holistic and sensitive approach to minimising dysphagic symptoms and caregiver education in the context of dying.	Your comment on speech and language therapies' involvement in hydration in the last days and hours of life will be forwarded to the guideline development group for discussion on this review area.
367	SH	Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)	3	General	It is noted that the current guideline development group excludes any allied health professionals as they are not listed as proposed co-optees either. It is suggested that representatives from professions such as physiotherapy may be helpful on the list of co-optees	Thank you for your comment. The list of proposed co-optees reflects the current requirements of the clinical areas included in the scope. Once convened, the guideline development group may consider adding further co-optees, including physiotherapists, to provide evidence on specific uses if they feel it is required.
297	SH	Norfolk and Suffolk Palliative Care Academy	3	General	Whilst silo working around conditions persists there will be territorialism around specific conditions and multi professional working is not possible. We need a new way of doing things if patients are to get a better deal.	Thank you for your comment, the content of which has been noted.
243	SH	Macmillan	20	General	No reference to the Mental Capacity Act and best interest process	Thank you for your comment. We have amended the scope to include the Mental Capacity Act.
278	SH	Department of Health	1	General	Thank you for the opportunity to comment on the draft scope for the above clinical guideline. **I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.**	Thank you for your comment
374	SH	Association of Chartered Physiotherapists in Oncology and Palliative Care	10	General	Suggested reading – Lienert B F (2013) *Physiotherapy in the terminal phase* in Taylor, J, Simader R and Nieland P (eds) 2013. *Potential and Possibility: Rehabilitation at end of life*. Urban and Fischer (Elsevier): Munich	Thank you for drawing our attention to this. We will not be prioritising a specific review on the role of physiotherapists in this guideline.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		(ACPOPC)				
385	SH	Motor Neurone Disease Association	1	General	About MND and the MND Association: Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no cure. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity	Thank you for your comment.
199	SH	Rowcroft Hospice	17	General comment	Often access to equipment such as hospital beds, commodes and slide sheets contributes to whether the person can achieve their preferred place of care. There is no reference to this in the scope.	Thank you for your comment. The focus of this guideline is on the clinical care of the dying adult in the last few days of life. It will not include service delivery. We are aware that NICE intend to commission an update of 'Improving supportive and palliative care for adults with cancer'. It is anticipated that the remit of this guideline will be extended to all people at the end of life, no longer specific to cancer. Further details will be made available in due course on the NICE website. We are unable to confirm the focus of this work but would encourage stakeholders to submit comments at the public consultation stage to ensure that their views are heard. The issue

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						you raise will not be covered within this guideline.
223	SH	Association for Palliative Medicine	17	general	Throughout the document, more emphasis needs to placed on out of hours care for dying patients and how this can be managed	Thank you for your comment. The focus of this guideline is on the clinical care of the dying adult in the last few days of life. It will not include service delivery. We are aware that NICE intend to commission an update of 'Improving supportive and palliative care for adults with cancer'. It is anticipated that the remit of this guideline will be extended to all people at the end of life no longer specific to cancer. Further details will be made available in due course on the NICE website. We are unable to confirm the focus of this work but would encourage stakeholders to submit comments at the public consultation stage to ensure that their views are heard. The issue you raise will not be covered within this guideline.
383	SH	The Royal College of Radiologists	9	General	The RCR supports the wider use of rating scales to provide some indication of efficacy of symptomatic management but not to lead to an expectation that all these have to be measured/recorded for every patient all of the time.	Thank you for your comment, the contents of which have been noted.
36	SH	Faculty of Intensive Care Medicine	1	GENERAL	In relation to "recognising dying", the fact that this is intimately related to decisions about withdrawing or withholding other elements of care (e.g. antibiotics, disease modifying drugs such as chemotherapy, organ support on intensive care) OR to failure to respond to such treatment seems to have been omitted. This is of importance as these broader care decisions are related to judgements about the balance of benefit (improvement in the duration or quality of life) and harm (adverse effects of the interventions or associated	Thank you for your comment, the contents of which have been noted. It will be beyond the scope of this guideline to make recommendations about withdrawing or withholding elements of care within the proposed review around signs and symptoms of the dying adult, which is intended to aid timely recognition that a person is likely

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					care). Therefore the exclusion of prognostic tools from this guideline may be a mistake as such tools may be of importance in guiding such decisions. In other words, the process of "recognising dying" is often linked to an appropriately made decision to withhold or withdraw care and this seems to have been omitted in the consideration of "symptoms and signs of dying" – the "diagnosis" ("recognising dying") has to be made in a broader context than simply the current symptoms and signs of the patient.	to be in the last days of life. We recognise the particular challenges in intensive care medicine around care of the dying adult. However, we feel that a review of evidence of withdrawing or withholding treatment would not add value to clinicians' practice, which should be tailored to each individual cared for.
205	SH	NHS England	6	General	I think the scope should be changed to better promote equality of opportunity, specifically by incorporating social and spiritual needs (which are currently excluded) and focussing on the delivery of person-centred care. This guidance currently concentrates on the medical model of death and dying. Without acknowledging and acting upon individuals' spiritual and social needs you cannot treat the "whole person" or be sure of delivering the kind of support that matters to that individual. Social and spiritual needs are inexplicably linked to equality of opportunity and care, most clearly through religion, belief and socio-economic status, but these needs are also linked to what defines any individual.	Thank you for your comment. Religion and beliefs and socioeconomic status are defined equality protected characteristics according to the Equality Act. This document is available on the NICE website. We have raised these needs as part of our equality impact assessment form and, as such, they will be discussed within the context of each review. There will not be a separate evidence review on spirituality as we do not consider this the best way to inform practice. We recognise that, for some, spirituality is not based within a particular faith or religion but may be reflected in other ways. We will consider those needs as equally important in this guideline .We have, therefore, removed spirituality from the list of areas not covered and will discuss the impacts of this issue in each of our review areas. The guideline development group may choose to co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						recommendations.
268	SH	Renal Association	5	General	There does not appear to be any discussion about cultural aspects of expectations of care at end of life, decision making, family involvement. This is particularly important for parts of the country, e.g., London, where there are many immigrants, and for diseases, such as kidney disease, which are more common in non-white populations	Thank you for your comment, the content of which has been noted. Religion and beliefs, ethnicity and socioeconomic status are defined equality protected characteristics according to the Equality Act. This document is available on the NICE website. We have raised these needs as part of our equality impact assessment form and, as such, the impact of these protected characteristics will be discussed within each review area.
288	SH	Catholic Bishops Conference of England and Wales	1	General	The absence of any reference to spiritual contentment and the role of Chaplains or specific faith representatives in this process is an oversight. Dying patients are often perceived to be holding on to life because they have 'unfinished' business that can be dealt with by Chaplains, social workers or family members.	Thank you for your comment. We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this important focus in each of our review areas. The guideline development group may choose to co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
54	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	1	General	The British Heart Foundation (BHF) is the nation's leading heart charity. Our vision is of a world in which no one dies prematurely or suffers from cardiovascular disease (CVD). Cardiovascular disease, which includes diseases of the heart and circulation such as heart failure, coronary heart disease (angina and heart attack) and stroke, kills more than one in four people in the UK.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. Please note that this guideline seeks to address

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					Heart failure, which is often the final outcome of a variety of cardiac diseases currently affects hundreds of thousands of people in the UK and thousands more are diagnosed each year.[1] Despite therapeutic advances, heart failure is a progressive clinical syndrome. For those that make it out of hospital to be discharged, the mortality rate is 37 per cent within three years.[2] **Although heart failure survival rates are worse than for some cancers, unlike cancer patients, very few people with heart failure receive specialist end of life care.** The National Heart Failure Audit shows that only 3.1 per cent of heart failure patients were referred to palliative care services following the first admission, and 7.3 per cent following a readmission.[3] If individuals are recognised as approaching the end of their life there can be proper planning for their needs and wishes. The Department of Health's first national survey of bereaved people showed clear discrepancies in the experiences of people whose loved ones died from CVD compared to those who died from cancer.[4] This has since been backed up by information collated by the National End of Life Care Intelligence Network. For most care settings, quality of care was rated as excellent less frequently for those who died of CVD than for those who died of cancer.[5] The relatively small numbers of people with heart failure receiving quality end of life care is due, in large part, to the unpredictable trajectory of heart failure. Some patients with heart failure have repeated acute and severe exacerbations that respond effectively to treatment. For others, the decline is relentless with worsening symptoms that are distressing and debilitating. Some	management in **all** conditions in the last days of life, as this is an area highlighted as requiring guidance by healthcare professionals.

1

3

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					die suddenly without warning yet others can show signs of being at the end of life for over a year. GPs say that introducing palliative care was fairly straightforward for those with cancer, who typically had a clear terminal decline but much more difficult for patients with other life-threatening illnesses.[6] In order to ensure that heart failure patients are identified for end of life care, and at a time far enough in advance for them to fully benefit, **we believe that patients must be identified when they reach end stage heart failure. This will likely be in their last months rather than days of life.** Patients with end stage heart failure and end of life care needs will continue to receive on-going medical therapy for their heart failure during this time. We believe that the focus, throughout this document, on identification of people who are in their last few days of life, therefore, is likely to exacerbate the existing inequity in delivery and quality of end of life care.	
263	SH	British Geriatrics Society	8	General	The British Geriatrics Society is delighted that the National Institute of Excellence will be developing a guideline on the care of the dying adult and welcomes that special consideration will be given to Dementia as it is a progressive and terminal disease.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We are aware, however, of the very specific needs of patients with dementia and these have been separately highlighted in our equalities impact assessment form which is available on the NICE website.
23	SH	Papworth Hospital	3	General	We feel that it should be restricted to guidelines for the last few days of life and not extended further than that.	Thank you for your comment. The focus of this guideline will be on the clinical care of the dying adult in the

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						last few days of life.
156	SH	Willowbrook Hospice	19	General	Agree that aiming for the last days of life is appropriate as the mode timeframe within which most people die. There is a challenge with managing more protracted dying phases which do occur in all conditions. Specialist palliative care teams are involved in these, especially in hospital and nursing homes where they are frequently of people without cancer.	Thank you for your comment. The focus of this guideline will be on the clinical care of the dying adult in the last few days of life.
207	SH	Association for Palliative Medicine	1	General	Agree scope should be those in whom death is anticipated within a few days only	Thank you for your comment. The focus of this guideline will be on the clinical care of the dying adult in the last few days of life
345	SH	Royal Brompton NHS Foundation Trust	1	general	This scope limits to the last few days of life, this is very difficult to identify particularly for patients with non-malignant disease and would be better as days-to weeks of life. It is over this time frame that the important decisions and communication often occurs. This is even more important for those patients dying with dementia	Thank you for your comment on the timing of this guideline. We have noted that stakeholders are mixed in their response; however, we feel it is appropriate, given the clinical focus of our work, to restrict the time frame to the last days and hours of life in order to add most value to practice, as this is an area highlighted as particularly needing clinical guidance.
355	SH	Royal Marsden NHS Foundation Trust	1	general	This scope limits to the last few days of life, this is very difficult to identify particularly for patients with non-malignant disease and would be better as days-to weeks of life. It is over this time frame that the important decisions and communication often occurs. This is even more important for those patients dying with dementia	Thank you for your comment on the timing of this guideline. We have noted that stakeholders are mixed in their response. However, we feel it is appropriate, given the clinical focus of our work, to restrict the time frame to the last days and hours of life in order to add most value to practice, as this is an area highlighted as particularly needing clinical guidance.
375	SH	The Royal College of Radiologists	1	General	The RCR agrees that the scope should be those in whom death is anticipated within a few days only	Thank you for your comment. The focus of this guideline will be on the clinical care of the dying adult in the last few days of life.
270	SH	Helen and Douglas	2	General	In response to your request for views re timeframe. I agree completely with your comment that some areas in the scope may arise at an earlier stage.	Thank you for your comment on the timing of this guideline. We have noted

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		House Hospices			Also, there is need to discuss, communicate, make decisions and *plan for various possible trajectories* at an earlier stage rather than wait for the last days. I would therefore support a broader time view within the overall 'end of life' scope, whilst probably retaining a strong focus on 'last days and hours' as there are specific unique issues associated with these last days. Furthermore, there is real difficulty in *prognostication*,(as you acknowledge in 4.1.1), particularly with some (non cancer) long term conditions associated with chronic vulnerability rather than clear disease progression. As these fragile patients near end of life, such 'parallel planning' is particularly important. It is not uncommon for such patients to deteriorate and die relatively suddenly (so planning ahead for the possibility is important). Equally planning and guidance need to recognise that it is not uncommon for such patients to have more than one period that clinicians think could be the 'last days', particularly during intercurrent destabilising episodes (such as infection) in a very vulnerable population towards the end of life.	that stakeholders are mixed in their response; however, we feel it is appropriate, given the clinical focus of our work, to restrict the time frame to the last days and hours of life in order to add most value to practice, as this is an area highlighted as particularly needing clinical guidance. We recognise the importance of uncertainty in recognising those in the last days and hours of life and anticipate that the guideline development group will discuss and make recommendations on how to manage this uncertainty.
108	SH	Royal Devon and Exeter NHS Foundation Trust	1	General	The scope of the document presented is much more narrow than "Care of the dying adult" particularly when you state the areas you are not going to examine. This is inappropriate- if due to the tight time frames this is essential – the guidance should reflect this in the name e.g. medical interventions for dying patients.	Thank you for your comment. It is not possible for a NICE clinical guideline to describe the totality of care in any given topic. We have prioritised our inclusions based on variation in clinical practice or issues identified as important by the 'More care, less pathway' document.
180	SH	Cochrane Pain, Palliative and Supportive Care Review Group]	3	General	Suggest the following additions to the consultation: To facilitate meaningful and comparative service delivery (and future research) the panel should consider defining terms that have lost clarity. End of life care, care in the last days of life, palliative care, specialist palliative care and terminal care mean different things to different audiences. Clarity should be sought to prevent any potential future misinterpretation. As stated above, management of imminently dying people should be personalised. Optimal care includes acknowledging that many people have declared their preferences and references; these should be understood and, wherever possible, met.	Thank you for your comment. We agree. The guideline development group will define the terms that they use for the purposes of this guideline development. We will consider how these reflect other definitions in more general use and clarify any differences.
235	SH	Macmillan	12	General	Although it is stated that palliative care NICE guidance MAY address care	Thank you for your comment. The

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
				1	provision no guidance regarding the care of the dying should in my opinion ignore the importance of high quality care being available- no amount of anticipatory prescribing communicating and planning will lead to a 'good death' when a patient is lying in a soiled/wet bed where no carers are available to deal with the basic needs of people. In addition well resourced and responsible district nursing teams who are able to attend promptly to administer injectable medications and also have time to attend GSF/MDT meetings are an essential aspect of care of the dying adult in the community	focus of this guideline is on the clinical care of the dying adult in the last few days of life. It will not include service delivery. We are aware that NICE intend to commission an update of 'Improving supportive and palliative care for adults with cancer'. It is anticipated that the remit of this guideline will be extended to all people at the end of life no longer specific to cancer. Further details will be made available in due course on the NICE website. We are unable to confirm the focus of this work but would encourage stakeholders to submit comments at the public consultation stage to ensure that their views are heard. The issue you raise will not be covered within this guideline.
236	SH	Macmillan	13	General 2	No clear reference is made to DNAR discussions- this seems necessary especially in the light of the recent Tracy judgement in the court of appeal which indicates that it is a requirement to discuss DNAR with the majority of patients who are identified in this cohort excepting only those in whom severe psychological distress would result.	Thank you for your comments, the contents of which are noted. We recognise that CPR and DNAR decisions are an important area in care of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas are more likely to have a wider impact on clinical practice. DNAR discussions will not be included in this guideline.
304	SH	Royal College of GPs	5	General - Patients with learning disabiliti	The Confidential Inquiry into the Premature deaths of people with learning disabilities 2013 http://www.bristol.ac.uk/cipold/fullfinalreport.pdf made 18 recommendations of which 3 are have direct relevance for this scoping. It is important that patients with cognitive impairment and or communication difficulties have reasonable adjustments made.	Thank you for your comment, the content of which is noted. We agree that there are inequalities in the care of these groups of people. They are, therefore, specifically referred to in our 'guideline equality impact assessment'

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
				es	13 Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Guidelines to be more clearly defined and standardised across England. 14 Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and to be flexible and responsive to change. 15 All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team. (MH)	document. A number of groups have been identified as requiring special consideration in relation to the Equalities Act and, as such, where evidence is available in our specific review areas, specific recommendations for these groups may be made if the guideline development group consider it necessary. We have also included a reference to the Mental Capacity Act in our introduction.
298	SH	Norfolk and Suffolk Palliative Care Academy	4	a)	Without proper multidisciplinary working anticipatory prescribing will not be possible,	Thank you for your comment, the content of which has been noted.
366	SH	Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)	2	1	It is also noted that care of the adult dying in the last hours versus days is very different. Eg: A person dying in an acute hospital setting in the last few hours of life will be cared for in situ whilst those in the last few days of life may require physiotherapy and occupational therapy to facilitate discharge home (or to a preferred place of care) They may wish to receive physical interventions to assist with independence eg: many people wish to be able to transfer out of bed to reduce the requirement for bed pans for as long as possible thus maintaining privacy and dignity.	Thank you for your comment on the timing of this guideline. We have noted that stakeholders are mixed in their response; however, we feel it is appropriate, given the clinical focus of our work, to restrict the time frame to the last days and hours of life in order to add most value to practice, as this is an area highlighted as particularly needing clinical guidance.
365	SH	Association of Chartered Physiotherapists in Oncology and Palliative	1	b) 1	"Dying adult" is an ambiguous title and could be misinterpreted as "palliative care". It does not reflect the limited scope of the guidance ie: dying in the last hours or days of life. It is suggested that perhaps the title would be more appropriately worded as: "Care of the adult who is actively dying".	Thank you for your comment. The wording of the guideline title has been amended to 'The clinical care of the dying adult in the last few days of life'

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Care (ACPOPC)				
63	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	2	1 & 1.1	In line with the terminology in Priorities for Care of the Dying Person should the title be **"Care of those thought likely to be Dying"**	Thank you for your comment. The wording of the guideline titles has been amended to 'The clinical care of the dying adult in the last few days of life' in order to provide clarity and focus to our work.
64	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	3	2	If this is a Guidelines on 'care of the dying adult' or 'those thought likely to be dying' then it must involve the holistic care of those people. The LCP debacle has taught us that you cannot just concentrate on that which appears to be important to one group be that doctors, nurses, patients, families or the public. Therefore we cannot just look at the recognition, prescribing & hydration/nutrition (or rather eating and drinking).	Thank you for your comment, the content of which has been noted. We agree, however, that the focus of this guideline will be on the clinical care of the adult in the last days of life. It has been focussed around areas of variation in practice. It is not possible for a NICE clinical guideline to cover all issues pertaining to the care of dying adults.
138	SH	Willowbrook Hospice	1	2 The remit	Clarity on who the target audience is for this guidance is required. The policy remit applies to England only. This is a shame and would be very beneficial for continuity if all devolved administrations could adopt too. It is important that the guideline reflects the language in the "one Chance to Get it Right" document i.e – family/relatives/those dear/loved ones = those important to the person who is dying.	Thank you for your comment. NICE guidance is developed for England only. We are aware that our sister countries often adopt the recommendations made in NICE guidelines. The guideline is aimed for those receiving care in the settings listed in section 4.2. We acknowledge the need to reflect the language used in other national policy documents and will aim for consistency where appropriate.
130	SH	Royal College of Physicians of Edinburgh	1	3	The College agrees that predicting death is complex and sometimes not possible. It is easier to recognise that death is imminent in patients with metastatic cancer. In contrast, a frail older person with dementia and multiple medical problems who decompensates may appear to be dying but 24 hours later rallies.	Thank you for your comment, the contents of which have been noted.
4	SH	Office of the	1	3 –		Thank you for your comments. We will

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Parliamentary and Health Service Ombudsmen		Need for Guidance (b) (d) (e)	'final stages of dying' 'death becomes imminent' ' maximise the dying persons comfort ..' These concepts are important but how are they measured by clinical staff? Guidance has to assist in this decision making process or guide clinicians to sources that may help with these decisions. What are the 'last days of life'? 1-2-3 days? Training on "difficult conversations' facilitated by organisations such as Dying Matters can help healthcare professionals develop skills in this area. Communication is the overarching principle of End of life Care work and impacts on every aspect of it. It should therefore feed into most aspects of the guidance.	pass the issues you raise on to the guideline development group for their consideration.
256	SH	British Geriatrics Society	1	3 a	The Society would totally support the need for the development of "Care of the dying adult". as stated in the remit.	Thank you for your comment.
65	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	4	3 a	The principles of care are the same for cancer and non-cancer patients. The term imminent is correct, and 'make death imminent' is poor English. Suggest Death is a natural part of the life cycle. For many death is expected or predicted due to advanced progressive disease and/or existing medical conditions.	Thank you for your comment. The text of this section has been amended.
97	SH	Marie Curie Cancer care	2	3 a)	'Death is a natural part of the life cycle' – this is a culturally determined value statement and is not accepted as correct by many, e.g. Muslims do not agree with this statement	Thank you for your comment. We feel that this text is acceptable for the purposes of the scope and does not preclude cultural beliefs.
335	SH	Help the	1	3 a)	We would add: "which emphasises the need to develop critical assessment	Thank you for your comment. We have

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Hospices			and communication skills to respond".	amended the text in this section of the scope.
255	SH	British Pain Society	5	3 b	The guideline is intended to address the final stages of dying and it would be inappropriate to include the whole topic of assisted dying that is being addressed elsewhere. However the BPS considers that the guideline group must refer to the evidence suggesting that already many patients, relatives and carers take active steps to assist dying for example by the administration of large quantities of medication and that this can have important medical and legal consequences and be the source of substantial distress. This has been publicised on popular media (e.g. Coronation Street) but is rarely acknowledged and cannot be excluded from this scope,	Thank you for your comment. Assisted dying is outside the remit of this guideline. This is a matter of medical law rather than NICE guidance.
139	SH	Willowbrook Hospice	2	3 b	Can also depend on the availability of beds not only choice and need.	Thank you for your comment. The focus of this guideline is on the clinical care of the dying adult in the last few days of life. It will not include service delivery. We are aware that NICE intend to commission an update of 'Improving supportive and palliative care for adults with cancer'. It is anticipated that the remit of this guideline will be extended to all people at the end of life no longer specific to cancer. Further details will be made available in due course on the NICE website. We are unable to confirm the focus of this work but would encourage stakeholders to submit comments at the public consultation stage to ensure that their views are heard. The issue you raise will not be covered within this guideline.
184	SH	Rowcroft Hospice	2	3 b	We need to acknowledge that death is social as well clinical.	Thank you for your comment. The title of this guideline has been amended to reflect that the focus of this piece of NICE guidance will be with the clinical care of the dying adult in the last few

