

ONE CHANCE TO GET IT RIGHT

Improving people's experience of care
in the last few days and hours of life.

Published June 2014 by the
Leadership Alliance for the Care of Dying People

Alliance members

This document has been developed by the Leadership Alliance for the Care of Dying People (LACDP), which was established following an independent review of the Liverpool Care Pathway for the Dying Patient (LCP). The LACDP is a coalition of 21 national organisations that was set up to lead and provide a focus for improving the care of people who are dying and their families. The Alliance members are listed below:

Care Quality Commission
College of Health Care Chaplains
Department of Health
General Medical Council
General Pharmaceutical Council
Health and Care Professions Council
Health Education England
Macmillan Cancer Support
Marie Curie Cancer Care
Monitor
National Institute for Health Research
NHS England
NHS Improving Quality
NHS Trust Development Authority
NICE (National Institute for Health and Care Excellence)
Nursing and Midwifery Council

Public Health England
Royal College of GPs
Royal College of Nursing
Royal College of Physicians
Sue Ryder

Marie Curie Cancer Care also represented Help the Hospices and the National Council for Palliative Care; Sue Ryder also represented the National Care Forum; Macmillan Cancer Support also represented the Richmond Group of Charities.

Throughout the development of the policies and processes cited in this document, the Leadership Alliance for the Care of Dying People has given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited in under the Equality Act 2010) and those who do not share it.

Contents

Executive summary	6
Background	9
The Liverpool Care Pathway	9
The Independent Review	9
The Leadership Alliance for the Care of Dying People	9
Acknowledgements	12
Priorities for Care of the Dying Person	13
Implementing the Priorities for Care	14
The Priorities for Care of the Dying Person	16
Priority 1	17
This possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.	
Recognising 'dying'	17
Communicating about dying	18
Priority 2	19
Sensitive communication takes place between staff and the dying person, and those identified as important to them.	
Priority 3	20
The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.	
Involvement of families in decision-making	20
Professional responsibility for decisions about care and treatment	21
Communicating professional responsibility for care and treatment	21
Capacity and advance decisions	21
Priority 4	23
The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.	

Priority 5	24
An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.	
Planning care	24
Food and drink	25
Use of sedatives and pain relief	26
Advice from specialist palliative care teams	27
Documenting treatment and care	27
Phasing out the LCP	30
Education, training and professional development	31
Training for doctors	31
Ongoing education and training for all health and care staff	32
Assessment and evaluation of training, education and learning to support health and care staff caring for dying people	33
Advice	34
Terminology relating to death	34
Terminology relating to guidance	34
Pathways	34
NICE	35
General Medical Council (GMC), Nursing and Midwifery Council (NMC), Health and Care Professions Council (HCPC), General Pharmaceutical Council (GPhC)	35
The Alliance's approach to terminology	36
Extent of existing guidance relevant to care in the last few days and hours of life	36
Advice on decision-making	37
Implementing the new Priorities for Care	38
Inspection and regulation	38
Commissioning	39
Organisational leadership and governance	40
A priority for NHS England in the Mandate	40
Research	41
Transforming Primary Care (