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						days or hours of life. Even though the emphasis in this guideline is on clinical aspects, we anticipate that the guideline development group will consider these issues where appropriate when drafting their recommendations.
279	SH	Intensive Care Society	1	3 b & 3 c	In the Intensive Care setting, there can be disagreement between the treating clinical team and family members. It would be helpful for the NICE guidance to address this issue (see: Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67 also Tracey, R (on the application of) v Cambridge University Hospitals NHS Foundation Trust & Anor [2014] EWCA Civ 33)	Thank you for drawing our attention to this. We recognise the particular challenges in intensive care medicine around care of the dying adult. However, we feel that a specific review of evidence of withdrawing or withholding treatment in this setting would not add value to clinicians' practice, which should be tailored to each individual cared for.
27	SH	Faculty of Intensive Care Medicine	1	3 b & 3)c)	In the Intensive Care setting, there can be disagreement between the treating clinical team and family members. It would be helpful for the NICE guidance to address this issue (see: Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67 also Tracey, R (on the application of) v Cambridge University Hospitals NHS Foundation Trust & Anor [2014] EWCA Civ 33)	Thank you for drawing our attention to this. We recognise the particular challenges in intensive care medicine around care of the dying adult. However, we feel that a specific review of evidence of withdrawing or withholding treatment in this setting would not add value to clinicians' practice, which should be tailored to each individual cared for.
117	SH	College of Occupational Therapists	1	3 b (last paragraph)	As death becomes imminent, the 'clinical' care provided should maximise the dying person's comfort. The word clinical should be deleted i.e. it should just be care – not just clinical care to emphasis the holistic nature of care and the wider multi-disciplinary team.	Thank you for your comment. We believe the addition of the word clinical clarifies the focus of the work of this clinical guideline and have not deleted.
99	SH	Marie Curie Cancer care	4	3 b)	'Death may take place in a variety of settings, depending on choice and individual need' – this is incorrect, as place of death is dependent on many other factors. At present, it is unlikely that people will die in the place they want to – although research suggests 63 per cent of people would prefer to die at home, 55 per cent of people die in hospital	Thank you for your comment, the content of which has been noted. This guideline will focus on specific clinical issues and the care of people provided in the settings outlined in section 4.2.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						We will not be addressing issues related to choice of place of death.
98	SH	Marie Curie Cancer care	3	3 b)	The phrase 'families or loved ones' is unhelpful – it would be better to refer to 'families or carers' instead.	Thank you for your comment, we have amended the scope accordingly.
178	SH	Cochrane Pain, Palliative and Supportive Care Review Group]	1	3 b)	Consider adding 'Wherever possible preferences and wishes should be acknowledged and met'.	Thank you for your comment. The text in this section has been amended.
66	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	5	3 b, line 1 3 b, line 2 3 b, line 3 3 b, line 4 3 b line 4… 3 b line 8	"Final stages of dying" should be "those who are thought likely to dying" "Families of loved ones" should be "families and those identified as important to the patient" Death may take place in a vriety of settings depending on choice, individual need <u>& circumstances.</u> "recognising that someone is entering the last days and hours of life" should be "recognising that someone is likely to be dying" Recognising that someone is thought likely to be dying is vital to ensure that the patient, their "family" and healthcare professionals understand what is happening and an individual plan for care can be developed. As death **approaches** (not 'becomes imminent') the clinical care provided should maximize the dying person's comfort <u>in line with their wishes and preferences</u> and aim to reduce **distressing symptoms.**	Thank you for your comments. Amendments have been made to this section accordingly.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
224	SH	Macmillan	1	3 c	Progressive weakness etc- suggest should add –'with no obviously reversible cause such as treatable infection/metabolic disturbance'	Thank you for your comment, this sentence has been amended accordingly.
67	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	6	3 c	~~The likely time of death is often difficult to anticipate or predict~~ In the event of a clinical deterioration, knowledge of the patients medical history, the exclusion of reversible causes and regular multi-professional clinical assessment will help clinical staff to recognise that a patient is dying	Thank you for your comment, the content of which is noted.
237	SH	Macmillan	14	3 d	Should this section reflect *One chance to get it right* and refer to personalised care plans not just care plans?	Thank you for your comment. We have amended the text here and elsewhere accordingly to refer to personalised care plans.
9	SH	Action on Hearing Loss	3	3 d	Communication needs must be identified, recorded and met as part of the process to understand an individual's needs and make suitable care plans for dying people. NHS England's forthcoming Accessible Information Standard provides a clear framework for all statutory health and social care services to follow to ensure the communication needs of patients and carers with hearing loss, sight loss and learning disabilities are properly identified, recorded and met.	Thank you for your comment. A number of groups have been identified as requiring special consideration in relation to the Equalities Act, including sensory and learning disabilities and, as such, where evidence is available in our specific review areas, specific recommendations for these groups may be made if the guideline development group consider it necessary.
100	SH	Marie Curie Cancer care	5	3 d	It is worth noting that families and the individuals themselves may also feel uncomfortable about having frank discussions about dying and therefore avoid them. It is not just healthcare professionals who experience these issues.	Thank you for your comment. We have amended the text to reflect this.
183	SH	Rowcroft Hospice	1	3 d	Likewise some patients and/or families may feel uncomfortable about having frank discussions and therefore avoid them (research evidence to support this (Horne, Seymour & Payne, 2012 'Maintaining Integrity in the face of death' Int. Journal of Nursing Studies)	Thank your comment. We have amended the text to reflect his.
225	SH	Macmillan	2	3 d	Healthcare professionals may feel uncomfortable but this is not a reason not to discuss –I think this sentence needs to reflect this	Thank your comment. We have amended the text to reflect this.
238	SH	Macmillan	15	3 d	By ending the paragraph with "may feel uncomfortable about having frank discussions and may therefore avoid them" feels like this is acceptable and it isn't. Although the next paragraph stresses the need for good communication it	Thank you for your comment. We have amended this paragraph accordingly.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					would sound better if this paragraph did not end with this sentence, could we even say it is unacceptable. If clinicians do feel uncomfortable they need to find someone who doesn't or address this through their own learning.	
68	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	7	3 d	Multi-professional not multi-disciplinary **Agree** care should be the same regardless of diagnosis or setting. Should it read - once the the multi professional team has recognised that a person is dying, a holistic assessment of the patients needs should be undertaken and an individualised plan for care developed with the patient and family. Health professionals must **not avoid difficult conversations**. (LACDP 2014)	Thank you for your comment. We have amended the scope and replaced multi-disciplinary with multi-professional to reflect this. We have further clarified the issues related to difficult conversations.
28	SH	Faculty of Intensive Care Medicine	2	3 d & 3 e	The Intensive Care clinical team is faced with difficult discussions with families on a regular basis (vide supra) and therefore has a wealth of experience that could be shared with other clinical teams that have less experience.	Thank you for your comment. We aim to include a perspective from intensive care practice as part of the guideline development group.
280	SH	Intensive Care Society	2	3 d & 3 e	The Intensive Care clinical team is faced with difficult discussions with families on a regular basis (vide supra) and therefore has a wealth of experience that could be shared with other clinical teams that have less experience.	Thank you for your comment. We aim to include a perspective from intensive care practice as part of the guideline development group.
118	SH	College of Occupational Therapists	2	3 d & 3 e	Both discuss potential difficulties arising from poor or avoided conversation. These need to be considered together, emphasising this skill for all those caring for patients and their family. This includes where prognostication is inaccurate and patients improve following withdrawal of medication, etc.	Thank you for your comment. The section of text you refer to is on current practice and does not refer to review questions. Review questions and protocols will be discussed and finalised by the guideline development group. We will pass on your comment to the guideline development group for their consideration.
56	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	3	3 d and 3. e	We welcome the recognition that communication between clinicians and patients at the end of life is currently poor. Research by Marie Curie showed that some GPs found it difficult to raise and discuss death and dying with patients, particularly with patients with a non-	Thank you for your comment. The detail will be passed on the guideline development group to aid their discussion around this review area.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					cancer diagnosis.[7] Further research studies have explored GP communication with people with heart failure approaching the end of life. The studies found that: • End of life care is rarely discussed, with conversations focusing largely on disease management. • Clinicians are unsure how to discuss the uncertain prognosis and risk of sudden death, fearing they may cause premature alarm and destroy hope. • Clinicians wait for cues from people before raising end of life care issues.[8] The VOICES survey found that 30 per cent of people whose loved ones died from cardiovascular disease felt that the patient definitely didn't know they were likely to die, compared to just five per cent for cancer.[9] We believe that **all clinicians must undertake end of life care communication training which directly addresses communication with people with an uncertain prognosis.** The BHF have funded guidance to help anyone caring for someone with heart failure to open up conversations about their end of life wishes and preferences. 'Difficult Conversations for Heart Failure' was published by the National Council for Palliative Care in May 2014. Time to allow this discussion between people with heart failure and clinicians must also be provided. Time for such discussions is often provided to cancer patients but must also be facilitated for people with heart failure to ensure that they are given the opportunity to discuss options and preferences can be recorded.	

7

8

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
38	SH	Faculty of Intensive Care Medicine	3	3 e	This section refers to good communication being essential for people to ***feel*** they are involved and about ***perceptions*** of being treated with dignity and respect. The tone of the language here (on contrast to other sections) is open to misinterpretation that this is only an issue of perception and not of substance.	Thank you for your comment. We have re-worded this paragraph accordingly and have removed 'perceptions' from this sentence altogether.
140	SH	Willowbrook Hospice	3	3 e	"Good communication is necessary to ensure that people feel they are APPROPRIATELY involved in the decision making process... Rationale – it is important the guidance reflects legal and professional guidance regarding treatment and care. There is a body of evidence that if relatives/those important to the dying person are not appropriately involved in decisions that they are left with a burden of responsibility up to an including feeling that they were responsible for the death of a loved one, even though death is expected. Reads as though spiritual needs are less important. End of life care should be viewed as holistic with equity for physical, psychological, social and spiritual not as an add on.	Thank you for your comment. We have amended the text to reflect the issue of appropriate communication. We agree that spiritual needs are important in the last days of life. Our intent was to clarify that we would not undertake a specific review of evidence in this area. This has now been removed but we anticipate that consideration will be given to addressing needs as appropriate in the included areas across the guideline.
311	SH	RCSLT	7	3 e	Should 'physical' symptoms also include swallowing impairment? Mouth care to enable speaking and eating Communication impairment – how is this considered?	Thank your comment, the text to which you refer is not meant to be an exhaustive list. We note the issues you raise and will forward these to the guideline development group for their consideration.
312	SH	RCSLT	8	3 e	Regarding good communication, it should be recognised that this applies to individuals with communication disorders – i.e. if required; patients should have a communication assessment to ensure they can be active participants in care decisions +/- communication aid.	Thank you for your comment. The narrative you refer to is a brief overview. Disability is a defined equality protected characteristics according to the Equality Act. This document is available on the NICE website. Where evidence is available in our specific review areas, specific recommendations for these groups, such as those with communication

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						difficulties, may be made if the guideline development group consider it necessary.
226	SH	Macmillan	3	3 e	For some people 'spiritual needs' –spiritualism is a human characteristic and to say that only some people have spiritual needs is like saying only some have physical needs – it gives the impression that spiritual needs are simply religious ones.	Thank you for your comment, the content of which has been noted. The scope has been amended. We recognise that, for some, spirituality is not based within a particular faith or religion but may be reflected in other ways. We will consider those needs as equally important in the care of the dying adult in this guideline. We have therefore now removed spirituality from the list of areas not covered and will discuss the impacts of this issue in each of our review areas. The guideline development group may choose to co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
69	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	8	3 e	**ALL** patients need physical, social, psychological **and spiritual** needs assessing. We do not understand why only some need a spiritual needs assessment. (Spiritual relates to meaning in life – we understand that only some will need religious needs assessment) Good communication to ensure the patient and their "family" (those important to them)……	Thank you for your comment, the content of which is noted. We have amended the scope. We recognise that, for some, spirituality is not based within a particular faith or religion but may be reflected in other ways. We will consider those needs as equally important in the care of the dying adult in this guideline. We have therefore now removed spirituality from the list of areas not covered and will discuss the impacts of this issue in each of our

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						review areas. The guideline development group may choose to co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
227	SH	Macmillan	4	3 e	Communication : suggest wording inappropriate –states people'feel they are involved in decisions' should not just *feel* they are involved-should *be* involved	Thank you for your comment, we have amended this sentence accordingly.
239	SH	Macmillan	16	3 e	This would be a good place to mention how important it is to undertake advance planning and make people aware of their prognosis as early as possible as it makes communication about dying easier.	Thank you for your comment, we have amended this sentence accordingly.
110	SH	Royal Devon and Exeter NHS Foundation Trust	3	3.0 e	The wording of this suggests that only a small number of people have spiritual needs. This will depend on your definition of spiritual need however the NCDAH audit suggests that these needs are insufficiently recognised and or managed by healthcare professionals and the wider team.	Thank you for your comment, the content of which has been noted. We have amended the scope. We recognise that, for some, spirituality is not based within a particular faith or religion but may be reflected in other ways. We will consider those needs as equally important in the care of the dying adult in this guideline. We have therefore now removed spirituality from the list of areas not covered and will discuss the impacts of this issue in each of our review areas. The guideline development group may choose to co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
228	SH	Macmillan	5	3.1	LCP should by now no longer be being used –July has passed-needs rewording	Thank you for your comment, we have amended this sentence accordingly.
240	SH	Macmillan	17	3.1 a	Is there any clarification as to why the predicted figure of people who die in hospital is expected to rise to 65%?	Thank you for your comment. These figures were provided by the 'Dying for Change' report (Leadbeater and Garbos, 2010). It is not NICE house

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						style to include references within scope documents.
257	SH	British Geriatrics Society	2	3.1 a	The uncertain and unpredictable outcome of severe acute illness in old age means that access to treatment in hospital must not be denied on the basis of age or conditions such as frailty or dementia. All sectors of care must aim to provide a better experience for dying people and their families, carers and friends.	Thank you for your comment, the contents of which are noted. This guideline is focussing particularly on care in the last days of life and will include care in settings listed in 4.2. We do not intend that our guideline will cover the care of people in whom active management is appropriate regardless of age or frailty.
185	SH	Rowcroft Hospice	3	3.1 a	Peoples' preferences also change over time, sometimes in relation to social circumstances (Dimblebycancercare.org 'Specified Place of Care' report by Dr Walker). For some they prefer to die in a hospital (acute or community) – is this an option? Some prefer to die in a hospice, but there may not be a bed available.	Thank you for your comment, the content of which has been noted. This guideline will focus on specific clinical issues and the care of people provided in the settings outlined in section 4.2. We are also aware that NICE intend to commission an update of 'Improving supportive and palliative care for adults with cancer'. It is anticipated that the remit of this guideline will be extended to all people at the end of life, no longer specific to cancer. Further details will be made available in due course on the NICE website. We are unable to confirm the focus of this work but would encourage stakeholders to submit comments at the public consultation stage to ensure that their views are heard in relation to choice of place of death. We will not be addressing issues related to choice of place of death.
162	NICE	Social Care	5	3.1 a	Might there be reference here to people dying in care homes, which whilst often preferable to dying in hospital does present its own problems.	Thank you for your comment, the content of which has been noted. This guideline will focus on specific clinical

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						issues and the care of people provided in the settings outlined in section 4.2, including care homes. We will not be addressing issues related to choice of place of death. We are also aware that NICE intend to commission an update of 'Improving supportive and palliative care for adults with cancer'. It is anticipated that the remit of this guideline will be extended to all people at the end of life no longer specific to cancer. Further details will be made available in due course on the NICE website. We are unable to confirm the focus of this work but would encourage stakeholders to submit comments at the public consultation stage to ensure that their views on choice of place of death are heard. The issue you raise, however, will not be covered within this guideline.
119	SH	College of Occupational Therapists	3	3.1 a	Cultural and spiritual beliefs need to be sensitively supported.	Thank you for your comment. Religion and beliefs, ethnicity and socioeconomic status are defined equality protected characteristics according to the Equality Act. This document is available on the NICE website. We have raised these needs as part of our equality impact assessment form and, as such, they will be discussed within each review. However, we recognise that for some spirituality is not based within a particular faith or religion but is equally important in the care of the dying adult and care should be provided that

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						reflects spiritual needs. We have therefore removed spirituality from the list of areas not covered and will discuss the impacts of important focus in each of our review areas. The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
29	SH	Faculty of Intensive Care Medicine	3	3.1 a	Annually, 28000 patients, who are admitted to Intensive Care, die on ICU [figures from ICNARC 2012/13]. Therefore, 5.6% of the annual deaths in England occur on Intensive Care. Therefore, we consider that the consultation should consider the deaths occurring in ICU as a separate group within the overall guideline. The Intensive Care Community would be prepared to participate in this process.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We will forward your comments for their consideration.
281	SH	Intensive Care Society	3	3.1 a	Annually, 28000 patients, who are admitted to Intensive Care, die on ICU [figures from ICNARC 2012/13]. Therefore, 5.6% of the annual deaths in England occur on Intensive Care. Therefore, we consider that the consultation should consider the deaths occurring in ICU as a separate group within the overall guideline. The Intensive Care Community would be prepared to participate in this process.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We will forward your comments for their consideration.
70	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	9	3.1 a	Free from pain should read free from **symptoms**.	Thank you for your comment, we have amended this sentence accordingly.
131	SH	Royal College of Physicians of Edinburgh	2	3.1 b	The LCP's fault was that there was misuse of the pathway and poor communication between the clinical team and the patient's family. Unfortunately, in some cases there was misuse, with patients being inappropriately put on the pathway. Out of hours cover was being provided by junior doctors unfamiliar with the patient, and in some cases perhaps undue pressure being exerted upon them by senior nurses. It is unfortunate that the adverse publicity about the LCP has resulted in some positive aspects being	Thank you for your comment, the content of which has been noted.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					lost.	

71	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	10	3.1 b	It seems counter productive to refer back to a model of care that has been discontinued. Maybe the comments should focus on the lessons learnt as contained in the More Care Less pathway report.
					- care for dying patients has been felt to be ?inadequate? due to
					  - Poor communication with patients and their families
					  - Lack of clarity for patients and their families about the use of medication
					  - Concerns about withdrawal of nutrition and hydration
					
					Would suggest that first **18 lines are removed** and this para just reads
					The challenge for the NHS is to provide a ~~framework~~ **culture** that ensures that care to people in the last days and hours of life is of high quality and based on individual needs.
						Thank you for your comment. We agree that the emphasis should be on the way forward, but there is a need to put the present position in context by referring to the Liverpool Care Pathway. We have amended this paragraph.

241	SH	Macmillan	18	3.1 b	"independent review panel on the use of the LCP has recommended that, where used in the UK, it should be phased out of practice by July 2014" needs to be written in the past tense and the Neuberger report was England only not the UK, there have been different responses and courses of action in the Celtic Nations.	Thank you for your comment, we have amended this sentence accordingly.
141	SH	Willowbrook Hospice	4	3.1 b	"the use of INTEGRATED CARE PATHWAYS FOR THE DYING PERSON" Add to sentence "There has been criticism, however, about how some elements of the LCP have been implemented, including issues of consent, use of painkillers and tranquilisers and communication about death and dying" Delete sentence "Some families.....tranquilisers" Insert "This criticism was examined in the "More Care, Less pathway" report which recognised the fundamental principles of care of the dying but that the use of the LCP... - Rationale – More Care, Less Pathway recognises some of the problems of the LCP use but also the core principles being ethically sound. It is important to recognise both aspects.	Thank you for your comment. We have amended this paragraph in the light of your and other stakeholders' comments.
72	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	11	3.1 c	Again, it seems counter-productive to refer to a report which was critical of care. It would be more appropriate to refer the the One Chance to get it Right document which details the new priorities for care of dying patients	Thank you for your comment. We agree that the emphasis should be on the way forward, but need to put the present position in context by referring to the Liverpool Care Pathway. The

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						paragraph has been amended.
242	SH	Macmillan	19	3.1 c	Would it be helpful to include one or two examples of the significant variations in care published in the audit?	Thank you for your comment. We do not believe this is necessary detail for the scope document.
229	SH	Macmillan	6	3.1 c	Audit indicated that *in some cases there is significant room fior improvement in care of the dying* ?worth a balancing statement that there are examples of excellent care	Thank you for your comment, we have amended this sentence accordingly.
290	SH	Catholic Bishops Conference of England and Wales	3	3.1 c, 3.2 e	LCP – If people are to have improved control over their own death and simple things like hydration are an issue, is there a way that families, carers or loved ones could be more involved in that human nurturing whether that be in hospital or at home. An empowered family is less likely to complain afterwards if they have been part of the 'care team' The Catholic Church contributed to the review of the LCP and nothing else needs to be added here.	Thank you for your comment. It will be passed on to the guideline development group to aid their discussion around this review area.
289	SH	Catholic Bishops Conference of England and Wales	2	3.1 Epidemiology	If such a large number wish to die at home, should there not be a target to improve this position rather than seemingly accepting that this is what will happen?	Thank you for your comment, the content of which has been noted. This guideline will focus on specific clinical issues and the care of people provided in the settings outlined in section 4.2. We will not be addressing issues related to choice of place of death.
186	SH	Rowcroft Hospice	4	3.1.b, 3.2.b	Can we add about the need to use the word 'dying' and support better communication about this with patients and families?	Thank you for your comment. We will share your comment with the guideline development group to consider as they develop the guideline.
5	SH	Office of the Parliamentary and Health Service Ombudsmen	2	3.2 – Current Practice (b)	Hydration – described as a 'burden' . …..are there 'burdens' to providing hydration in the last days of life? I don't think this is the correct terminology. It suggests that if we do provide hydration it is a burden (difficult to achieve) which it doesn't have to be and certainly is not something that the family of the person dying want to feel or hear. Whether hydration at this stage of a persons life is necessary/ has any impact on their quality of life is a different matter.	Thank you for your comment. This section has been re-phrased.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
277	SH	Helen and Douglas House Hospices	9	3.2 , 4.5a and general	Please talk about recognising when a person 'may be' or 'is likely to be' rather than 'is' entering the last hours or days of life. Uncertainty needs to be acknowledged throughout.	Thank you for your comment. We particularly recognise the importance of uncertainty in recognising patients in the last days to hours of life. We will continue to acknowledge the issue of uncertainty whilst we develop the guidance.
326	SH	Together for Short Lives	1	3.2 a	It is also challenging to anticipate when young adults are entering their end of life phase, particularly when they are living with a life-threatening or life-limiting condition and/or are cognitively impaired. Young people have a range of conditions with unpredictable trajectories, which may mean they have repeated 'end of life' episodes, any of which could be the final one. Palliative care services also have relatively little experience of caring for such individuals. The guideline should recognise these factors.	Thank you for your comment. As there is an 'End of life care for infants, children and young people' guideline in planning we anticipate that this issue could be covered in this guideline. However, we acknowledge the importance of considering the transition between children and adult services and will pass your comment to the guideline development group for their consideration.
13	SH	Leeds Teaching Hospitals	1	3.2 a	Making a prognosis of imminent death is not in line with the current guidance ' one chance to get it right', which suggest professionals should be communicating uncertainty 'the possibility that a person may die within the next few days or hours is recognised and communicated clearly ……	Thank you for your comment**.** We recognise the importance of uncertainty in recognising those in the last days and hours of life and anticipate that the guideline development group will discuss and make recommendations on how to manage this uncertainty.
258	SH	British Geriatrics Society	3	3.2 a	A palliative care approach can be delivered alongside interventions ensuring that patients, families and carers are treated with dignity and compassion.	Thank you for your comment, the content of which has been noted.
101	SH	Marie Curie Cancer care	6	3.2 a	As predicting time of death is extremely difficult, it is important that clinicians communicate not only the prognosis sensitively, but also the range of possible	Thank you for your comment. We agree and will pass it on to the

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					survival times and adverse events leading up to death.	guideline development group to aid their discussion around this review area.
308	SH	RCSLT	4	3.2 a	What norms are we using to compare across the dying process in different patient groups? How do we assess the "cognitive norm" for someone? This is a crucial question that SLTs need to be involved with early on in the disease process, so that as cognition changes, someone can say with some degree of accuracy what is indicating capacity and what is not. And this changes for each decision (i.e. not competence). Might need to ref Mental Capacity Act (2005) here – presume capacity unless proven otherwise. Clinicians need to be supporting active participation of the patient (and family) in healthcare decision making (and that includes decisions about dying). Whilst simultaneously minimising disease burden.	Thank you for your comment. In section 3.2.a, the difficulties in recognising dying in patient groups with chronic conditions compared to those with cancer is commented on. The scope does not make reference to 'cognitive norm'. This guideline will not comment on assessing 'cognitive norms'. The scope has been amended to include reference to the Mental Capacity Act.
187	SH	Rowcroft Hospice	5	3.2 a	Can we add in re role of CPN in helping to diagnose dying in those with dementia and need for 'shared care' model to support prognostication of those with non-cancer illnesses	Thank you for your comment, the content of which has been noted. It is anticipated that recommendations will aid all clinicians, including clinical psychiatric nurses, in recognising the dying adult in the last days to hours of life.
142	SH	Willowbrook Hospice	5	3.2 a	These groups (dementia, frailty) don't always have input from palliative care professionals at all. Providing guidance that supports clinicians to recognise dying [delete to make a prognosis of imminent death] and communicate this [delete prognosis] Rationale – the sentence in the draft has two issues intermingled – one of prognosis, i.e time and natural history and one of diagnosis – i.e. making the decision that someone is dying. It is important that these issues are separate and clear. There is also a move away from diagnosing dying to recognising	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. The scope text has been further amended following consultation.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					dying. "Diagnosing" implies a pathological process, recognising supports the assertion made in 3a that dying and death is a natural process. Some people die over a matter of seconds to minutes, others die over a period of days to weeks. "the ~~approach~~ NATURE of death AND DYING in cancer has HISTORICALLY been a relatively EASIER ~~path~~ NATURAL HISTORY THAN IN OTHER LIFE LIMITING ILLNESS.	
231	SH	Macmillan	8	3.2 a	Need to acknowledge that patients with non cancer life limiting illness especially heart failure and airways disease are very prone to fluctuations in their condition	Thank you for your comment. In section 3.2.a in the scope it is acknowledged that patients with COPD and heart failure 'from which temporary remissions occur anticipating dying may be more difficult'.
111	SH	Royal Devon and Exeter NHS Foundation Trust	4	3.2 a	The tone of the document suggests that end of life care is lead by specialist palliative care teams. It states that "Because of the long experience of palliative care in people with cancer, the approach of death in cancer is a relatively easier path to predict." and suggests that palliative care teams have less experience in recognizing end of life in other disease areas. This is likely to be true however it should be remembered that the majority of end of life care, even for cancer patients is not provided by specialist palliative care but by oncologists and general practitioners. Only a small percentage of patients with cancer or other medical conditions receive input from specialist palliative care clinicians. These non-specialist palliative care teams have a good understanding of the disease processes and are well placed to lead end of life care, their input should be integral to the review. The guidance when published should be directed to these non-specialist palliative care teams.	Thank you for your comment, the contents of which have been noted. We did not mean to infer that specialist palliative care teams lead end of life care exclusively. Our guidance will be of relevance to all who provide care to people in the last days of life.
264	SH	Renal Association	1	3.2 a	Kidney failure, or dialysis, should be mentioned as chronic disease. Although less common than heart failure and pulmonary disease, there is a high mortality for patients with CKD 5, particularly in elderly – and such patients have specific requirements at end of life, e.g., withdrawal of dialysis, or not starting dialysis.	Thank you for your comment. The guideline development group will decide specific subgroups for individual protocols for each review question. We will pass your comment to the guideline

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						development group for their consideration.
73	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	12	3.2 a	Language should be consistent across all guidelines for care of the dying patient therefor rather than 'entering the last hours and days of life' and 'making a prognosis of imminent death' should be rephrased **'when it is thoughts that a person is likely to be dying in the next hours or days'**. This should be communicated sensitively with patient and their family (those important to the patient) and any concerns addressed. Again I do not think it is helpful to separate cancer and and non cancer as the aims of care should be the same. All the 'relatively' comments are unhelpful as they relate to each other's uncertainties! Dying **can be** difficult to predict sometimes, but it is **not** difficult always. This does not always relate to cancer or non cancer illness. It maybe helpful just to state **'an understanding of the persons existing medical conditions and an assessment for reversible causes for the clinical deterioration in the presence of clinical deterioration will support the clinical recognition that a person is likely to be dying**.' It can be difficult to be **certain** that a person is dying and this difficulty and uncertainty should be acknowledged. However where a person is seriously ill and at risk of dying during that episode, the patient and the family should be informed that the person is 'ill enough to die'.	Thank you for your comment, we have amended this first sentence accordingly. We plan to consider the impact of uncertainty in recognition of dying as part of our review of evidence.
271	SH	Helen and Douglas House Hospices	3	3.2 a	First line: I would reframe as 'recognising when a person is *likely* to be entering the last hours or days of life…'.	Thank you for your comment, we have amended this accordingly.
179	SH	Cochrane Pain, Palliative and Supportive Care Review Group]	2	3.2 a	Consider amending second sentence to 'Providing guidance that supports clinicians to make an assessment that death is imminent and communicate the prognosis sensitively...'	Thank you for your comment, we have amended this accordingly.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
120	SH	College of Occupational Therapists	4	3.2 a	This patient group has a more variable range of patterns of deterioration than other groups. Some qualitative statement here, rather than only inferring the lack of exposure by Palliative Care services.	Thank you for your comment.
230	SH	Macmillan	7	3.2 a	'Make a prognosis' could be replaced with 'uses the information available from the team and their knowledge and experience to make an assessment that death is likely within days'	Thank you for your comment, we have amended this accordingly.
55	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	2	3.2 a and 4.1.1	It is acknowledged that the identification of people with heart failure, as well as other conditions, will be more difficult and should be given special consideration. The difficulties in identification, however, as explained above, can be effectively overcome by identifying people when they reach end stage heart failure. **The focus on the last few days of life, throughout this document, is only likely to exacerbate the status quo.**	Thank you for your comment on the timing of this guideline. We have noted that stakeholders are mixed in their response; however, we feel it is appropriate, given the clinical focus of our work, to restrict the time frame to the last days and hours of life in order to add most value to practice, as this is an area highlighted as particularly needing clinical guidance. When considering the evidence, the guideline development group will identify subgroups of people in whom they may wish to gather evidence. The previous text of groups that may require special consideration has been removed.
327	SH	Together for Short Lives	2	3.2 b	Some young adults will want their parents or guardians to be involved in decisions about withholding or withdrawing hydration. We ask that the Royal College of Paediatric and Child Health's document 'Witholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice' is used to inform the guideline.	Thank you for your comment. As there is an 'end of life' guideline for infants, children and young people in planning we believe that a reference to this document would be better placed in this guideline. However,we acknowledge the importance of considering the transition between children and adult services**.**
254	SH	British Pain Society	4	3.2 b	The BPS particularly supports clear guidance regarding the practice of providing artificial hydration to patients.	Thank you for your comment.
309	SH	RCSLT	5	3.2 b	Assisted hydration – basic care or medical intervention? Need to check what	Thank you for drawing this to our

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					UK courts consider this as. And acknowledgement that some cultural groups (e.g. Roman Catholic) might disagree.	attention. The ethnical and cultural issues related to areas of the guideline, such as sedation and hydration, have been highlighted in the Equalities Impact Assessment form. The guideline development group will be cognisant of these issues when considering the evidence and writing recommendations.
74	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	13	3.2 b	Again, rather than 'last days of life' it is clearer to state **'when a person is thought likely to be dying'.** This section fails to highlight the need for thorough assessment, individual plan, taking into account the wishes and preferences of the patient and conversations with patient and family. If the focus is on dying as a 'normal' rather than 'medical' process the first sentence should be on the ability to drink and then assessment of hydration status and any symptoms caused by its disturbance. Not all those who are mildly dehydrated are symptomatic, indeed symptoms may be better controlled in some if they are slightly dry. The first approach to management is supporting drinking, mouth care to reduce the symptom of thirst and then consideration of hydration support in line with the GMC guidance where this would be beneficial. …some studies show positive effects on specific symptoms **in some circumstances**. The decision to give, ~~withhold or withdraw~~ **or not give, clinically** assisted hydration…. **Basic care** relates to assisting eating and drinking The ethical and cultural issues are **complex** rather than ~~controversial~~. The application of evidence is controversial.	Thank you for your comments. Some changes to wording have been made to this section. Please note, medically assisted hydration is a medical treatment in UK law rather than a basic need. We have further clarified the text around the use of clinically assisted hydration. We recognise the basic care principles of mouth care and supporting drinking as being important but feel a review of the evidence around assisted hydration is specifically warranted.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
121	SH	College of Occupational Therapists	5	3.2 b	'Assisted hydration' needs clarification, as for some this is oral, others sub-cutaneous and some would consider IV hydration appropriate at this time	Thank you for your comment. We recognise that different routes are possible and the guideline development group will consider these issues when finalising the evidence protocols for this review.
232	SH	Macmillan	9	3.2 b	After 1st sentence statement that positive effects can be seen need a sentence stating that it is well recognised that injudicious hydration especially parenterally can cause tissue oedema and breakdown or fluid accumulation in the lungs with resulting suffering.	Thank you for your comment. The text in this section has been amended.
310	SH	RCSLT	6	3.2 b, d, e	Assisted hydration – impact on dysphagia and communication Pain control - impact on dysphagia and communication MDT decision making does not always include the SLT	Thank you for your comment, the content of which has been noted.
328	SH	Together for Short Lives	3	3.2 c	Some young adults with life-limiting conditions will have been treated with palliative medication over long periods of time. The pharmokinetics and pharmodynamics of these medications will make decisions about initiating treatment for terminal restlessness more challenging in young adults. We ask that advice is sought from specialists in children's palliative care to ensure that the clinical guideline addresses this issue.	Thank you for your comment. As there is an 'end of life care for infants, children and young people' guideline in planning we anticipate that this issue could be covered in this guideline. However, we acknowledge the importance of considering the transition between children and adult services and will pass your comment to the guideline development group for their consideration. .
246	SH	Royal College of Anaesthetists	2	3.2 c	We acknowledge that the guidelines recognise that the use of opioid drugs and palliative sedation is seen as controversial. Our clinical members believe that the confusion around this issue would benefit from open discussions between clinicians and patients (and their families), making it clear that, when opioids are administered in order to relieve pain and distress, the doses required often also reduce respiratory drive and ability to clear bronchial secretions. Clinicians are sometimes fearful that their actions might be misinterpreted as 'assisted dying' and this may make clinicians reluctant to prescribe adequate doses of opioids.	Thank you for your comment. We acknowledge that these are important considerations and anticipate that issues such as these will be discussed when drafting recommendations related to sedation.
102	SH	Marie Curie Cancer care	7	3.2 c	Despite there being concerns about injudicious use of these drugs, this document fails to call for clinical research that would give better guidance on	Thank you for your comment. The guideline development group can, if

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					the use, dosage, combinations and effects of these drugs when used in terminal care.	deemed necessary after the evidence is presented to them, make research recommendations related to this area. Such potential areas are not highlighted in the scope.
282	SH	Intensive Care Society	4	3.2 c	This is an integral component of good Intensive Care Medicine. Intensive Care clinicians have extensive experience of these drugs and others that are not available on a general ward (such as propofol, dexmetomidine, remifentanil amongst others)	Thank you for your comment, the content of which has been noted.
30	SH	Faculty of Intensive Care Medicine	4	3.2 c	This is an integral component of good Intensive Care Medicine. Intensive Care clinicians have extensive experience of these drugs and others that are not available on a general ward (such as propofol, dexmetomidine, remifentanil amongst others)	Thank you for your comment, the content of which has been noted.
122	SH	College of Occupational Therapists	6	3.2 c	Restlessness may also be in response to symptomatic issues such as retention or pain, therefore staff recognition and management of these problems should be stressed.	Thank you for your comment, the content of which has been noted and will be passed to the guideline development group for their consideration.
20	SH	Leeds Teaching Hospitals	8	3.2 c	We suggest that the definition of terminal restlessness is changed - terminal restlessness is not always a form of delirium - it could be agitation or delirium or a mixture of both.	Thank you for your comment we have amended this accordingly.
252	SH	British Pain Society	2	3.2 c	The proposed scope notes current concerns regarding 'injudicious use' of opioids and sedatives. The BPS considers that this is an area that needs to be explored with explicit clarification of the 'double effect' – prescribing and administering medications for symptom control in the knowledge that they are likely to have the other effect of bringing forward the time of death.	Thank you for your comment, the content of which has been noted .
208	SH	Association for Palliative Medicine	2	3.2 c	It should be made clear that current practice for managing terminal restlessness would include assessing for and treating any reversible causes before using sedative doses of medication	Thank you for your comment, we have amended this accordingly.
376	SH	The Royal College of Radiologists	2	3.2 c	The RCR suggests it is made clear that current practice for managing terminal restlessness would include assessing for, and treating, any reversible causes before using sedative doses of medication.	Thank you for your comment, we have amended this accordingly.
75	SH	SOUTHPORT AND ORMSKIRK	14	3.2 c	This section highlights on terminal restlessness and distress rather than discuss common symptoms. Terms such as 'tranquillisers' and 'sedation' do not reflect the intentions of care that is given and are some of the terms which	Thank you for your comment, We have amended the scope text. We will now be looking at nausea and vomiting and

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		HOSPITAL NHS TRUST			when misused or misunderstood led to the misconceptions surrounding the LCP. The intention should always be to relieve symptoms with the smallest doses of anxiolytics required titrated against symptoms. There is no widely agreed definition of terminal restlessness and therefore we do not think it should be included in these guidelines. It is not helpful to talk about injudicious use of drugs, but instead focus on appropriate use and safe titration of meditation according to need. The aim is to control symptoms for patients thought likely to be dying. The common symptoms are pain, breathlessness, nausea & vomiting, respiratory tract secretions, restlessness, agitation & delirium. Medications should be targeted at specific symptoms and titrated according to need. Their use should be explained to patients and families It is ~~sometimes~~ necessary to use ~~sedative~~ **appropriately effective** doses of medication such as ~~opioids~~ (NO – opioids should not be used for agitation unless the cause is uncontrolled pain/breathlessness), benzodiazepines and major tranquillisers to control such forms of distress…. **However in situations where this is necessary symptoms should be addressed by senior and experienced specialists who have been able to communicate with the patient (where conscious) and their family and all understand the rationale for use.**	respiratory secretions. The final approach to this review area will be greed with the guideline development group. .
112	SH	Royal Devon and Exeter NHS Foundation Trust	5	3.2 c	The way this is worded suggests that opioids are being used as sedative medications. Whilst this was raised in the media and family anxieties in the Neuberger review, this would not be recognised practice in my own Hospital Trust nor in wider clinical practice. This wording is therefore unhelpful. The role of medication for different symptoms should be separated out.	Thank you for your comment, we have amended the text in this section.
233	SH	Macmillan	10	3.2 c	Need to state that terminal restlessness is that where there is no identifiable reversible cause eg constipation/urinary retention/pain	Thank you for your comment. We have amended this accordingly.
188	SH	Rowcroft Hospice	6	3.2 c –d	Concerns about sedation and use of anticipatory drugs have been raised nationally but what, if any, evidence is there to support this is happening in practice?	Thank you for your question. The scope has reflected evidence from concerns raised by families captured by the 'More care, less pathway' report. After the protocols for each review area are finalised by the guideline

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						development group we will undertake a detailed literature search examining all applicable evidence and draft recommendations for the NHS in this area.
253	SH	British Pain Society	3	3.2 d	The BPS supports good communication practices so that patients' views on their own death are respected and adhered to when possible.	Thank you for your comment.
14	SH	Leeds Teaching Hospitals	2	3.2 d	What is the evidence behind reports behind family members perceptions of the use of drugs? Does this need to be referenced?.	Thank you for your question. The scope has reflected evidence from concerns raised by families captured by the 'More care, less pathway' report. After the protocols for each review area are finalised by the guideline development group we will undertake a detailed literature search examining all applicable evidence. NICE scopes do not include references.
76	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	15	3.2 d	The clinical condition of patients who are dying can change quickly and symptoms can develop at any time. Anticipatory prescribing ensures that medication targeted at specific symptoms can be given in a timely manner. In the community, particularly, waiting until symptoms arise before prescribing can result in the family driving an entire city for hours hunting for a community pharmacy which has the drugs required, the patient suffering symptoms unnecessarily, and in the worst case scenario, the relative being away from the bedside when the patient dies. There should not be need for criticism of storage and disposal of medication in the community if good policies and procedures are in place and followed. This section appears critical of this practice of anticipatory prescribing. Whilst it is important that medication are only given according to need, and the doses titrated according to need, it would be harmful to patients if anticipatory prescribing was discouraged leading to delays in care.	Thank you for your comment. The narrative you refer to intended to capture the background perspective to anticipatory prescribing. Whilst we acknowledge that the concept of anticipatory prescribing is sound and it is probably practised well with good outcomes, we will undertake a literature review to identify any basis for the concerns voiced by some.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					'Furthermore there have been reports that family members perceive these drugs, if start too early, or without good justification and communication, to hasten death.' This cannot happen if the drugs are prescribed to be given 'as required' according to symptoms, just enough to relieve the symptoms, where district and ward nurses are thoroughly trained and audited, where staff are used to documenting clearly their rationale for their actions and have undertaken good communication skills training and put this into practice.	
143	SH	Willowbrook Hospice	6	3.2 d	To alleviate distressing symptoms of pain …and other common symptoms e.g. nausea and vomiting, breathlessness	Thank you for your comment. We have now added vomiting, nausea and respiratory secretions to the scope.
132	SH	Royal College of Physicians of Edinburgh	3	3.2 d and 3.2 e	Communication between the clinical team and the patient and the family is the key. No family member wants their loved one to suffer, and the explanation of what is happening should be carried out by either the middle grade or senior member of the team. This should not be left to junior medical staff. But junior medical staff should be there to learn how to approach and communicate with a family about death.	Thank you for your comment. Your comments will be passed on the guideline development group to aid their discussion around this topic.
10	SH	Action on Hearing Loss	4	3.2 e	We welcome the recognition of the necessity of good communication to ensure that people are involved in the decision-making process about the care that they or their loved ones receive. To communicate well, people with hearing loss may require working hearing aids, equipment (such as a personal listener), or communication support (such as an interpreter). Staff can take simple steps to ensure that people with hearing loss are able to communicate, which are outlined above.	Thank you for your comment. A number of groups have been identified as requiring special consideration in relation to the Equalities Act, including sensory disabilities and, as such, where evidence is available in our specific review areas, specific recommendations for these groups may be made if the guideline development group consider it necessary.
77	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	16	3.2 e	It is very critical to focus on the negatives contained within More Care Less Pathway. It is also true to say that there are some excellent out of hours clinicians who have excellent handover from GP/DN and liaise well with specialist palliative care services If the key message is to avoid out-of-hours decision making by on call teams the focus on the statement would be more supportive if it encouraged the	Thank you for your comments, the content of which have been noted. We have corrected multi-disciplinary to multi-professional throughout the scope document.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					anticipation of change by the patient's own team. Again multi-disciplinary should read multi professional	
103	SH	Marie Curie Cancer care	8	3.2 e	Although this guidance does exclude service delivery, such as out of hours provision and how services should be structured, it is worth highlighting that the Neuberger review specifically indicated that there should be out of hours provision of palliative care and that as part of the service, there should be access to advice from a clinician responsible for palliative care.	Thank you for your comment. We are also aware that NICE intend to commission an update of 'Improving supportive and palliative care for adults with cancer'. It is anticipated that the remit of this guideline will be extended to all people at the end of life no longer specific to cancer. Further details will be made available in due course on the NICE website. We are unable to confirm the focus of this work but would encourage stakeholders to submit comments at the public consultation stage to ensure that their views are heard on the availability of out of hours care. The issue you raise will not be covered within this guideline.
15	SH	Leeds Teaching Hospitals	3	3.2 e	Are decisions about dying patients 'frequently' being made - or rather occasionally?	Thank you for your comment.
234	SH	Macmillan	11	4. 3. 2	When artificial nutrition is given at the end of life loss of digestive function can result in discomfort gastric stasis and vomiting –although it is not considered a priority for this guideline –I feel this needs at least to be acknowledged	Thank you for your comment. The rationale section of 4.3.2 was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template. Artificial nutrition will not be covered in this guideline.
39	SH	Faculty of Intensive Care Medicine	4	4.1 & 4.2	The scope and setting are appropriate.	Thank you for your comment.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
3	SH	Association of British Clinical Diabetologists,	1	4.1.1	Under the heading of 'groups that will be covered', the Association of British Clinical Diabetologists feels that people with diabetes should be included. There is an issue over whether diabetes medications, including insulin, should be continued or ommitted during the dying process. The question of whether finger prick blood sugar readings should continue is also a common problem. The concern is that, managed poorly, a diagnosis of diabetes could contribute to an uncomfortable death. Mention is made, under exclusions, of the fact that the issue of measurements will not be included in the consultation, but this is a bigger issue than the simple measurements. Although ABCD has produced guidance on this issue, it is true to say that there is no universally adopted guideline. It would be very useful to take the opportuniy of this consultation to address this issue and agree some uniformity of practice.	Thank you for your comment. People with diabetes are covered within the guideline. The section on subgroups has now been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question and we will pass your comment to the guideline development group for their consideration.
16	SH	Leeds Teaching Hospitals	4	4.1.1	Groups that will be covered - should this also include families of the adults who are dying in the first section?	Thank you for your comment. The focus of the guideline is on the person who is dying, but the guideline will take into consideration the impact of care on those important to them as well as carers and healthcare professionals, as is done in all other NICE guidance.
50	SH	Mid Cheshire Hospital NHS Trust	2	4.1.1	Although people with communication, cognitive or learning difficulties are not included separately because they do not have the same poor prognosis I do think that this group of patients may have specific needs when they are dying and can suffer from inequalities in access to existing support and services so specific consideration to their needs should be considered.	Thank you for your comment. We agree that there are inequalities in the care of these groups of people. They are, therefore, specifically referred to in our 'guideline equality impact assessment' document. A number of groups have been identified as requiring special consideration in relation to the Equalities Act and, as such, where evidence is available in our specific review areas, specific recommendations for these groups may be made if the guideline development group consider it necessary.
123	SH	College of Occupational	7	4.1.1	There are significant health inequalities for people with learning difficulties related to timely diagnosis and appropriate symptom management. Irene	Thank you for your comment. We agree that there are inequalities in the

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Therapists			Tuffry-Wijne chairs the European Association of Palliative Care Task force on 'Palliative Care for People with Intellectual disabilities. They have an interim report available on their website- http://www.eapcnet.eu/Themes/Specificgroups/Peoplewithintellectualdisabilities.aspx PCPLD Network is 'Palliative Care for People with Learning Difficulties', a UK based charity. They are signposting a report by Dr Pauline Hislop, manager of 'The Confidential Enquiry into the Premature Deaths Premature Deaths of People with Learning Difficulties'. http://www.bris.ac.uk/cipold/fullfinalreport.pdf and the government's response: https://www.gov.uk/government/publications/response-to-the-confidential-inquiry-into-learning-disability This would be an ideal opportunity to reflect and balance these experiences.	care of these groups of people. They are, therefore, specifically referred to in our 'guideline equality impact assessment' document. A number of groups have been identified as requiring special consideration in relation to the Equalities Act and, as such, where evidence is available in our specific review areas, specific recommendations for these groups may be made if the guideline development group consider it necessary.
314	SH	RCSLT	10	4.1.1	Inequalities may also relate to dysphagia or communication and ability to access/state preferences etc.	Thank you for your comment. Our obligations in relation to inequalities are defined by the characteristics outlined in the Equality Act. A number of groups have been identified as requiring special consideration in relation to the Equalities Act, and, as such, where evidence is available in our specific review areas, specific recommendations for these groups may be made if the guideline development group consider it necessary.
133	SH	Royal College of Physicians of Edinburgh	4	4.1.1	Relatives of patients dying of cancer were more satisfied with the care that they received. The College notes that it is very rare for patients with dementia to have hospice care and that it is often the complications of a patient's dementia which leads to death. These complications lead to increasing frailty and estimating likely time of death accurately can be extremely challenging. Registrars in Geriatric Medicine are encouraged to undertake a palliative care course. This helps them manage frail older people with multiple medical problems as they approach their terminal phase of life. However, not all frail older people are looked after by Geriatricians and there is a need to develop clinicians who have a specialist interest in palliative care for the older patient.	Thank you for your comment, the contents of which are noted. We will forward your comment on to the guideline development group for discussion.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					This type of clinician could work across primary and secondary care and minimise admissions to hospital for frail elderly patients in their terminal phase of life.	
31	SH	Faculty of Intensive Care Medicine	5	4.1.1	We would advocate special group to be considered: Patients requiring Level 2 or Level 3 care (as defined in DH document 'Comprehensive Critical Care' 2000, DH http://tinyurl.com/nzbdsmd	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We will forward your comments for their consideration.
49	SH	Mid Cheshire Hospital NHS Trust	1	4.1.1	*Special consideration will be given to people with: dementia, cancer and organ system failure (including heart failure)* When discussing inequalities it seems wrong to then specifically talk about heart failure when of course other end stage disease is equally as burdensome – for example End Stage Respiratory Diseases such as COPD or Pulmonary Fibrosis, End Stage Renal Failure and End Stage Liver Disease.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We will forward your comment for their consideration.
78	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	17	4.1.1	Special considerations Mike Richards referred to 'inequalities' in care of the dying. We are concerned that separating disease groups at this level may further exacerbate those inequalities. The 5 priorities contained within 'One Chance to Get it Right' are applicable across all groups (dementia, cancer and organ system failure) and the emphasis on individualised assessments and plans encourages the clinician to focus on the patient not the disease.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question.
189	SH	Rowcroft Hospice	7	4.1.1	We know many patients have more than one co-morbidity; therefore this will present a challenge in delineating a special consideration for 3 different diseases groups. Some patients may have all 3 illnesses. Many in future will have dementia as one of their illnesses.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question.
272	SH	Helen and Douglas House Hospices	4	4.1.1	Would you consider including 'overall frailty' as a 4th group for 'special consideration'? There are significant challenges in prognostication and hence planning and prioritising care, and the lack of a specific diagnosis may reduce both attention to the issues, and resources for care.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					Where might neurological and neuromuscular conditions feature in the guidance? (Another big group but won't obviously come within 'organ system failure').	individual protocols for each review question.
283	SH	Intensive Care Society	5	4.1.1	We would advocate special group to be considered: Patients requiring Level 2 or Level 3 care (as defined in DH document 'Comprehensive Critical Care' 2000, DH http://tinyurl.com/nzbdsmd	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question.
295	SH	Norfolk and Suffolk Palliative Care Academy	1	4.1.1	"Special consideration should be given to people with….." If this approach is adopted we will continue with the silo working that currently existing. All people die – a collaborative workforce working solely in the interest of patients – whatever their condition/conditions is the only way to change the culture of specialism within end of life/palliative care. It simply does not make sense to identify certain conditions when ALL patients will have multiple co morbidities.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question.
313	SH	RCSLT	9	4.1.1	I note that MND is not mentioned in this section. This is an important group of individuals who despite their physical deterioration generally retain cognitive function and dying may be difficult to diagnose.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question.
329	SH	Together for Short Lives	4	4.1.1	Although we recognise that adults with dementia, cancer and organ system failure represent a significant proportion of adults who need end of life care, we ask that the guideline also considers individuals with rare, life-threatening or life-limiting conditions. We also ask that people with life-threatening or life-limiting conditions (or combination of conditions) which may not have been diagnosed are considered. Both of these groups will include young adults who will have lived with life-limiting conditions as children and young people - and in some instances from birth. They will have undergone transition from children's to adult's palliative care services. This group of young adults in growing in number due to improved medical treatments, information and support (Fraser LFK et al 2013, Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010). Adulthood is often the time when young people with life-	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. The focus of this guideline is on the clinical care of the dying adult in the last few days of life. We are aware that there is an 'end of life care for infants, children and young people' guideline currently in planning that will address the specific needs for this group. More

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					limiting conditions (for example, Duchenne Muscular Dystrophy) experience a deterioration in their condition. This means that they are more likely to need end of life care once they have started to use adult services. The needs of young adults at the end of their lives are different from older adults - and also from children. The clinical guideline should emphasise the need for age-appropriate end of life care to be provided to this unique group, in age-appropriate settings.	information can be found on the NICE website. We recognise the issue around transition to adult services and will forward your comments for their consideration across the issues prioritised.
337	SH	Help the Hospices	3	4.1.1	Does this need to be either "dementia and/or increasing frailty" or should increasing frailty be another key group? The pattern of prognostication and progression is similar enough to dementia to sit together.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We recognise the issues you raise and will forward them to the guideline development group for their consideration when prioritising subgroups.
338	SH	Help the Hospices	4	4.1.1	It is not clear to us what is behind the term 'organ system failure (including heart disease)' as you do not state which organ/disease related failure you are including. However, the final days of people dying from respiratory failure, heart failure, liver failure etc. are all symptomatically and holistically often quite similar and probably could be grouped as long as the guideline specifies what is included.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We recognise the issues you raise and will forward them to the guideline development group for their consideration when prioritising subgroups.
339	SH	Help the Hospices	5	4.1.1	Under the special consideration listing you could include sepsis as a discrete entity, although it may be associated with organ system failure. The incidence of sepsis is increasing in all areas of the world where epidemiology studies have been conducted. Despite falling proportional fatality rates with sepsis, the total number of people dying with sepsis each year continues to increase due to the growing number of cases each year.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We recognise the issues you raise and will forward them to the guideline development group for their

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						consideration when prioritising subgroups.
340	SH	Help the Hospices	6	4.1.1	We would recommend that neurological conditions are included. The final days of somebody with neurological illness may be different from dementia, cancer and other organ failures – there may be more difficult decisions for instance to stop ventilation, hydration and nutrition so they might need extra special consideration.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We recognise the issues you raise and will forward them to the guideline development group for their consideration when prioritising subgroups.
259	SH	British Geriatrics Society	4	4.1.1	The British Geriatrics Society would welcome the inclusion of Dementia but would recommend that frailty is given special consideration. The two conditions are discrete but often co-exist. (See BGS Fit for Frailty Guidance at	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We recognise the issues you raise and will forward them to the guideline development group for their consideration when prioritising subgroups.
386	SH	Motor Neurone Disease Association	2	4.1.1	We do not believe that the proposed areas for special consideration will be sufficient to produce a guideline that meets the full range of needs presented by people who are dying. We strongly recommend that neurological conditions are also given special consideration. People who are dying from neurological conditions such as motor neurone disease, Parkinson's disease and complications arising from multiple sclerosis, often have the most physically demanding needs of any dying people: they may have drastically impaired movement and mobility, they may be unable to communicate and they may have developed respiratory insufficiency (and go on to die of respiratory failure). These considerations have profound and obvious implications for the care that such people need at the end of life. The challenge these needs pose is so substantial that some specialist palliative care units have been reluctant to admit people with MND,	Thank you for your comment, the contents of which have been noted. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We recognise the issues you raise and will forward them to the guideline development group for their consideration when prioritising subgroups.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					for instance, or to take more than one person with MND at a time. Despite improvements in recent years, access to specialist palliative care services by people with neurological condtions remains very low. The current proposed areas of special interest will not capture people with this level of need, which will result in an incomplete guideline of limited use. Neurological conditions must be considered in the guideline to the same extent as dementia, cancer and organ system failure. This recommendation is supported by the MS Society, Parkinson's UK and the Neurological Alliance. (Contacts: Andrew Boaden, Senior Policy and Campaigns Officer, MS Society Andrew.Boaden@mssociety.org.uk / 020 8438 0998; Laura Cockram, Policy and Campaigns Manager, Parkinson's UK lcockram@parkinsons.org.uk / 020 7963 3915; Alex Massey, Senior Policy and Campaigns Advisor alex.massey@neural.org.uk / 020 7584 6457)	
25	SH	Teva UK	1	4.1.1	What warrants few days'? Should this be clarified?	Thank you for your comment. The Guideline development group will define this as part of the development process.
336	SH	Help the Hospices	2	4.1.1	It makes it clear in the first box that this guideline refers to people who are expected to die in the next few days – however the title only mentions the Care of the Dying Adult. As the NHS definition of dying is the last 12 months of life, the guideline has to be very specific that it is about the final days.	Thank you for your comment. The guideline development group will provide definitions for terms used throughout the guideline.
209	SH	Association for Palliative Medicine	3	4.1.1 and 4.3.1 (e)	Agree need to consider dementia, cancer and 'non-malignant diagnoses' as challenge is the uncertainty around the latter disease trajectories. The term 'organ system failure ' is unhelpful as applies to any dying patient whatever the underlying chronic condition.	Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We recognise the issues you raise and will forward them to the guideline development group for their consideration when prioritising subgroups.
377	SH	The Royal	3	4.1.1	The RCR agrees that there is a need to consider dementia, cancer and 'non-	Thank you for your comment.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		College of Radiologists		and 4.3.1 (e)	malignant diagnoses'. However, it feels that the term 'organ system failure 'is possibly not helpful as this applies to any dying patient whatever the underlying chronic condition.	Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. We recognise the issues you raise and will forward them to the guideline development group for their consideration when prioritising subgroups.
210	SH	Association for Palliative Medicine	4	4.1.1 and 4.3.1(a)	The needs of those with learning difficulties at end of life should be specifically included and this might be most appropriate within the communication section (4.3 (b))	Thank you for your comment. We agree that there are inequalities in the care of these groups of people. They are, therefore, specifically referred to in our 'guideline equality impact assessment' document. A number of groups have been identified as requiring special consideration in relation to the Equalities Act and, as such, where evidence is available in our specific review areas, specific recommendations for these groups may be made if the guideline development group consider it necessary.
378	SH	The Royal College of Radiologists	4	4.1.1 and 4.3.1(a)	The RCR suggests that the needs of those with learning difficulties at end-of-life should be specifically included. This could be added to the section on 'shared decision-making and communication' (4.3 (b)).	Thank you for your comment. We agree that there are inequalities in the care of these groups of people. They are, therefore, specifically referred to in our 'guideline equality impact assessment' document. A number of groups have been identified as requiring special consideration in relation to the Equalities Act and, as such, where evidence is available in our specific review areas, specific recommendations for these groups

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						may be made if the guideline development group consider it necessary. The rationale section of 4.3.1 was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template
341	SH	Help the Hospices	7	4.1.2	**We agree with the groups that will not be covered. However, there should be an acknowledgement that care of older adolescents and young adults may need input from both adult and paediatric services and therefore these guidelines may be relevant to some under 18s.**	Thank you for your comment. As there is an 'end of life care for infants, children and young people' guideline in planning we anticipate that this issue could be covered in this guideline. However, we acknowledge the importance of considering the transition between children and adult services and will pass your comment to the guideline development group for their consideration.
387	SH	Motor Neurone Disease Association	3	4.1.2	We recognise the rationale for addressing the needs of children and young people at end of life in separate guidance. However, there may be a lack of clarity about whether the needs of young people who are carers or relatives of the person who is dying are to be covered in the current item of guidance, or the young people's item. This should be made clear, and the issue not allowed to fall into a gap between different pieces of guidance.	Thank you for your comment. The focus of the guideline is on the person who is dying, but the guideline will take into consideration the impact of care on those important to them (including family members, regardless of age), carers and healthcare professionals, as is done in all other NICE guidance.
79	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	18	4.2	NHS funded care is not the only care available for the dying – all care in all settings needs to be excellent	Thank you for your comment. While it is acknowledged that NICE guidelines may be useful for professionals working outside NHS care (such as for those working in social care), NICE's clinical guidelines are developed for the NHS and NHS commissioned services. As such, the guideline will

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						only include settings in which NHS funded care is received.
6	SH	Office of the Parliamentary and Health Service Ombudsmen	3	4.2	? Change order of setting. I am aware that this is not a 'priority' list but if most people would choose to die in their own home this should be reflected in this list. Placing 'home' at the top of the list makes it seem like the first choice and as it is for most individuals then I feel consideration should be given to the order in this list. It may also act to shift professionals views to making care of the dying at home a priority if this is their choice.	Thank you for your comment. The listing was not meant to reflect an order of importance in terms of either choices or actual frequency of place of death. We have re-ordered the list alphabetically to avoid inference of priority.
201	SH	NHS England	2	4.2	Setting (a) 'hospitals' – could this include community hospitals explicitly?	Thank you for your comment. We believe that the use of the word hospital is inclusive of community hospitals.
211	SH	Association for Palliative Medicine	5	4.2	"Places of detention" is more inclusive than "Prisons"	Thank you for your comment, we have amended this accordingly.
190	SH	Rowcroft Hospice	8	4.2.1	Add mental health and learning disability institutions?	Thank you for your comment. We believe that the existing settings are inclusive of these locations.
276	SH	Helen and Douglas House Hospices	8	4.3	Overall I think the choice of questions and broad scope are appropriate, with the caveats above.	Thank you for your comment.
346	SH	Royal Brompton NHS Foundation Trust	2	4.3	The scope recognises that we need to work more with the 'uncertainty of recognising dying' and this is important and hence the time-frame for hours-days should be extended so that guidance is applied where there is still uncertainty.	Thank you for your comment on the timing of this guideline. We have noted that stakeholders are mixed in their response; however, we feel it is appropriate, given the clinical focus of our work, to restrict the time frame to the last days and hours of life in order to add most value to practice, as this is an area highlighted as particularly

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						needing clinical guidance. We recognise the importance of uncertainty in recognising those in the last days and hours of life and anticipate that the guideline development group will discuss and make recommendations on how to manage this uncertainty.
356	SH	Royal Marsden NHS Foundation Trust	2	4.3	The scope recognises that we need to work more with the 'uncertainty of recognising dying' and this is important and hence the time-frame for hours-days should be extended so that guidance is applied where there is still uncertainty.	Thank you for your comment on the timing of this guideline. We have noted that stakeholders are mixed in their response; however, we feel it is appropriate, given the clinical focus of our work, to restrict the time frame to the last days and hours of life in order to add most value to practice, as this is an area highlighted as particularly needing clinical guidance. We recognise the importance of uncertainty in recognising those in the last days and hours of life, and anticipate that the guideline development group will discuss and make recommendations on how to manage this uncertainty.
260	SH	British Geriatrics Society	5	4.3 1 a-e	The British Geriatrics Society agrees with the key clinical issues identified in the draft scope.	Thank you for your comment.
124	SH	College of Occupational Therapists	8	4.3 b	The team make up is not clear from this description. The place of occupational therapists in this is essential for facilitating and supporting patients' Preferred Place of Death (PPD). **Route to success in end of life care – achieving quality for occupational therapy** * provides a detailed discussion of occupational therapy core skills, and how they can be implemented in the context of end of life care is given in Appendix 1.	Thank you for your comment. As this guideline focusses on the clinical care in the last days/hours of life, we do not feel that further detail along the lines you suggest is required. We believe that the composition of the multi-disciplinary team may fall into the remit

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						of service provision, which is not covered in this guideline. Further detail on this proposed guidance will be made available in due course.
125	SH	College of Occupational Therapists	9	4.3 d	This statement of intent is not entirely clear as The More Care, Less Pathway and Mid-Staffordshire Report both identified the withdrawal of oral fluids by staff who had not fully considered the implications or needs of patients.	Thank you for your comment, the content of which has been noted
146	SH	Willowbrook Hospice	9	4.3 e	Guidance is needed …without causing undue sedation. This is not always possible; some level of sedation is inevitable. This should be more about using minimal doses for doses control with appropriate titration.	Thank you for your comment. We recognise the challenges of managing symptoms and the importance of using minimal doses for control. This comment will be forwarded to and discussed with the guideline development group.
44	SH	Faculty of Intensive Care Medicine	9	4.3.1	The consideration of clinically assisted hydration should include the mode of hydration (oral, subcutaneous, rectal, intravenous) as the different approaches have different implications in terms of the expertise that needs to be available (e.g. intravenous cannulation) to achieve hydration.	Thank you for your comment. The details of the review strategy for assisted hydration are not yet finalised (they will be agreed with the guideline development group). Mode of hydration may be covered as a sub-analysis of this topic.
51	SH	Mid Cheshire Hospital NHS Trust	3	4.3.1	**Section d)** Clinically Assisted Hydration. • Whilst welcoming the need to have more evidence about the use and effectiveness of assisted hydration at the end of life, it is essential that there is no 'blanket recommendation' about their use. • The need for assisted hydration needs to be always made on an individual patient basis and based on clinical need. For example, A patient who is suffering from pulmonary oedema and struggling with respiration is not likely to benefit from further fluid burden at this time. A patient who is severely peripherally oedematous with limited (if any) peripheral access is not likely to gain any benefit from further fluids. A patient who appears very dehydrated and symptomatic from this may benefit from fluids and this should be considered. Each patient is individual. • Patient and family involvement in decision making supported by	Thank you for your comment. NICE recommendations are made to apply to the 'majority' of people with a particular decision. It is 'guidance' and clinicians can make individual decisions based on the particular circumstances of the person in front of them that may differ.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					excellent communication is essential for each case. Patients should be encouraged and assisted with oral intake for as long as it is possible of both food and fluids	
41	SH	Faculty of Intensive Care Medicine	6	4.3.1	The highlighting that uncertainty in "recognising dying" is common is welcome. Recommendations about the communication of such uncertainty should be considered.	Thank you for your comment, the contents of which are noted. It is anticipated that the guideline will address this issue.
330	SH	Together for Short Lives	5	4.3.1	We call for the guideline to emphasise the need for clear communication between children's and adults services at the time of a young person's transition to adulthood.	Thank you for your comment. As there is an 'end of life care for infants, children and young people' guideline in development we anticipate that this issue could be covered in this guideline. However, we acknowledge the importance of considering the transition between children and adult services and will raise your comment with the guideline development group for discussion.
32	SH	Faculty of Intensive Care Medicine	6	4.3.1	We support the aims of this section, but consider that there are aspects to dying in the Intensive Care Unit that have not been considered – i.e. the issues around withholding or withdrawing organ support on Intensive Care	Thank you for your comment, the contents of which have been noted. It will be beyond the scope of this guideline to make recommendations about withdrawing or withholding elements of care outside of the proposed review areas. We recognise the particular challenges in intensive care medicine around care of the dying adult. However, we feel that a review of evidence of withdrawing or withholding treatment would not add value to clinicians' practice which should be tailored to each individual cared for.
33	SH	Faculty of Intensive Care Medicine	7	4.3.1	We are of the opinion that the guidance should address whether cardiopulmonary resuscitation should be delivered to patients who are actively dying, and if so identify why? If a patient is successfully resuscitated after cardiopulmonary arrest, then they would require multi-organ support on ICU. If	Thank you for your comments, the contents of which have been noted. We recognise that CPR and DNAR decisions are an important area in care

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					they have been identified as dying, then all that has been achieved by resuscitating them is that their dying process has been prolonged. In our opinion the need/requirement for resuscitation needs clear guidance, particularly in light of Tracey, R (on the application of) v Cambridge University Hospitals NHS Foundation Trust	of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas are more likely to have a wider impact on clinical practice. CPR decisions will not be included in this guideline.
266	SH	Renal Association	3	4.3.1	• Consideration should be given to an additional section on withdrawal of treatment – includes medications, e.g. antibiotics as well as life supporting treatment such as dialysis. Questions would include about whether withdrawing treatment at end of life hastens death, how to communicate decision making with family, etc	Thank you for your comment, the contents of which have been noted. It will be beyond the scope of this guideline to make recommendations about withdrawing or withholding elements of care outside of the proposed review areas. However, we feel that a review of evidence of general withdrawing or withholding treatment would not add value to clinicians' practice which should be tailored to each individual cared for.
284	SH	Intensive Care Society	6	4.3.1	We support the aims of this section, but consider that there are aspects to dying in the Intensive Care Unit that have not been considered – i.e. the issues around withholding or withdrawing organ support on Intensive Care	Thank you for your comment, the contents of which have been noted. It will be beyond the scope of this guideline to make recommendations about withdrawing or withholding elements of care outside of the proposed review areas. We recognise the particular challenges in intensive care medicine around care of the dying adult. However, we feel that a review of evidence of withdrawing or withholding treatment would not add value to clinicians' practice which should be tailored to each individual cared for.
285	SH	Intensive Care Society	7	4.3.1	We are of the opinion that the guidance should address whether cardiopulmonary resuscitation should be delivered to patients who are actively dying, and if so identify why? If a patient is successfully resuscitated after	Thank you for your comments, the contents of which have been noted. We recognise that CPR and DNAR

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					cardiopulmonary arrest, then they would require multi-organ support on ICU. If they have been identified as dying, then all that has been achieved by resuscitating them is that their dying process has been prolonged. In our opinion the need/requirement for resuscitation needs clear guidance, particularly in light of Tracey, R (on the application of) v Cambridge University Hospitals NHS Foundation Trust	decisions are an important area in care of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas are more likely to have a wider impact on clinical practice. CPR decisions will not be included in this guideline.
343	SH	Help the Hospices	9	4.3.1	**However it may be difficult to draw up guidance that is any more concrete due to a lack of evidence and individual variation. It is likely to come down to: assess, communicate, review. Rather than focussing purely on hydration, does withdrawal of other treatment need to be a topic, especially in the light of the high court ruling on CPR?**	Thank you for your comment, the contents of which have been noted. The guideline development group will finalise protocols for the review areas listed, and a systematic review of literature will be undertaken. Please note, it will be beyond the scope of this guideline to make recommendations about withdrawing or withholding other elements of care outside of the proposed review around clinically assisted hydration in dying adults in the last days of life. It has been highlighted that there is a wide variety of practice in the use of clinically assisted hydration, and so required clarification, and was prioritised for this reason. We recognise that CPR and DNAR decisions are an important area in care of the dying adult. However, given time and resource constraints, this topic was not prioritised for this guideline as other review areas are more likely to have a wider impact on clinical practice. CPR decisions will not be included in this guideline.
43	SH	Faculty of Intensive Care	8	4.3.1	Anticipatory prescribing merits review.	Thank you for your comment.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Medicine				
212	SH	Association for Palliative Medicine	6	4.3.1	Agree with all headings within key clinical issues	Thank you for your comment.
342	SH	Help the Hospices	8	4.3.1	We agree that the 5 clinical issues you have scoped for the guidelines are the key issues – e.g. recognising dying, decision making and communication, correct anticipatory prescribing, the issue of hydration and the role of key drugs for the most common symptoms.	Thank you for your comment.
379	SH	The Royal College of Radiologists	5	4.3.1	The RCR agrees with all the headings within 'key clinical issues that will be covered'.	Thank you for your comment.
42	SH	Faculty of Intensive Care Medicine	7	4.3.1	Recommendations about the seniority of clinical decision makers "recognising dying" should be considered and would be consistent with the recommendation 14 of "More care, less pathway".	Thank you for your comment. We will highlight this comment to the guideline development group prior to discussing the review on recognising dying.
40	SH	Faculty of Intensive Care Medicine	5	4.3.1	The scope of the question "Signs and symptoms: recognising dying" should be broadened as it is unlikely that signs and symptoms along will sensitively or specifically identify dying patients (until very close to the time of death) – the clinical context (case note review +/- prognostic scores) is critically important.	The time frame for the scope has been finalised to the last day or hours of life. We are not aware of any validated prognostic tools for use within this time frame; however, we do recognise the value of prognostic tools outside of this period. Because of this, the appropriate review to conduct within this time frame is of the signs and symptoms, as proposed.
391	SH	Motor Neurone Disease Association	7	4.3.1	In addition to management of respiratory symptoms, the guidance should address secretion management, including cough assist, suction and physiotherapy. Secretions can cause significant distress for people whose ability to swallow is impaired, and this can be particularly difficult at the end of life – it is highly unusual for a person with MND to die as a result of choking, but the sensation of choking can be deeply unpleasant..	Thank you for your comment. The management of symptoms will be addressed by a review of pharmacological therapies. We will not be addressing secretion management. However, we will forward your comments to the guideline development group for consideration as part of this evidence review.
11	SH	Faculty of	1	4.3.1	A key criticism of the LCP (perhaps unfairly) was how clinicians recognise	Thank you for your comment. We will

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Pain Medicine, Royal College of Anaesthetists			when someone is in the last days of life. This is inherently a difficult challenge but one that requires greater clarity. One approach is to lower the 'risk' associated with this decision. In other words, staff may currently feel that they have to be certain before they can commence an end of life care pathway, or that this decision is irreversible. A more flexible approach (and the LCP always advocated regular review) is to adopt the concept currently used for the Amber care bundle. The eligibility for this is an uncertain prognosis, i.e. may recover or may deteriorate. If an end of life care pathway embraced a similar concept ('a high chance of death in next few days but with possibility of the patient rallying for a little longer') this might reframe the purpose of a pathway and allow burdensome interventions to be withheld or withdrawn, but still making provision for basic comfort care including food and fluid, medications for basic symptom control. Staff and families may perceive this more positively as 'expecting the worst but hoping for the best' rather than an approach which is designed to facilitate death.	bring the issues your raise to the guideline development group for consideration.
247	SH	Royal College of Anaesthetists	3	4.3.1	Our clinical members feel that a clearer definition of what constitutes 'end of life' and the days leading up to this is needed in the guideline.	Thank you for your comment. The guideline development group will define the terms used through the development of the guideline.
293	SH	Compassion in Dying	1	4.3.1 a	Given that a large portion of people will die in hospital or other care settings, it is crucial that non-palliative care professionals across these settings have the skills to recognise when a patient is dying. Undergraduate education of doctors and nurses needs to contain more end-of-life training. Our understanding is that at the moment professionals only learn these skills in any depth if and when they decide to specialise. This needs to be addressed if professionals (predominantly doctors and nurses) across multiple settings are able to recognise when a patient is in the final stages of dying (or to have the skill to recognise that they *may* be entering the final stage of life and refer them on to specialists) – and to manage clinical uncertainty. Talking to care professionals and research has highlighted that many dying or 'expected to die' **patients are not identified early enough**. One study found that consensus between medical staff, nursing staff and the Gold Standard Framework was poor regarding the identification of patients with palliative care needs.*	Thank you for your comment, the content of which has been noted. We would anticipate that recommendations made within this guideline can be used to inform medical education programmes at all levels, however, medical training is outside of the remit of this guidance.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					Whilst this falls outside of the remit of the proposed guidance – which focuses on the last days of life - it is crucial to acknowledge that palliative/end-of-life patients are often missed out. If people are put on appropriate care pathways and their wishes recorded, this would clearly help to identify when they are in the final stages of dying and their treatment preferences could be adhered to. However, we acknowledge that predicting illness trajectories with cancer or MND can be easier than with heart failure.** *Gardiner C et al (2012) Extent of palliative care need in the acute hospital setting: A survey of two acute hospitals in the UK *Palliative Medicine* 27(1):76-83 **Thompson D (2007) Editorial: Improving end-of-life care for patients with chronic heart failure *Heart* 93:901-902	
134	SH	Royal College of Physicians of Edinburgh	5	4.3.1 a	Educating the public about death and the recognition of dying is required.	Thank you for your comment. NICE has an implementation team as well as a public involvement team. We anticipate that these teams may facilitate the uptake of this guidance and address this issue if the guideline development group also consider it an issue on publication.
273	SH	Helen and Douglas House Hospices	5	4.3.1 a	I welcome the emphasis on 'recognising dying' as well as the management of uncertainty around this, and the emphasis on multidisciplinary decision making (4.3.1b). Could you also consider an emphasis on 'parallel planning' (planning for both death and survival) so that patients / relatives are prepared for more than one immediate outcome, and resources can be promptly redirected as appropriate.	Thank you for your comment. We anticipate that the guideline development group will discuss the management of uncertainty in recognising dying. The scope has been changed to reflect this. We will pass on the detail of your comment to the guideline development group for their consideration.
347	SH	Royal Brompton NHS Foundation	3	4.3.1 a	This should include some guidance on frequency of review of patients in different settings and how uncertainty is managed	Thank you for your comment. We anticipate that the guideline development group will discuss the management of uncertainty in

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Trust				recognising dying. The scope has been changed to reflect this.
357	SH	Royal Marsden NHS Foundation Trust	3	4.3.1 a	This should include some guidance on frequency of review of patients in different settings and how uncertainty is managed	Thank you for your comment. We anticipate that the guideline development group will discuss the management of uncertainty in recognising dying. The scope has been changed to reflect this.
80	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	19	4.3.1 a	'uncertainty of recognizing dying' or 'recognizing the uncertainty of dying'?	Thank you for your comment. As this is a quote from an article, it cannot be changed.
213	SH	Association for Palliative Medicine	7	4.3.1 b	Should include those with learning difficulties	Thank you for your comment. We agree that there are inequalities in the care of these groups of people. They are, therefore, specifically referred to in our 'guideline equality impact assessment' document. A number of groups have been identified as requiring special consideration in relation to the Equalities Act and, as such, where evidence is available in our specific review areas, specific recommendations for these groups may be made if the guideline development group consider it necessary.
26	SH	Teva UK	2	4.3.1 b	Should there be a reference to the timelines within which effective communication to the dying and their family members is made?	Thank you for your comment. The rationale section of 4.3.1 b was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template. We acknowledge, however, the issue

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						you raise about timeliness of communication and anticipate addressing this as part of our review of evidence in this area.
104	SH	Marie Curie Cancer care	9	4.3.1 b	With regards to communication, assessing the effectiveness of communications training for clinicians' ability to talk about end of life care issues requires studies using patient experiences rather than measuring behavioural change	Thank you for your comment, the contents of which are noted.
24	SH	St Lukes Hospice	1	4.3.1 b	Communication skills required needs to have a section of its own. Hidden within MDT section under values the importance of this	Thank you for your comment. We recognise the importance of communication in the care of the dying adult in last days of life. The scope refers to draft review questions, and these will be discussed and finalised by the guideline development group. It was prioritised to focus on communication and shared decisions between health care professionals, the dying person, their families, carers and others important to them, as it was felt that recommendations in these areas would have a greater impact on patient care.
135	SH	Royal College of Physicians of Edinburgh	6	4.3.1 b	It is important that there are adequate trained nurses on a ward to contribute to decisions about end of life care. More importantly, ensuring Nursing Homes have adequately trained staff to help the primary care team recognise a frail patient is dying and prevent a crisis admission. Secondly, to develop an expectation that a patient who is in a Nursing Home should be cared for in their terminal phase of their life in the place that is their home and where the staff know the patient. This will require training and support to deliver high quality terminal care and may be suitable as an additional inspection standard for Nursing Homes.	Thank you for your comment. The focus of this guideline is on the clinical care of the dying adult in the last few days of life. It will not include service delivery. We are aware that NICE intend to commission an update of 'Improving supportive and palliative care for adults with cancer'. It is anticipated that the remit of this guideline will be extended to all people at the end of life no longer specific to cancer. Further details will be made available in due course on the NICE

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						website. We are unable to confirm the focus of this work but would encourage stakeholders to submit comments at the public consultation stage to ensure that their views are heard. The issue you raise will not be covered within this guideline.
331	SH	Together for Short Lives	6	4.3.1 b	The clinical guideline should address the fact that some adults will lack mental capacity to make decisions about their end of life care. In such cases, their family may be involved in making such decisions. This should be addressed in any subsequent recommendations which are not covered in this clinical guideline. The extent to which young adults are regarded as having capacity to make decisions about their care should take into account the importance of the issue in question. The capacity needed by an individual to decide whether to refuse food and drink, for example, is different to that required to decide which clothes to wear.	Thank you for your comments. We recognise capacity is an important issue. We have amended the scope to make reference to this. Please note this guideline will focus on adults over the age of 18 years old. As there is an 'end of life care for infants, children and young people' guideline in development we anticipate that this issue could be covered in this guideline. We would strongly encourage you to contribute to the consultation exercise on this guideline. Further detail is available on the NICE website.
191	SH	Rowcroft Hospice	9	4.3.1 b	Does this section also need to make reference to 'best interests' decisions when patients lack capacity?	Thank you for your comment. The rationale section of 4.3.1 b was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template. We have amended the scope to include reference to the Mental Capacity Act and we will raise this issue with the guideline development group.
144	SH	Willowbrook Hospice	7	4.3.1 b	As highlighted in earlier comments, it is critical that the framework for answering this question follows legal and professional guidance and	Thank you for your comment. The review questions and protocols will be

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					recognises areas that have are difficult including the difference between informing, consulting and giving decisions to dying people and those important to them. A lot of the problems currently experienced in care of the dying is because of misinformation and poor communication based on this. It is also important to note that shared decision making has its own terminology and there is little evidence applying shared decision making in medical decisions within the English context.	discussed and finalised by the guideline development group. We will forward on your comments for their discussion during the development of this review question. We have amended the scope to include reference to the Mental Capacity Act and we will raise this issue with the guideline development group. We acknowledge your comment regarding shared decision making. In the absence of any identified evidence when considering a question, the guideline development group are able to make recommendations for future research, which may be helpful.
202	SH	NHS England	3	4.3.1 b	There will need to be clarity in the definition of the term 'multidisciplinary' – in this context, this is usually the multiprofessional team (i.e. doctor, nurse, etc.); sometimes it does involve the multidisciplinary team (e.g. specialist palliative care, geriatrician, oncologist, etc.).	Thank you for your comment. We have amended the scope and replaced multi-disciplinary with multi-professional to reflect this.
388	SH	Motor Neurone Disease Association	4	4.3.1 b	We welcome the inclusion of multidisciplinary shared decision-making and communication in the guideline; this is absolutely essential.	Thank you for your comment
301	SH	Royal College of GPs	2	4.3.1 b	Emphasis needs to be not just on MDT decision making, but shared decision making – i.e. including the patient/family/carers (CJ)	The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion during the development of this review question.
316	SH	RCSLT	12	4.3.1 b	*Should* include MDT decision making as this is a key issue for SLTs. Support for families should be explored as it is often encountered by AHPs	Thank you for your comment. The rationale section of 4.3.1 b was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						will not be included in the final scope in accordance with the NICE template. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion on the development of this review question
348	SH	Royal Brompton NHS Foundation Trust	4	4.3.1 b	There needs to be identification of who the MDT are and what is minimum requirement in terms of number/mix of decision makers	Thank you for your comment. We believe that the composition of the multi-disciplinary team would fall into the remit of service provision which is not covered in this guideline. Further detail on the development of this guideline will be made available on the NICE website in due course.
358	SH	Royal Marsden NHS Foundation Trust	4	4.3.1 b	There needs to be identification of who the MDT are and what is minimum requirement in terms of number/mix of decision makers	Thank you for your comment. We believe that the composition of the multi-disciplinary team would fall into the remit of service provision, which is not covered in this guideline. Further detail on the development of this guideline will be made available on the NICE website in due course.
265	SH	Renal Association	2	4.3.1 b	Section on anticipatory prescribing should include section on patients with poor kidney function (includes worsening of kidney function or acute kidney injury secondary to major illness, as well as patients with known advanced kidney disease. There is a tendency to underprescribe in such patients because of fear of giving inappropriate drug or wrong dose	Thank you for your comment. We recognise the issue of prescribing in patients with poor renal function, and we will forward your comments on to the guideline development group for discussion.
57	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	4	4.3.1 b	We welcome the priority given to multidisciplinary working at the end of life. Multidisciplinary working across health and social care is vital to quality, person-centred care at the end of life for people with CVD. Large numbers of people dying from cardiovascular diseases have coexisting medical conditions and with an ageing population, this looks set to increase.	Thank you for your comment. We will be reviewing shared decision making with the patient and carers about clinical care in the last days of life, as outlined in section 4.3.1.b.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					Primary, secondary and out-of hours services and social care will all be required to work together to support people approaching the end of life. It is vital that not only physical health needs but also the spiritual, psychological and social needs of patients are considered and addressed at the end of life. The identification, recording and communication of patient and carer needs and preferences for care to all members of multidisciplinary teams is essential to maintaining patients in their preferred place of care. Yet, only 40 per cent of people whose loved ones died from cardiovascular disease felt that community services worked well together.[10] The BHF has invested over £2 million in trialling models of care for improving end of life for people with CVD, including our Caring Together programme.[11] The Caring Together programme's approach works across the acute, community and out-of-hours care teams enabling the delivery of consistent and coordinated services to people with heart failure and their carers in all care settings.	We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this important focus in each of our review areas. The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
81	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	20	4.3.1 b	Multi-disciplinary (different specialities) should read Multi -professional (different professions).	Thank you for your comment. We have amended this.
315	SH	RCSLT	11	4.3.1 c	I agree that people have reduced desire for food but due to disease effects and medical interventions (e.g. oxygen, opiates) thirst is often an issue. In my experience, SLT can assess and provide advice to minimise dysphagia symptom burden and educate families / healthcare professionals so they can provide meaningful intervention without inadvertently burdening the patient.	Thank you for your comment. We are planning to draw on the experience of a speech and language therapist as an adviser for this topic.
296	SH	Norfolk and Suffolk Palliative Care	2	4.3.1 c	Until correct data is collected about end of life/palliative care is useless. While data is collected about individual conditions and not about end of life/palliative we can't conduct research into essential issues such as recognising dying.	Thank you for your comment. After the protocol is finalised by the guideline development group, a systematic

10

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Academy				review of the literature will be undertaken, including a quality assessment of all research included. The guideline development group are also able to make recommendations for research if they identify a gap in the evidence.
389	SH	Motor Neurone Disease Association	5	4.3.1 c	We welcome the proposed content about anticipatory prescribing, and particularly the acknowledgement of 'just in case' medication. The MND Association makes a 'Just In Case Kit' available to people with MND; they must obtain it via their GP, who prescribes suggested medication for inclusion in it. It can occasionally be a problem that out-of-hours doctors, who are unfamiliar with the patient and may well be unfamiliar with MND, can ignore the presence of the kit or decline to use it; we hope this guidance may help to address this.	Thank you for your comment. The content of which has been noted. Please be aware that we will not be able to make specific recommendations about the content of just in case boxes for MND patients.
136	SH	Royal College of Physicians of Edinburgh	7	4.3.1 c	National Guidelines are required for anticipatory prescribing.	Thank you for your comment.
192	SH	Rowcroft Hospice	10	4.3.1 c	National guidance on principles for anticipatory prescribing may be useful, but need to allow for local application/protocols and drug formularies.	Thank you for your comment. We recognise the issue you raise. We will forward your comments on to the guideline development group for discussion.
302	SH	Royal College of GPs	3	4.3.1 c	It seems to refer to anticipatory prescribing occurring in hospital and Just in Case boxes being used in community. This suggests that anticipatory prescribing does not occur in community. Just in Case box prescribing AND targeted anticipatory prescribing both occur in the community and are not mutually exclusive. Administration of these drugs(and timing of administration) is a slightly separate issue from their initial prescribing (CJ)	Thank you for your comment. The rationale section of 4.3.1 c was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template. We agree with the points you make and will forward them on to the guideline development group for consideration when they discuss this review area.
145	SH	Willowbrook	8	4.3.1 c	There is variation in what is included…unclear what the inclusion of hyoscine	Thank you for your comment. The

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Hospice			means. The level of anticipatory prescribing in hospitals is variable so guidance on a national level would be very beneficial	rationale section of 4.3.1 c was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template. We agree that guidance is needed in anticipatory prescribing and anticipate that, following review, the guideline development group will aim to make recommendations to inform clinical practice nationally in this area.
82	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	21	4.3.1 c	Anticipatory prescribing enables access to medication in ours and out of hours, not just out of hours. The term 'palliative care medication' suggests medicines that are only used by palliative care and this could exacerbate misconceptions about hastening death. It would be more accurate to use the term 'anticipatory 'as required' medication for symptom control' Although there are no national guidelines for prescribing it is widely recognised that the common symptoms requiring anticipatory prescribing are - pain - nausea and vomiting - Respiratory tract sections - Breathlessness - Agitation - We would be concerned that a national guidance takes away the need for an individual assessment of the patients needs. National use of the LCP guidance did not resolve this issue. Local areas need to own what they are educating. Concerns re inappropriate administration should be addressed with education and training. Perceptions of hastening death can be prevented with clear aims of treatment	Thank you for your comment. The rationale section of 4.3.1 c was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template. The exact nature of the protocol for the review will be discussed and defined by the guideline development group. We have now added nausea, vomiting and respiratory secretions to the scope and we will forward your comments to the guideline development group for discussion.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					and clear, timely, explanations to patients and families.	
274	SH	Helen and Douglas House Hospices	6	4.3.1 c	I appreciate 'service delivery' won't be addressed, but in the area of anticipatory prescribing, it would be helpful to comment on *access to medication out of hours,* which can be a separate concern.	Thank you for your comment. The focus of this guideline is on the clinical care of the dying adult in the last few days of life. We are aware that NICE intend to commission an update of improving supportive and palliative care for adults with cancer. It is anticipated that the remit of this guideline will be extended to all people at the end of life, no longer specific to cancer, and will likely address service delivery, which is beyond the remit of this guideline. Further details will be made available in due course on the NICE website. We are unable to confirm the focus of this work but would encourage stakeholders to submit comments at the public consultation stage to ensure that their views are heard. We will forward your comment to the guideline development group (guideline development group) to consider the issues of out of hours availability when considering the review questions.
203	SH	NHS England	4	4.3.1 c	The rationale seems to imply a leaning towards providing clinically assisted hydration, which seems a bit premature at this stage. A balancing statement pointing out that clinically assisted hydration carries an element of adverse consequences that need to be weighed against potential benefit, would be helpful.	Thank you for your comment, we have amended this accordingly.
317	SH	RCSLT	13	4.3.1 d	Include the effect on mouth of low hydration and the impact this has on nutrition, and communication. Include how SLT intervention can help to manage risk when someone wants to continue oral intake Not only guidance for nurses lacking, it is also lacking for AHPs	Thank you for your comment. We are planning to draw on the experience of a speech and language therapist as an adviser for the topic of hydration.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
318	SH	RCSLT	14	4.3.1 d	This is a good example of where the balance of disease burden cf. least restrictive practice is important. Least restrictive might mean allowing an acutely dying person to have something to eat or drink (even if they have a disordered swallow) but if this results in massive coughing fits then that would cause more distress.	Thank you for your comment.
248	SH	Royal College of Anaesthetists	4	4.3.1 d	There should be specific mention that hydration can be oral, intravenous, nasogastric and naso-jejunal.	Thank you for your comment. We feel that this level of detail is not necessary at the scoping stage of the guideline. The review strategy for assisted hydration is not yet finalised (it will be agreed with the guideline development group). Mode of hydration may be covered as a sub-analysis of this topic.
349	SH	Royal Brompton NHS Foundation Trust	5	4.3.1 d	The decision to look at hydration and not nutrition is valid in the last few hours, but where patients are dying over days withholding nutrition creates equal anxiety and distress for families and carers	Thank you for your comment. Following consultation with stakeholders, it has been agreed that the scope of this guideline will focus on the last few days of life and not on a longer time frame. As such we will not be prioritising the issue of nutrition.
359	SH	Royal Marsden NHS Foundation Trust	5	4.3.1 d	The decision to look at hydration and not nutrition is valid in the last few hours, but where patients are dying over days withholding nutrition creates equal anxiety and distress for families and carers	Thank you for your comment. Following consultation with stakeholders, it has been agreed that the scope of this guideline will focus on the last few days of life and not on a longer time frame. As such we will not be prioritising the issue of nutrition.
83	SH	SOUTHPORT AND ORMSKIRK HOSPITAL	22	4.3.1 d	There is no mention of the need to assess the individual ability to drink, hydration status and symptoms or distress caused by that status. Many, but not all, retain thirst. The natural withdrawal from food and fluids is	Thank you for your comment. We will bring this to the guideline development group's attention when the details of the topic of hydration are planned. It is

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		NHS TRUST			evident. The statement that fluids stopped without medical review, in someone who is thought likely to be dying, accelerates the dying process – needs a reference.	not part of the standard NICE process to include references within a scope. This section has been amended in the final scope.
137	SH	Royal College of Physicians of Edinburgh	8	4.3.1 d	There is no mention of mouth care in addition to hydration problems which can help a dying patient and relieve suffering, albeit more demanding on nursing time. .	Thank you for your comment, this review will be looking at artificial hydration only. We will not undertake a review of mouth care but we will forward your comments to the guideline development group for consideration as part of this evidence review.
214	SH	Association for Palliative Medicine	8	4.3.1 e	Very important that there is a clear definition of 'inappropriate or injudicious sedation' in the guidance. Some mild sedative side-effects can be beneficial and welcomed by the patient- important to get messages clear	Thank you for your comment. The rationale section of 4.3.1 e was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template. The exact nature of the protocol for the review will be discussed and defined by the guideline development group. We will forward your comments on to the guideline development group for discussion.
380	SH	The Royal College of Radiologists	6	4.3.1 e	The RCR feels there needs to be a very clear definition of 'inappropriate or injudicious sedation' in the guidance. Although some mild sedative side-effects can be beneficial and welcomed by the patient, it is important to be clear on this point.	Thank you for your comment. The rationale section of 4.3.1 c was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template. The exact nature of the protocol for the review will be discussed and defined by the guideline development group. We will forward your comments on to

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						the guideline development group for discussion.
390	SH	Motor Neurone Disease Association	6	4.3.1 e	The proposed scope covers sedation in relation to respiratory depression. It does not, however, consider sedation in relation to the withdrawal of respiratory support, and managing that process. Since the introduction of NICE clinical guideline 105 ('The use of non-invasive ventilation in the management of motor neurone disease'), it has become increasingly common for people with MND to use non-invasive ventilation (NIV) in the later stages of their illness. This can present people with the option of choosing to have the NIV withdrawn and thereby exercise control over the timing of their death. The guideline should include guidance on the management of this process, including the use of sedation (this is not covered by clinical guideline 105). It should also include guidance on issues relating to capacity, as some people with MND develop fronto-temporal dementia or other cognitive impairment; assessing this can be made more complicated by the communication problems that are also often caused by the disease. These issues will also be salient for the withdrawal of other treatments that prolong life.	Thank you for your comments. We recognise that this is an important clinical issue for patients with MND on NIV nearing the end of life. However, given time and resource constraints this topic was not prioritised for this guideline as other review areas are more likely to have a wider impact on clinical practice. The review area of NIV withdrawal will not be covered in this guideline. We do anticipate that our review on the pharmacological management of symptoms at the end of life may be of relevance to MND patients who have had their NIV withdrawn. The MND guideline currently in development is addressing other end of life issues for the MND population.
17	SH	Leeds Teaching Hospitals	5	4.3.1 e	Palliative sedation needs defining here - there is often confusion when talking about this as many people are talking about the use of low dose anxiolytics for the treatment of agitation, which is very different from palliative sedation which is used far less frequently	Thank you for your comment. The rationale section of 4.3.1 e was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template.
303	SH	Royal College of GPs	4	4.3.1 e	Pain control is mentioned – need to also clarify that opioids are also often used to manage SOB. Also as the topic of minimising unwanted sedation is highlighted, there may be need to also cover the management of respiratory secretions and nausea, as the drugs used to manage these symptoms can often contribute to sedation. (CJ)	Thank you for your comment. The rationale section of 4.3.1 e was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						The exact nature of the review question will be finalised by the guideline development group. We will forward your comments regarding pharmacological management of respiratory secretions and nausea for discussion around this protocol development.
292	SH	Dignity in Dying	2	4.3.1 e	As stated in the consultation document, **clarity around the purpose and use of palliative sedation is needed.** UK research indicates that around 19%* of doctors attending a dying patient reported the use of continuous deep sedation (also known as palliative/terminal sedation). There was palliative care team involvement in half of these cases, and prescription of opioids alone for sedation occurred in one-fifth of the cases but was not reported by specialists in palliative care. The tensions between this being a not-uncommon practice and what doctors are actually doing when they sedate someone need to be examined. Research from the VOICES surveys gives an indication of the extent of symptom control. In hospices - where we can assume that excellent palliative care is available - more than 2% of patients with pain were reported as experiencing no relief during their last three months of life.** Figures for poor relief of symptoms and pain control in the last two days of life are similar.*** This estimate is conservative, because it considers only symptom control and not the loss of dignity, autonomy etc. **The frequency of dying patients with uncontrollable symptoms needs to be further explored, so that policy can be developed on their care needs.** The Seale research**** indicates that a 'significant minority' of end-of-life decisions involve the expectation (28.9%) or intention (7.4%) to hasten the end of life by withholding/withdrawing treatment or giving a drug for pain or other symptoms. In 10% of cases, patients expressed a request (verbally) for the end of his or her life to be hastened. In the majority of cases (74%) the request stayed consistent.	Thank you for your comments, the content of which has been noted. We will forward your comments to the guideline development group guideline development group for consideration when reviewing pharmacological management. After evidence review and discussion the guideline development group will aim to provide recommendations on the use of pharmacological management of certain symptoms, including pain.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					Managing the expectations of patients and families is crucial to ensure that the purpose of sedation is understood and in the patient's interest. We would welcome thorough guidance on the control of pain, refractory and existential symptoms in dying patients – whether through pain relief, sedation etc. *Seale C (2010) Continuous Deep Sedation in Medical Practice: A Descriptive Study Journal of Pain and Symptom Management 39(1): 44-53 ** Office of National Statistics. (2013, July). National Bereavement Survey VOICES 2012. Q31 Retrieved from http://www.ons.gov.uk/ons/publications/re-reference tables.html?edition=tcm%3A77-313468 ***Office of National Statistics. (2014, April 22). Relief of pain and its relationship to quality of care Table 5 Retrieved from http://www.ons.gov.uk/ons/about-ons/business-transparency/freedom-of-information/what-can-i-request/published-ad-hoc-data/health/april-2014/index.html ****Seale C (2009) Hastening death in end-of-life care: A survey of doctors Social Science & Medicine 69(11): 1659-66	
84	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	23	4.3.1 e	Major tranquillisers are not the mainstay of care of the dying and inclusion of the terms tranquillisers and sedation in these guidelines may add to the misunderstandings about the use of drugs and goals of treatment for dying patients. 'Palliative sedation' is a poor choice of phrase where sedation is not the primary intent. If symptoms exist then anxiolytics should be titrated against those symptoms until symptom control is achieved and they no longer cause distress. This should mean using the smallest effective doses required to relieve symptoms and no more. This is NOT palliative sedation. The intent is **not** to sedate but to **relieve** symptoms. Titration in this way does **not** risk accelerating death, nor cause respiratory depression nor aspiration. The goal of pharmacological management is to control symptoms.	Thank you for your comments. Clinical guidance surrounding the use of major tranquilisers, or neuroleptic medications has been highlighted as an area requiring clarification and will likely be included in this review. The guideline development group will be forwarded your comments for discussion and will formulate protocols. Please note the rationale section of 4.3.1 e was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					The goals of care should be clearly communicated. It would be helpful to comment that for most patients who are dying symptoms can be controlled with small doses of analgesics, anxiolytics, antiemetics and antisecretory agents. Specialist advice can be given by specialist palliative care services e.g. refractory symptoms, renal impairment	NICE template.
113	SH	Royal Devon and Exeter NHS Foundation Trust	6	4.3.1 e	Palliative sedation is a very unhelpful term. It is extremely rare that sedative drugs are given in terminal care to "sedate" the patient i.e. with the express intention to diminish their level of consciousness. Rather they are used to palliate a symptom. The idea that the use of a sedative drug should be seen as a "last resort" is extremely alarming. The correct i.e. most appropriate drug should be used to address the symptom being experienced. The emphasis in this scoping document regarding risk that opioids or benzodiazepines may hasten death my causing respiratory suppression or aspiration seems incorrect as other symptoms of toxicity are more common at the doses used in end of life care.	Thank you for your comment. The rationale section of 4.3.1 e was included at consultation to clarify the scoping group's discussions around the key clinical issues to be included. It will not be included in the final scope in accordance with the NICE template. We note the points you raise
319	SH	RCSLT	15	4.3.1 e	Also the effect on eating and drinking when pharmacological impact is inconsistent - it may increase risk of aspiration or obstruction	Thank you for your comment, the content of which is noted. This review is likely to focus on minimising sedation as this was prioritised as an area particularly needing clinical guidance. Other adverse symptoms of pharmacological management will likely not be looked at. The guideline development group will finalise the protocols for these reviews after discussion.
350	SH	Royal Brompton NHS Foundation Trust	6	4.3.1 e	Social and spiritual needs often impact on pain and agitation and there should be direct reference to the impact of this as pharmacological management should not be used in isolation	Thank you for your comment. We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this important focus in each of our review

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						areas, including pharmacological management (section 4.3.1.e). The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
360	SH	Royal Marsden NHS Foundation Trust	6	4.3.1 e	Social and spiritual needs often impact on pain and agitation and there should be direct reference to the impact of this as pharmacological management should not be used in isolation	Thank you for your comment. We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this important focus in each of our review areas, including pharmacological management (section 4.3.1.e). The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
332	SH	Together for Short Lives	7	4.3.2	Together for Short Lives regards all the stated issues which will not be covered in this clinical guideline as important for young adults with life-threatening or life-limiting conditions. We ask that they are included in the scope of the proposed guidelines on palliative care for adults.	Thank you for your comment. As there is an 'end of life care for infants, children and young people' guideline in planning we anticipate that this issue could be covered in this guideline. However, we acknowledge the importance of considering the transition between children and adult services and will pass your comment to the guideline development group for their consideration.
19	SH	Leeds Teaching Hospitals	7	4.3.2	Clinically assisted nutrition - should how to communicate about this issue be included in the guidance - this is an area that can cause distress to families (withdrawal of and also not commencing?)	Thank you for your comment. We anticipate that communication will be an important component of all clinical topics in the scope. However, we will

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						not be addressing the issue of nutrition in this guideline.
115	SH	Royal Devon and Exeter NHS Foundation Trust	8	4.3.2	• It is regrettable that artificial feeding and nutrition is not to be examined alongside hydration. One reason given is that the technologies to deliver it are different. This is not correct; PICC lines and feeding tubes are often a component of hospital based care of sick patients. It would be via these that fluids would be given and hence the separation seems artificial given the anxieties raised in the report More Care Less Pathway	Thank you for your comment. Clinically assisted hydration (CAH) was prioritised by the scoping group for the following reasons detailed in the scope document: '[CAH] was highlighted as an issue in the Rapid evidence review carried out by the University of Nottingham (Parry et al., 2013) as part of More care, less pathway (recommendations 17–22). People who are dying commonly experience a reduced need for food, but many retain thirst but may not be able to drink for various reasons… The General Medical Council provides general guidance in End of life care: meeting patients' nutrition and hydration needs. However, this guidance combines hydration with nutrition and is not specific to the last days and hours of life'. As such we will not be looking at assisted nutrition in this guideline. Please also note the review questions for this topic will be finalised by the guideline development group.
324	SH	RCSLT	20	4.3.2	Clinically assisted nutrition is important and should be included as the use of PEG feeding can prolong a life of poor quality	Thank you for your comment. Clinically assisted hydration (CAH) was prioritised by the scoping group for the following reasons detailed in the scope document: '[CAH] was highlighted as an issue in the Rapid evidence review carried out by the University of Nottingham (Parry et al., 2013) as part

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						of More care, less pathway (recommendations 17–22). People who are dying commonly experience a reduced need for food, but many retain thirst but may not be able to drink for various reasons… The General Medical Council provides general guidance in End of life care: meeting patients' nutrition and hydration needs. However, this guidance combines hydration with nutrition and is not specific to the last days and hours of life'. As such we will not be looking at assisted nutrition in this guideline. Please also note the review questions for this topic will be finalised by the guideline development group.
392	SH	Motor Neurone Disease Association	8	4.3.2	We strongly recommend that nutrition be included. For people with MND, guidance on feeds and fluids delivered by gastrostomy as death approaches is important as many people with the disease will be fed in this way by the later stages of their illness.	Thank you for your comment. Clinically assisted hydration (CAH) was prioritised by the scoping group for the following reasons detailed in the scope document: '[CAH] was highlighted as an issue in the Rapid evidence review carried out by the University of Nottingham (Parry et al., 2013) as part of More care, less pathway (recommendations 17–22). People who are dying commonly experience a reduced need for food, but many retain thirst but may not be able to drink for various reasons… The General Medical Council provides general guidance in End of life care: meeting patients' nutrition and hydration needs. However, this guidance combines

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						hydration with nutrition and is not specific to the last days and hours of life'. As such we will not be looking at assisted nutrition in this guideline. Please also note the review questions for this topic will be finalised by the guideline development group.
344	SH	Help the Hospices	10	4.3.2	We agree that you should not cover any of the clinical issues listed as long as they eventually will be covered by the proposed Palliative Care Guidance.	Thank you for your comment. The exact scope of the proposed NICE guideline is yet to be agreed so it is not possible to ensure that all these areas are all covered in this guideline at this stage. We would strongly encourage you to contribute to the consultation exercises on these developing guidelines with the issues you raise. Further detail will be made available on the NICE website in due course.
321	SH	RCSLT	17	4.3.2	The need for a service to include SLTs, should be included	Thank you for your comment. We believe that the composition of the multi-disciplinary team would fall into the remit of service provision, which is not covered in this guideline. Further detail on the development of this guideline will be made available on the NICE website in due course.
323	SH	RCSLT	19	4.3.2	MDT structure should be covered as it is crucial	Thank you for your comment. We believe that the composition of the multi-disciplinary team would fall into the remit of service provision, which is not covered in this guideline. Further detail on the development of this guideline will be made available on the NICE website in due course.
45	SH	Faculty of	10	4.3.2	The exclusion of Prognostic Tools from the decision making about end of life	The time frame for the scope has been

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Intensive Care Medicine			care is questionable (see comment 1).	finalised to the last day or hours of life. We are not aware of any validated prognostic tools for use within this time frame; however, we do recognise the value of prognostic tools outside of this period. Because of this, the appropriate review to conduct within this time frame is of the signs and symptoms, as proposed. The purpose of this review is intended to aid timely recognition and communication that a person is in the last days of life.
59	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	6	4.3.2	The draft guideline notes that rather than prognostic tools, the identification of specific signs and symptoms has been prioritised for this guideline. **Prognostic tools, however, can help to identify people with heart failure entering the end of life phase of their illness.** BHF pilots have shown that by assessing patients against certain criteria, including existing needs, Heart Failure Specialist Nurses can identify a significant proportion of those in their final months of life. Referral criteria used in our Caring Together project were: • The patient has advanced heart failure[12] • The patient has distressing or debilitating symptoms despite optimal tolerated medical therapy • The patient has supportive or palliative care needs. Supplementary considerations include: • Increasing age (>75) [frail and elderly] • Co-morbidities (one or more)	The time frame for the scope has been finalised to the last day or hours of life. We are not aware of any validated prognostic tools for use within this time frame; however, we do recognise the value of prognostic tools outside of this period. Because of this, the appropriate review to conduct within this time frame is of the signs and symptoms, as proposed. The purpose of this review is intended to aid timely recognition and communication that a person is in the last days of life.

12

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					• Increasing symptom burden/symptomatic • Hospital admissions or requiring increased home visits in last year • Assessment for transplant/advanced specialist intervention Question: "Would you be surprised if this patient died in the next year?"	
105	SH	Marie Curie Cancer care	10	4.3.2	With regards to the use of prognostic tools, as there is currently an absence of effective ones, the analysis of how healthcare professionals make a terminal prognosis must include processes other than criterion-based decisions. At present, pattern recognition appears to be the means by which clinicians reach this kind of clinician decisions.	Thank you for your comment. We hope the evidence review of signs and symptoms will support the development of recommendations to allow clinicians to have confidence in the recognition of dying.
18	SH	Leeds Teaching Hospitals	6	4.3.2	Social and spiritual needs of the dying person and their families and carers - we believe this should be addressed in the guidance as it is an important aspect of the caring for dying patients and their families	Thank you for your comment. We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this important focus in each of our review areas. The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
114	SH	Royal Devon and Exeter NHS Foundation Trust	7	4.3.2	It is unacceptable that social and spiritual should be excluded from this guidance. Although full implementation of the chapter regarding spiritual care in the previously published NICE quality standards was far from universal, it was an important statement that care of the dying requires a holistic approach. To remove it sends a message that it is not integral to good clinical care and that there is a need for spiritual distress to be recognised and response made by every member of the clinical team. Indeed spiritual and social distress can often underlie the most difficult to manage symptoms. For these symptoms to be seen as the domain of specialist palliative care clinicians or specialist chaplaincy teams would be a very retrograde step.	Thank you for your comment. We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this important focus in each of our review areas. The guideline development group may co-opt an expert, such as chaplaincy representation, to support

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						the guideline development group in developing appropriate recommendations.
147	SH	Willowbrook Hospice	10	4.3.2	Social and spiritual needs of the dying…This is an integral component of end of life care and shouldn't be seen as separate guidance.	Thank you for your comment. We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this important focus in each of our review areas. The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
148	SH	Willowbrook Hospice	11	4.3.2	This is an integral component of dignity and compassion for the patient and relative at end of life. It shouldn't be seen as separate guidance.	Thank you for your comment. We assume you are referring to spirituality as an issue. We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this important focus in each of our review areas. The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
215	SH	Association for Palliative Medicine	9	4.3.2	If clinical guidance is to address anxiety and terminal restlessness, then spiritual/existential anguish and fear should be included within addressing psychological symptoms.	Thank you for your comment. We recognise that spirituality is an important element in care of dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						important focus in each of our review areas, including pharmacological management (section 4.3.1.e). The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
320	SH	RCSLT	16	4.3.2	Not covering social and spiritual because this "may" be covered in the palliative care guidance. It had better BE COVERED ideally in both documents because this is a major issue that can cause distress to the dying patient, distress to the family and complicate how they feel about their loved one's death after the event. And no amount of high tech medicine will compensate for this.	Thank you for your comment. We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this important focus in each of our review areas. The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
381	SH	The Royal College of Radiologists	7	4.3.2	If clinical guidance is to address anxiety and terminal restlessness, then the RCR suggests that spiritual/existential anguish and fear should be included when covering psychological symptoms.	Thank you for your comment. We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this important focus in each of our review areas, including pharmacological management, and will not therefore include it as a separate symptom (section 4.3.1.e). The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						appropriate recommendations.
393	SH	Motor Neurone Disease Association	9	4.3.2	We note that social and spiritual needs will not be covered in this guideline, but potentially in the palliative care guideline. We recommend that this should include not only support for carers and loved ones once bereaved, but also before bereavement, to help them prepare for their loss.	Thank you for your comment, the contents of which have been noted. We recognise that there are many important areas in the care of dying adults, including bereavement counselling for families. It is not possible to look at all areas due to time and resource constraints. Other areas were prioritised above this for review as it was felt there was a wider variety and uncertainty of current practice in these, and recommendations here would add the most value in regards to changing and standardising practice.
322	SH	RCSLT	18	4.3.2	Longer term should be included	Thank you for your comment on the timing of this guideline. We have noted that stakeholders are mixed in their response; however, we feel it is appropriate, given the clinical focus of our work, to restrict the time frame to the last days and hours of life in order to add most value to practice, as this is an area highlighted as particularly needing clinical guidance.
58	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	5	4.3.2	We understand that NICE are planning to develop further guidance on 'Palliative Care for Adults' and that this intends to look at longer term end of life care needs. As outlined above, we believe that all guidance on end of life care should be extended beyond the last few days of life, in order to prevent the current inequity in end of life care. In addition, the term 'palliative care' is often used to refer only to care in the last few days of life. For this reason, the BHF and others recommend using the more inclusive term 'palliative and supportive care.' This term extends the	Thank you for your comment, the contents of which have been noted. We will pass your comments to NICE for their consideration of these issues.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					definition beyond the last few days of life and reflects that end of life care should take into account the support needs of people. We believe that this wider definition will help to prevent the reluctance exercised by GPs in referring patients for end of life care when a prognosis is not entirely certain. Patients too, do not perceive themselves as needing 'palliative care'. It is an alien term to them and this presents an additional barrier to accessing care. **We recommend that NICE adopt the wider term 'palliative and supportive care' in all guidance and Quality Standards in this area.**	
85	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	24	4.3.2 a 4.3.2 b 4.3.2 c 4.3.2 d 4.3.2 e 4.3.2 f 4.3.2 g 4.3.2 h 4.3.2 i	Entirely appropriate for service delivery to be covered elsewhere As social and spiritual care are **integral** to good care of the dying it would **not** be appropriate to have guidelines on care of the dying which do not include them. Entirely appropriate for longer term palliative care or end of life care (as described in the One Chance to get it Right document – i.e. those approaching the end of life months/year) to be covered elsewhere Care after death and support of bereaved relatives again are an essential continuum of good care of the dying and those important to them and should be considered for inclusion. Entirely appropriate for prognostic tools not to be included Entirely appropriate for case note review to be covered elsewhere Entirely appropriate for laboratory evidence not to be included Entirely appropriate for MDT structure to be covered elsewhere Clinically assisted nutrition. Although clinically assisted nutrition is rarely required in patients who are thought likely to be dying, concerns around eating and nutrition are common for patients and their families. Would it therefore be appropriate to include the	Thank you for your comment. We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impact of this important focus in each of our review areas. The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations. Thank you for your thoughts related to the timing of this guideline. We have agreed to focus on the last days of life. We recognise that there are many important areas in the care of the dying adult, including bereavement counselling for families. It is not possible to look at all areas due to time and resource constraints. Other areas were prioritised above this for review

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					need for individual assessment of ability to eat, an individual plan for eating, nutritional requirements and the need for conversations. Because the evidence base is small that is a reason to include this topic, not to exclude it. It is a priority for families and evidence based guidance for health professionals is required. If there isn't any evidence it will be important to say so in this guideline.	as it was felt there was a wider variety and uncertainty of current practice in these, and recommendations here would add the most value in regards to changing and standardising practice. Thank you for your comments regarding your agreement with our exclusions. We recognise that there are many important areas in the care of the dying adult, including clinically assisted nutrition. It is not possible to look at all areas due to time and resource constraints. Other areas were prioritised above this for review as it was felt there was a wider variety and uncertainty of current practice in these, and recommendations here would add the most value in regards to changing and standardising practice.
193	SH	Rowcroft Hospice	11	4.3.2 e	Equally managing families' expectations and their distress in observing patients distressing symptoms needs to be covered.	Thank you for your comment. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion on the development of this review question**.**
195	SH	Rowcroft Hospice	13	4.3.2 issues not covered	Immediate care after death should be covered in this guidance. Verification of death and immediate support/communication with family as a minimum should be within the scope.	Thank you for your comment. We recognise that care after death is an important issue. However, given time and resource constraints, this topic was not prioritised for this guideline as

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						other review areas are more likely to have a wider impact on clinical practice. Care after death will not be included for review in this guideline
194	SH	Rowcroft Hospice	12	4.3.2 Issues not covered .	We believe it is important to include the social and spiritual aspects in a standard on care of the dying; otherwise the guidance will not be holistic. The social and spiritual aspects of dying are integral to the dying experience.	Thank you for your comment. We recognise that spirituality is an important element in care of the dying adult. We have removed spirituality from the list of areas not covered and will discuss the impacts of this important focus in each of our review areas. The guideline development group may co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
126	SH	College of Occupational Therapists	10	4.3.2, 4.5	There is no explicit consideration of the maintenance of clear communication and decision making across settings, particularly when patients are transferred to their PPD. This is a significant issue for the continuity of effective care and support, but is often fragmentary, so should be specified.	Thank you for your comment. Shared decisions between health care professionals, the dying person, their families, carers and others important to them is an included review area. The review question in section 4.5 you refer to is a draft. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion during the development of this review question.
34	SH	Faculty of Intensive Care Medicine	8	4.4	We support this section	Thank you for your comment.
286	SH	Intensive Care Society	8	4.4	We support this section	Thank you for your comment.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
60	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	7	4.4	The Department of Health's VOICES survey showed that whilst two-thirds of relatives of people who died from cancer felt that the person had enough choice over their place of death (65 per cent) this compared to about 40 per cent of non-cancer deaths.[13] The majority of people, about 70 per cent, indicate that they would prefer to die in their usual place of residence, yet, between 2004 and 2011 a large proportion (59 per cent) of CVD deaths occurred in hospital.[14] Although the proportion of CVD patients who are able to die in their usual place of residence has been increasing (it stood at 43 per cent in 2011 compared with 37 per cent in 2004)[15] more work is required to ensure that CVD patients are supported to die with dignity in their preferred place of death. For this reason, we believe that **'death in place of choice' should be included in the outcomes for this guideline.** In light of the current inequity for CVD patients in access to end of life care, **we would also like to see the outcomes disaggregated by condition**. In addition, **we would like to see the outcomes disaggregated by equality classifications.** Whilst the mortality rate for heart failure is 37 per cent within three years, it is higher still for women, older people and those who didn't receive the best specialist care while in hospital.[16] These additional measures would help to ensure that the guideline is effective in improving care for all groups of people at the end of life.	Thank you for your comment, the content of which is noted. This guideline will focus on specific clinical issues and the care of people provided in the settings outlined in section 4.2. We will not be addressing issues related to choice of place of death, and it will not be included as an outcome. Thank you for your comment. Subgroups have been removed from the scope. The guideline development group will decide specific subgroups for individual protocols for each review question. A number of groups have been identified as requiring special consideration in relation to the Equalities Act, including age and gender, and, as such, where evidence is available in our specific review areas, specific recommendations for these groups may be made if the guideline development group consider it necessary. We are also aware that NICE intend to commission an update of 'Improving supportive and palliative care for adults with cancer'. It is anticipated that the remit of this guideline will be extended to all people

13

14

16

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						at the end of life no longer specific to cancer. Further details will be made available in due course on the NICE website. We are unable to confirm the focus of this work but would encourage stakeholders to submit comments at the public consultation stage to ensure that your views on choice of place of death are heard. However, this issue will not be covered within this guideline.
46	SH	Faculty of Intensive Care Medicine	11	4.4	Outcome c) might be refined to include the sensitivity and specificity of approaches to "recognising dying". This will also contribute to the understanding and communication of uncertainty relating to this "diagnosis".	Thank you for your comment. You describe a diagnostic review of the evidence, however, the approach has not yet been finalised and will be discussed with the guideline development group. We particularly recognise the importance of managing the uncertainty of recognising dying and we will consider this issue as the protocol for this review area is finalised.
351	SH	Royal Brompton NHS Foundation Trust	7	4.4 a	In last few hours, subjective rating is likely to be from carers and professionals rather than patients.	Thank you for your comment. Even though it may not be likely that such ratings are available, it would be important information and, therefore, we will search for such evidence. We anticipate that we will also look for ratings from carers and healthcare professionals.
361	SH	Royal Marsden NHS Foundation Trust	7	4.4 a	In last few hours, subjective rating is likely to be from carers and professionals rather than patients.	Thank you for your comment. Even though it may not be likely that such ratings are available, it would be important information and, therefore, we will search for such evidence. We anticipate that we will also look for

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						ratings from carers and healthcare professionals.
86	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	25	4.4 a	How would this be collected especially when altered / fluctuating consciousness is a feature of this period of life? Would objective rating be more appropriate?	Thank you for your comment. These are very general outcomes. More precise details about measurement scales or rating scales will be included when the review protocol for each topic is discussed with the guideline development group. We will highlight your comment at this stage.
196	SH	Rowcroft Hospice	14	4.4 a	Judging whether there was 'undue sedation' would require complex after death analysis	Thank you for your comment. We recognise the challenge in defining measures or outcomes for this guideline and the issues around 'undue sedation' you raise. The guideline development group will prioritise outcomes for each review questions based on their knowledge of the literature and their clinical experience
218	SH	Association for Palliative Medicine	12	4.4 a	Agree that wider use of rating scales to provide some indication of efficacy of symptomatic management is important, but not to lead to expectation all these have to be measured / recorded for every patient all the time.	Thank you for your comment, the content of which has been noted.
384	SH	The Royal College of Radiologists	10	4.4 a	The RCR suggests that there should be acknowledgement that some symptoms are intractable (for example, vomiting in a patient dying with bowel obstruction who has declined nasogastric drainage, and many with breathlessness.	Thank you for your comment. We will discuss the issue of intractable symptoms with the guideline development group.
219	SH	Association for Palliative Medicine	13	4.4 a	There should be acknowledgement that some symptoms are intractable- e.g. vomiting in someone dying with bowel obstruction who has declined nasogastric drainage, and many with breathlessness.	Thank you for your comment. We will discuss the issue of intractable symptoms with the guideline development group.
149	SH	Willowbrook Hospice	12	4.4 a	The main outcomes are unclear in this scope. The adverse events are sometimes outcomes of the dying process. By using the term adverse events this suggests it is linked to healthcare interventions – therefore it needs to be clearly linked to evidence.	Thank you for your comment. We recognise the challenge in defining measures or outcomes for this guideline and the issues around adverse events you raise. The

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					Are tools to be recommended to undertake this consistently? Or to at least have a degree of consistency as it would be problematic to expect absolute consistency.	guideline development group will prioritise outcomes for each review questions based on their knowledge of the literature and their clinical experience. Until we undertake the evidence review and discuss this with the guideline development group we are unable to comment on the nature of the recommendations in this area.
261	SH	British Geriatrics Society	6	4.4 a-e	The British Geriatrics Society agrees with the main outcomes.	Thank you for your comment.
150	SH	Willowbrook Hospice	13	4.4 b	How are their views to be sort for consistency? Comments as above.	Thank you for your comment. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion on the development of this review question.
87	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	26	4.4 b	Agree	Thank you for your comment.
151	SH	Willowbrook Hospice	14	4.4 c	Unsure about an outcome being the number of people correctly being identified to being in the last hours and days of life – not aware of an evidence supporting this outcome nor what an appropriate percentage would be. There is also the risk that to ensure that people are absolutely sure that high quality care of the dying would be denied to people as clinicians would be unsure.	Thank you for your comment. We recognise the challenge in defining measures or outcomes for this guideline and the issues around adverse events you raise. The guideline development group will prioritise outcomes for each review questions based on their knowledge of the literature and their clinical

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						experience. To minimise uncertainty, an outcome to correctly identify those in the last days or hours of life will be a desirable reported outcome. The guideline development group will finalise their protocol after further discussion.
197	SH	Rowcroft Hospice	15	4.4 c	As current research evidence suggests that prognostication is difficult and invariably inaccurate it will be difficult to determine the 'correct' identification of people in last days/hours of life.	Thank you for your comment.
88	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	27	4.4 c	How will this be measured?	Thank you for your comment. These are very general outcomes. More precise details about measurement scales or rating scales will be included when the review protocol for each topic is discussed with the guideline development group.
352	SH	Royal Brompton NHS Foundation Trust	8	4.4 c	Given the issues re prognostication, particularly for those with non-malignant disease, this outcome needs to encompass the uncertainty of decision making. Discussions happening within last 24hrs are often too late and may not reflect the true clinical picture.	Thank you for your comment. We plan to carry out a review on effective communication and shared decision making to try to prevent the kind of scenario you describe.
362	SH	Royal Marsden NHS Foundation Trust	8	4.4 c	Given the issues re prognostication, particularly for those with non-malignant disease, this outcome needs to encompass the uncertainty of decision making. Discussions happening within last 24hrs are often too late and may not reflect the true clinical picture.	Thank you for your comment. We plan to carry out a review on effective communication and shared decision making to try to prevent the kind of scenario you describe.
152	SH	Willowbrook Hospice	15	4.4 d	At what point of care? From when?	Thank you for your comment. The time frame for the scope has been finalised to the last day or hours of life. More precise details about how outcomes are measured will be included when the review protocol for each topic is discussed with the guideline development group.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
204	SH	NHS England	5	4.4 d	I agree with the outcome 'Length of wait for palliative care drugs' – it would help to clarify the end point, i.e. 'length of wait for palliative care drugs to be administered'? This would pick up on delays that may be caused by waiting for assessment, prescription, supply or administration.	Thank you for your comment. We have amended this accordingly.
89	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	28	4.4 d	Palliative care drugs a term which may exacerbate misunderstandings about drugs. A more helpful term & measure may be the time to administration of medication for symptom control after the reporting of symptoms.	Thank you for your comment. We have amended this accordingly.
153	SH	Willowbrook Hospice	16	4.4 e	How is this to be measured?	Thank you for your comment. These are very general outcomes. More precise details about measurement scales or rating scales will be included when the review protocol for each topic is discussed with the guideline development group.
116	SH	Royal Devon and Exeter NHS Foundation Trust	9	4.4 e	The list of adverse events does not suggest equipoise in the panels' views. To be complete this should include the risks of over hydration, injection/ infusion site infections and uncontrolled symptoms	Thank you for your comment. These are very general outcomes. More precise details about measurement scales or rating scales will be included when the review protocol for each topic is discussed with the guideline development group. We will highlight your comment at this stage when considering the review protocol for clinically assisted hydration.
198	SH	Rowcroft Hospice	16	4.4 e	How will 'adverse' events including 'thirst' and 'nausea' for people in last of days of life be identified if the person is unconscious by this stage? Would monitoring adverse events such as inappropriate interventions such as blood tests be more appropriate?	Thank you for your comment. These are very general outcomes. More precise details, and discussions about specific situations such as the level of consciousness, will take place when the review protocol for each topic is discussed with the guideline development group. We will highlight your comment at this stage.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
90	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	29	4.4 e	It is not clear what is meant by adverse events. Are these symptoms experienced, side effects of medication or the impact of not being able to give appropriate medication?	Thank you for your comment. These would vary according to the topic and could include all of these. At this stage they are broad outcomes only because not all possible outcomes for all included topics can be listed here. We will highlight your comment when the details of the review is discussed with the guideline development group.
48	SH	Faculty of Intensive Care Medicine	13	4.5	Question d) could be refined by adding consideration of the mode of administration of medically assisted hydration (oral, subcutaneous, rectal, intravenous) (see comment 9 above).	Thank you for your comment. We feel that this level of detail is not necessary in the scope. The review strategy for assisted hydration is not yet finalised (it will be agreed with the guideline development group). Mode of hydration may be covered as a sub-analysis of this topic.
52	SH	Mid Cheshire Hospital NHS Trust	4	4.5	**Section d)** *For adults in the last days of life, is medically assisted hydration effective in improving quality of care?* Again I think this is impossible to answer as a general question and must be addressed on an individual patient basis.	Thank you for your comment. NICE recommendations are made to apply to the 'majority' of people with a particular decision. It is 'guidance' and clinicians can make individual decisions based on the particular circumstances of the person in front of them that may differ. However, we feel a review of the evidence to guide practice is warranted.
106	SH	Marie Curie Cancer care	11	4.5	Another useful question to include would be to ask what the evidence is of effective communications training on conversations between healthcare professionals and patients and healthcare professionals and families.	Thank you for your comment. Your comment refers to a draft review question. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion during the development of this specific review question.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
267	SH	Renal Association	4	4.5	Would suggest review question on withdrawal of treatment – when to consider, how to communicate, impact on time to death	Thank you for your comment, the contents of which have been noted. It will be beyond the scope of this guideline to make recommendations about withdrawing or withholding elements of care outside of the proposed review areas. We feel that a review of evidence of withdrawing or withholding treatment would not add value to clinicians' practice which should be tailored to each individual cared for.
35	SH	Faculty of Intensive Care Medicine	9	4.5	We support this section, but note that the answers to some of these questions are significantly different in the Intensive Care environment, particularly if they have been sedated for some time during their period of active treatment.	Thank you for your comment. We recognise the specific needs of people dying in the intensive care setting. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion during the development of these review questions.
262	SH	British Geriatrics Society	7	4.5	The British Geriatrics Society supports the review questions.	Thank you for your comment.
287	SH	Intensive Care Society	9	4.5	We support this section, but note that the answers to some of these questions are significantly different in the Intensive Care environment, particularly if they have been sedated for some time during their period of active treatment.	Thank you for your comment. We recognise the specific needs of people dying in the intensive care setting. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						discussion during the development of these review questions.
299	SH	Norfolk and Suffolk Palliative Care Academy	5	4.5	Without input and recognition of the informal carer workforce nothing will change. Without continued and concerted efforts to educate the existing workforce in palliative and end of life care all attempts at reform will fail	Thank you for your comment, the contents of which are noted.
12	SH	Faculty of Pain Medicine, Royal College of Anaesthetists	2	4.5	Review question on 'most effective level of sedative medication': this question requires far greater clarification in meaning. Patients vary greatly in their sensitivity and response to medication (particularly when frail and old) and so a specific dose of a medication may cause unconsciousness in one patient but have no effect in another; the principle issue is titration to effect, based on some measurable end point (the patient stops fitting, or ceases to be agitated – though the latter is not easy to agree). Staff and families also vary greatly in their perception of effect. For some families, only deep sedation to unconsciousness for their loved one's agitation is perceived as effective management and respecting the patient's dignity. For other families, any hint of tiredness or drowsiness brought about by medication for distress is perceived as medical error and a clear indication of clinicians hastening the patient's death.	Thank you for your comment, the contents of which have been noted. The review questions and protocols will be finalised by the guideline development group during development. We recognise the challenge in defining measures or outcomes for this guideline and the issues around 'Effective level of sedation' you raise. The guideline development group will prioritise outcomes for each review questions based on their knowledge of the literature and their clinical experience and develop clear protocols. We do not anticipate a recommendation on a specific dose of a medication will be made by the guideline development group. We will raise your comments with the guideline development group for discussion.
53	SH	Mid Cheshire Hospital NHS Trust	5	4.5	**Section e)** *For adults who are in the last days of life, what is the most effective level of sedative medication (opioids, benzodiazepines and major tranquillisers)in the management of pain, anxiety, terminal agitation and breathlessness?* Again there will never be a most effective level as every patient is individual. The effective level for each individual will be dependent upon the severity of their symptom, their usual medication and patient preference in what level of sedation is appropriate for them.	Thank you for your comments. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion on the development of this review question. We do not anticipate a recommendation on a specific dose of

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						a medication for all patients will be made by the guideline development group.
127	SH	College of Occupational Therapists	11	4.5	How answerable is e)? There are a wide variety of implications, parameters and challenges with this question.	Thank you for your comment. We agree. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion on the development of this review question.
47	SH	Faculty of Intensive Care Medicine	12	4.5	Question a) could be broadened beyond "Signs and symptoms" to include other contributory information including clinical context and prognostic scores (see comments 1 & 5 above).	The time frame for the scope has been finalised to the last day or hours of life. We are not aware of any validated prognostic tools for use within this time frame; however, we do recognise the value of prognostic tools outside of this period. Because of this, the appropriate review to conduct within this time frame is of the signs and symptoms, as proposed. We will not be including specific clinical contexts in the review question but aim to draw more generically applicable conclusions.
353	SH	Royal Brompton NHS Foundation Trust	9	4.5 a	There needs to be come reference as to how predictive these signs/symptoms are for the last hours/days (ie acute emergency cases can often have similar picture where there are reversible features)	Thank you for your comment, the content of which has been noted. We will pay attention in this review to the management of uncertainty in recognising those in their last days and hours of life. Your comments will be discussed with the guideline development group.
363	SH	Royal Marsden NHS Foundation Trust	9	4.5 a	There needs to be come reference as to how predictive these signs/symptoms are for the last hours/days (ie acute emergency cases can often have similar picture where there are reversible features)	Thank you for your comment, the content of which has been noted. We will pay attention in this review to the management of uncertainty in

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						recognising those in their last days and hours of life. Your comments will be discussed with the guideline development group.
91	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	30	4.5 a	Signs and symptoms need to be considered alongside the patient's medical history, progress of disease, comorbidities and an assessment of reversible causes of deterioration. Should that be included in the review question? Pattern recognition of the experienced clinician cannot always be described in signs and symptoms.	Thank you for your comment. The final review questions will be formulated by the guideline development group. Your comment will be passed on to them for discussion regarding this issue which we recognise.
92	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	31	4.5 b	Agree	Thank you for your comment.
154	SH	Willowbrook Hospice	17	4.5 b	Reword importance with 1) adults in the last days of life 2) their relatives 3) and those important to t them 4) healthcare professionals	Thank you for your comment. The list of persons in this sentence is not written in any particular order of importance.
93	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	32	4.5 c	What is the role of anticipatory prescribing **of 'as required' drugs for symptom management** in the clinical care of adults **thought likely to be** in the last days and hours of life?	Thank you for your comment. The review questions listed here are draft versions and will be finalised with the guideline development group. We will forward your suggested edit to the guideline development group for consideration.
275	SH	Helen and Douglas House Hospices	7	4.5 c	I like the use of the review questions to guide literature review and think the choice of questions is appropriate. The question about anticipatory prescribing is important, but please also include consideration of *route for medication*, and also *access* to the prescribed medications in the home ahead of need, which should be considered in the guidance.	Thank you for your comments. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion on the development of this review question.
220	SH	Association for Palliative	14	4.5 c	Is too vague and would be better to say "What are the common symptoms in dying patients that anticipatory medication should be prescribed for and what is	Thank you for your comment. The final wording of the review question will be

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Medicine			the most safe and effective way of ensuring medication is available and can be administered when the patient needs it?"	agreed by the guideline development group, as expressed in the introductory section to 4.5
94	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	33	4.5 d	Should the question be whether **assisting the patient to drink** and/or ~~medically~~ clinically assisted hydration are effective in a) 'maintaining symptom control' b) 'improving quality of care' c) 'improving the perception of care by those important to the patient'	Thank you for your comment. Even though the details of each review are not yet finalised, we anticipate that these aspects will be captured by the review.
221	SH	Association for Palliative Medicine	15	4.5 d	It would be better to say "For adults in the last days of life, are there clinical signs or symptoms or conditions that indicate that medically assisted hydration will improve or worsen patient comfort?"	Thank you for your comment. The final review questions will be formulated by the guideline development group. Your comment will be passed on to them for discussion regarding this.
217	SH	Association for Palliative Medicine	11	4.5 e	This needs rephrasing as it feeds the myth that opioids are used as sedatives and uses an out-dated term for the antipsychotics. Suggest: "For adults who are in the last days of life, what is the most effective level of medication (opioids, benzodiazepines and anti-psychotics) in the management of pain, anxiety, terminal agitation and breathlessness with particular reference to the balance between intended effect and sedative side effects?"	Thank you for your comment. We have altered the terminology used in the scope.
354	SH	Royal Brompton NHS Foundation Trust	10	4.5 e	Rather than a 'level of sedative medication' it is more important to give guidance on which drugs to use and how to titrate effectively for the individual based on assessment and re-assessmnet.	Thank you for your comment. We will pass your thoughts on to the guideline development group when they are developing the protocol for this review.
364	SH	Royal Marsden NHS Foundation Trust	10	4.5 e	Rather than a 'level of sedative medication' it is more important to give guidance on which drugs to use and how to titrate effectively for the individual based on assessment and re-assessmnet.	Thank you for your comments. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion on the development of this review question.
155	SH	Willowbrook Hospice	18	4.5 e	This is confounded by type of illness, pattern of illness, co-illnesses, co-prescription of drugs, genomic factors, organ function. Is the aim of this question to identify a suitable dose?	Thank you for your comments. We do not anticipate a recommendation on a specific dose of a medication will be made by the guideline development

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						group. We will raise your comments with the guideline development group for discussion.
95	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	34	4.5 e	This question is very poorly phrased and is back to front. The question should perhaps be 'What is the most effective and acceptable management of pain, anxiety/agitation, breathlessness, nausea/vomiting and respiratory tract secretions for those thought likely to be in the last days/hours of life' The term sedative medication is not helpful and potentially harmful as it may lead to confusion about the goals of care. When titrated for pain opioids are not usually sedating. Benzodiazepines are used to manage agitation and restlessness not to intentionally sedate. Tranquillisers should not be used routinely. There is no mention anywhere in the guidelines about non drug management of symptoms. For example in patients who are agitated full bladder, full rectum or full stomach can be the cause of agitation and best treated by emptying the bladder, bowel or stomach. Unresolved spiritual distress may lead to agitation. The term terminal agitation has no agreed definition and use may distract from clinical assessment for reversible causes of agitation.	Thank you for your comments. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comments for their discussion during the development of this review question. The pharmacological management of symptom relief was highlighted as an area particularly requiring clinical guidance. Non pharmacological relief of symptoms will not be covered in this guideline. We have now included the management of nausea an vomiting and respiratory secretions to the scope We recognise that spirituality is an important element in care of the dying adult. We will discuss the impact of this important focus in each of our review areas including pharmacological management. The guideline development group may choose to co-opt an expert, such as chaplaincy representation, to support the guideline development group in developing appropriate recommendations.
216	SH	Association for Palliative Medicine	10	4.5 e, 3.1 b	There should not be an intention to specify a 'most effective level' of sedative medication in the guidance, as this will need to be part of the clinical judgement with the individual patient; we need a statement on when it is reasonable for the intention to cause some level of sedation in support of the	Thank you for your comment. We recognise this is a review question requiring further clarification. The review questions and protocols will be

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					dying process, a distinction between mild and 'blanket 'sedation i.e. that completely removes awareness and opportunities to converse/take oral fluids; and an unequivocal definitions of what would be deemed to be inappropriate or excessive 'over zealous' use of sedative drugs.	discussed and finalised by the guideline development group. We will forward on your comment for their discussion on the development of this review question.
382	SH	The Royal College of Radiologists	8	4.5 e, 3.1 b	The RCR suggests that the guidance should not attempt to specify a 'most effective level of sedative medication' as this will need to be part of the clinical judgement made for individual patients. What would be of assistance is a statement on when it is reasonable for the intention to cause some level of sedation in support of the dying process, a distinction made between mild and 'blanket 'sedation (ie that completely removes awareness and opportunities to converse/take oral fluids); and a clear and unequivocal definition of what would be an inappropriate or excessive 'over zealous' use of sedative drugs.	Thank you for your comment. We recognise this is a review question requiring further clarification. The review questions and protocols will be discussed and finalised by the guideline development group. We will forward on your comment for their discussion on the development of this review question.
61	SH	SOUTHPORT AND ORMSKIRK HOSPITAL NHS TRUST	8	4.6	We welcome the inclusion of cost effectiveness in the scope of the guideline. Providing the right care, in the right place, at the right time is crucial, not only for improving individuals' wellbeing at the end of life but also economically. Hospital beds are expensive: the mean cost of hospital care in the last year of life for those who died in hospital was £11,298. The mean cost of hospital care for those who died outside of hospital was £7,730.[17] Heart failure accounts for two per cent of all NHS inpatient bed-days and five per cent of all emergency medical admissions to hospital. **Hospital admissions because of heart failure are projected to rise by 50 per cent over the next 25 years.**[18] Admissions might be avoided with anticipatory care planning and the provision of community health and social care support.[19] We know that access to social care services, as part of a package of end of life care, can help people nearing the end of life be cared for and die in their own home, if this is what they want. Yet, an analysis of hospital care and local authority-funded social care services	Thank you for your comment. Economic implications of interventions included in the guideline will be considered by the guideline development group when making recommendations.

17

18

19

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					provided in the final 12 months of life found that only seven per cent received only social care during the last year of life, with just 23 per cent receiving social and hospital care and **49 per cent receiving only hospital inpatient care.**[20] The BHF's Better Together programme helped manage heart failure symptoms as well as wider care needs.[21] In addition to reducing isolation and improving quality of life, this scheme was also cost saving. **It helped 55 out of 74 patients spend the end of life in their place of choice, which was usually at home.** Heart failure specialist nurses are a key component of multidisciplinary teams working in secondary care to meet the needs of people living with heart failure. An evaluation of BHF heart failure specialist nurses showed that they significantly improved the quality of life of their patients. **The work of heart failure nurses led to a 35 per cent drop in admissions** compared to historic data and this led to an estimated £1,826 saving per patient.[22]	
107	SH	Marie Curie Cancer care	12	4.6	There is an issue for using QALY in this area of care. As it relates to an extra year of life multiplied with a quality of life measure for a healthcare intervention, this is irrelevant to palliative care, as no extra time will result from a palliative care intervention. A simple modification of this whereby a QALY gain is multiplied by the duration before death would give a useful health economic unit for palliative care, which could be a quality-adjusted death year (QADY?).	Thank you for your comment. The scope acknowledges that QALY is the NICE preferred outcome measure, however, we do realise that for this guideline this outcome may not be appropriate and other outcomes may be considered instead. We are unfamiliar with the outcome measure you have proposed in your comment but we believe this would not be methodologically appropriate as it would simply be a QALY, which is a quality of life value multiplied by time, multiplied by time again. Therefore, it

20

21

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						would still have the limitations that the QALY approach has in this topic area and would not be methodologically sound.
128	SH	College of Occupational Therapists	12	4.6	Is QALY the best measure when this is considering the last hours/days of patients' lives?	Thank you for your comment. The scope acknowledges that QALY is the NICE preferred outcome measure, however, we do realise that for this guideline this outcome may not be appropriate and other outcomes may be considered instead.
394	SH	Motor Neurone Disease Association	10	5.1.1	It may be helpful to specify that clinical guideline 105 relates to the use of NIV, rather than covering MND as a whole.	Thank you for your comment. We will confirm this is the correct title and amend as appropriate
333	SH	Together for Short Lives	8	5.2	This section should include 'Transition from children's to adult services'. This is expected to be published in February 2016.	Thank you for your comment, this has been added to section 5.2.
334	SH	Together for Short Lives	9	7	We suggest adding: • Fraser LFK et al 2013, Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010 (available to download from: http://www.togetherforshortlives.org.uk/assets/0000/6736/TFSLAdultReport2013Final.pdf) Royal College of Paediatrics and Child Health. 2004. Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for practice: Second edition (available to download from: http://www.rcpch.ac.uk/system/files/protected/page/Witholding%20....pdf)	Thank you for drawing our attention to these documents. As there is an 'end of life' guideline for infants, children and young people in planning, we believe that a reference to these documents would be better placed in this guideline. We would strongly encourage you to contribute to the consultation exercises on this guideline in development. Further detail is available on the NICE website.
373	SH	Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)	9	9, 10	A) "Dying adult" is an ambiguous title and could be misinterpreted as "palliative care". It does not reflect the limited scope of the guidance ie: dying in the last hours or days of life. It is suggested that perhaps the title would be more appropriately worded as: "Care of the adult who is actively dying". B) Passive mobilisations and positioning – Physiotherapists assist nursing staff in comfort measures such as positioning. Both of these aid pain	Thank you for your comments. We have amended the title of this guideline to the clinical care of the adult in the last days of life. We note your comment about positioning but we are not prioritising a review in this area.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					relief and inducing feelings of well being C) Pain management – physiotherapy can alter directly or indirectly the experience of pain at end of life in the context of "total pain". Interventions may include cold/heat treatment, massage and therapeutic touch, TENS, relaxation techniques and lymphatic physiotherapy. Some physiotherapists are also trained in complementary therapy such as acupuncture and aromatherapy. D) Breathlessness, fatigue and anxiety – these distressing symptoms can have a major impact on an individual's experience at the end of life. This scoping document states on page 4 (3). "Managing pain, breathlessness, anxiety and distress is key to a peaceful death". It goes on to say " concern has been voiced about injudicious use of such drugs causing undue sedation, which may increase distress for the person who is dying and their families of carers." Physiotherapists use a range of non-pharmacological techniques to ease symptoms of breathlessness, anxiety and distress at end of life which can be used alongside pharmalogical agents. Physiotherapy management of these symptoms might include sputum clearance and breathing control techniques, positioning, fan therapy, relaxation techniques, cognitive behavioural therapy and acupunture	The pharmacological management of symptom relief was highlighted as an area particularly requiring clinical guidance. Non pharmacological relief of symptoms, including physiotherapy, will not be covered in this guideline.
368	SH	Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)	4	9, 10	Symptom control – The role of physiotherapy of physiotherapy is completely excluded in the current scoping document. Importantly it is not even listed as an exclusion on the table commencing on page 10 (4.3.2). This failure to recognise the role of AHPs in the last hours/days of life is likely to have an impact on commissioning and developing our services in the future and fails to recognise the excellent work being done by our palliative care AHP colleagues around the country.	Thank you for your comment, the content of which is noted. The scope of this guideline focusses on the clinical care to be provided as prioritised in the scoping document. We are not able to address all issues of relevance for this topic. We believe that the composition of the multi-disciplinary team would fall into the remit of service provision, which is not covered in this guideline. We hope that the guidance derived will be of benefit to all clinicians and allied health professionals in the clinical care of the dying adult in the last days and hours of life. Further detail on the development of this guideline will be

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
						made available on the NICE website in due course.
369	SH	Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)	5	9, 10	Symptom control – the needs of patients vary greatly at end of life and so indications for physiotherapy must be assessed on an individual basis, dependently largely on the wishes of the individual and their family	Thank you for your comment. The pharmacological management of symptom relief was highlighted as an area particularly requiring clinical guidance. Non pharmacological relief of symptoms, including physiotherapy, will not be covered in this guideline.
370	SH	Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)	6	9, 10	Physiotherapy in the last hours or days of life can assist with: • Mobility and Independence – even in the last hours and days of life many patients wish to remain as physically independent as possible. The physiotherapist has a key role to play in facilitating physical autonomy at the end of life	Thank you for your comment, the content of which has been noted.
371	SH	Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)	7	9, 10	Passive mobilisations and positioning – Physiotherapists assist nursing staff in comfort measures such as positioning. Both of these aid pain relief and inducing feelings of well being	Thank you for your comment. We note your comment about positioning but this has not been prioritised as an area for review in this guideline.
372	SH	Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)	8	9, 10	Pain management – physiotherapy can alter directly or indirectly the experience of pain at end of life in the context of "total pain". Interventions may include cold/heat treatment, massage and therapeutic touch, TENS, relaxation techniques and lymphatic physiotherapy. Some physiotherapists are also trained in complementary therapy such as acupuncture and aromatherapy.	Thank you for your comment. The pharmacological management of symptom relief was highlighted as an area particularly requiring clinical guidance. Non pharmacological relief of symptoms, including physiotherapy, will not be covered in this guideline.

The following comments were made as a late submission from a non-registered stakeholder. NCGC have not responded.

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Category	Developer's Response Please respond to each comment
1b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		General	It is important that the guideline reflects the language in the "one Chance to Get it Right" document i.e. – family/relatives/those dear/loved ones = those important to the person who is dying.		
2b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		3e	"Good communication is necessary to ensure that people feel they are APPROPRIATELY involved in the decision making process... Rationale – it is important the guidance reflects legal and professional guidance regarding treatment and care. There is a body of evidence that if relatives/those important to the dying person are not appropriately involved in decisions that they are left with a burden of responsibility up to an including feeling that they were responsible for the death of a loved one, even though death is expected.		
3b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		3.1b	"the use of INTEGRATED CARE PATHWAYS FOR THE DYING PERSON" Add to sentence "There has been criticism, however, about how some elements of the LCP have been implemented, including issues of consent, use of painkillers and tranquilisers and communication about death and dying" Delete sentence "Some families.....tranquilisers" Insert "This criticism was examined in the "More Care, Less pathway" report which recognised the fundamental principles of care of the dying but that the use of the LCP... Rationale – More Care, Less Pathway recognises some of the problems of the LCP use but also the core principles being ethically sound. It is important to recognise both aspects.		
4b		Cheshire & Merseyside Palliative and End of Life Strategic		3.2a	"Providing guidance that supports clinicians to recognise dying [delete to make a prognosis of imminent death] and communicate this [delete prognosis] Rationale – the sentence in the draft has two issues intermingled – one of prognosis, i.e. time and natural history and one of diagnosis – i.e. making the		

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Category	Developer's Response Please respond to each comment
		Clinical Network			decision that someone is dying. It is important that these issues are separate and clear. There is also a move away from diagnosing dying to recognising dying. "Diagnosing" implies a pathological process, recognising supports the assertion made in 3a that dying and death is a natural process. Some people die over a matter of seconds to minutes, others die over a period of days to weeks. "the ~~approach~~ NATURE of death AND DYING in cancer has HISTORICALLY been a relatively EASIER ~~path~~ NATURAL HISTORY THAN IN OTHER LIFE LIMITING ILLNESS.		
5b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.1.1	The groups covered are appropriate *Special consideration will be given to people with: dementia, cancer and organ system failure (including heart failure)* When discussing inequalities it seems wrong to then specifically talk about heart failure when of course other end stage disease is equally as burdensome – for example End Stage Respiratory Diseases such as COPD or Pulmonary Fibrosis, End Stage Renal Failure and End Stage Liver Disease.		
6b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.1.1	Although people with communication, cognitive or learning difficulties are not included separately because they do not have the same poor prognosis I do think that this group of patients may have specific needs when they are dying and can suffer from inequalities in access to existing support and services so specific consideration to their needs should be considered.		
7b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.2	The settings are appropriate		
8b		Cheshire &		4.3.1a	Agree with clinical issue		

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Category	Developer's Response Please respond to each comment
		Merseyside Palliative and End of Life Strategic Clinical Network					
9b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.3.1b	As highlighted in earlier comments, it is critical that the framework for answering this question follows legal and professional guidance and recognises areas that have are difficult including the difference between informing, consulting and giving decisions to dying people and those important to them. A lot of the problems currently experienced in care of the dying is because of misinformation and poor communication based on this. It is also important to note that shared decision making has its own terminology and there is little evidence applying shared decision making in medical decisions within the English context.		
10b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.3.1c	Agree with issues and rationale		
11b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.3.1d	Agree with issue and rationale **Section d)** Clinically Assisted Hydration. • Whilst welcoming the need to have more evidence about the use and effectiveness of assisted hydration at the end of life, it is essential that there is no 'blanket recommendation' about their use. • The need for assisted hydration needs to be always made on an individual patient basis and based on clinical need. For example, A patient who is suffering from pulmonary oedema and struggling with respiration is not likely to benefit from further fluid burden at this time. A patient who is severely peripherally oedematous with limited (if any) peripheral access is not likely to gain any benefit from further fluids. A		

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Category	Developer's Response Please respond to each comment
					patient who appears very dehydrated and symptomatic from this may benefit from fluids and this should be considered. Each patient is individual. • Patient and family involvement in decision making supported by excellent communication is essential for each case. Patients should be encouraged and assisted with oral intake for as long as it is possible of both food and fluids Regarding GMC guidance, the GMC guidance in treatment and care towards the end of life does give guidance on hydration and nutrition separately and specifically highlights issues of hydration in the last hours and days of life.		
12b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.3.1e	Agree with issues and rationale		
13b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.3.2	The omission of social needs of the dying person and their family and carers is disappointing and it should be included in this guidance. The omission of the spiritual needs of the dying person and their family and carers from this guidance is disappointing. It should be included, particularly as this has been highlighted as an area of need in the National Care of the Dying Audit Hospitals in terms of both patient care and relatives' care.		
14b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.4	The main outcomes are unclear in this scope. The adverse events are sometimes outcomes of the dying process. By using the term adverse events this suggests it is linked to healthcare interventions – therefore it needs to be clearly linked to evidence. Unsure about an outcome being the number of people correctly being identified to being in the last hours and days of life – not aware of an evidence supporting this outcome nor what an appropriate percentage would be. There is also the risk that to ensure that people are absolutely sure that high quality care of the dying would be denied to people as clinicians would be unsure.		

ID	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Category	Developer's Response Please respond to each comment
15b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.5	Agree with questions apart from e) this is confounded by type of illness, pattern of illness, co-illnesses, co-prescription of drugs, genomic factors, organ function. Is the aim of this question to identify a suitable dose?		
16b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.5 d	**Section d)** *For adults in the last days of life, is medically assisted hydration effective in improving quality of care?* Again I think this is impossible to answer as a general question and must be addressed on an individual patient basis.		
17b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		4.5 e	**Section e)** *For adults who are in the last days of life, what is the most effective level of sedative medication (opioids, benzodiazepines and major tranquillisers)in the management of pain, anxiety, terminal agitation and breathlessness?* Again there will never be a most effective level as every patient is individual. The effective level for each individual will be dependent upon the severity of their symptom, their usual medication and patient preference in what level of sedation is appropriate for them.		
18b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		General	Agree that aiming for the last days of life is appropriate as the mode timeframe within which most people die. There is a challenge with managing more protracted dying phases which do occur in all conditions. Specialist palliative care teams are involved in these, especially in hospital and nursing homes where they are frequently of people without cancer.		
19b		Cheshire & Merseyside Palliative and End of Life Strategic Clinical Network		General	Regarding the aspects of difficulty with clinical decision-making and symptom management in the last few weeks of life: Some issues here include decisions about introduction of anticipatory prescribing, decisions around communication strategies at a time of advancing ill health and use of health services		

These organisations were approached but did not respond:

AMORE health Ltd
Association of Ambulance Chief Executives
Association of Anaesthetists of Great Britain and Ireland
Association of Respiratory Nurse Specialists
Barnsley Hospital NHS Foundation Trust
Belfast Health and Social Care Trust
Bereavement Advice Centre
BeTr Foundation
British Acupuncture Council
British Association of Dramatherapists
British Gynaecological Cancer Society
British Heart Foundation
British Infection Association
British Medical Association
British Medical Journal
British Nuclear Cardiology Society
British Psychological Society
British Red Cross
Care Not Killing Alliance
Care Quality Commission
Complementary and Natural Healthcare Council
Cumbria Partnership NHS Foundation Trust
CWHHE Collaborative CCGs
Department of Health, Social Services and Public Safety - Northern Ireland
East and North Hertfordshire NHS Trust
Economic and Social Research Council
False Allegations Support Organisation
Gloucestershire Hospitals NHS Foundation Trust
GP update / Red Whale
Health & Social Care Information Centre
Health and Care Professions Council
Healthcare Improvement Scotland
Healthcare Inspectorate Wales
Healthcare Quality Improvement Partnership

Hertfordshire Partnership University NHS Foundation Trust
Home Instead Senior Care
Humber NHS Foundation Trust
Imperial College Healthcare NHS Trust
King's College Hospital NHS Foundation Trust
Lancashire Care NHS Foundation Trust
Making Space
Medicines and Healthcare products Regulatory Agency
Mencap
Ministry of Defence (MOD)
National Clinical Guideline Centre National Collaborating Centre for Cancer
National Collaborating Centre for Mental Health
National Collaborating Centre for Women's and Children's Health
National Council for Palliative Care
National Deaf Children's Society
National Institute for Health Research
NHS Coastal West Sussex CCG
NHS Great Yarmouth and Waveney CCG
NHS Hardwick CCG
NHS Health at Work
NHS Leeds West CCG
NHS Lincolnshire East CCG
NHS North Somerset CCG
NHS Portsmouth Clinical Commissioning Group
NHS Sheffield CCG
NHS South Norfolk CCG
NORTH EAST LONDON FOUNDATION TRUST
Northern Health and Social Care Trust
Nottinghamshire Healthcare NHS Trust
Nottinghamshire Hospice
Nursing and Midwifery Council
Oxleas NHS Foundation Trust
Pathfinders Specialist and Complex Care
PHE Alcohol and Drugs, Health & Wellbeing Directorate
Public Health England
Public Health Wales NHS Trust
Public Health Wales NHS Trust
Pumping Marvellous

Rainbows Children's Hospice
Resuscitation Council UK
Rotherham Doncaster and South Humber NHS Foundation Trust
Royal College of General Practitioners in Wales
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Physicians
Royal College of Psychiatrists
Royal College of Surgeons of Edinburgh
Royal College of Surgeons of England
Royal Cornwall Hospitals NHS Trust
Royal Pharmaceutical Society
Sarcoma UK
Scottish Intercollegiate Guidelines Network
Sheffield Teaching Hospitals NHS Foundation Trust
Social Care Institute for Excellence
Society for Acute Medicine
South Eastern Health and Social Care Trust
South West Yorkshire Partnership NHS Foundation Trust
Southern Health & Social Care Trust
St Mungo's Broadway
Sue Ryder
Tenovus
Tenovus The Cancer Charity
The Wiltshire Trust
UK Council for psychotherapy
Welsh Government
Welsh Scientific Advisory Committee
West Suffolk Hospital NHS Trust
Western Health and Social Care Trust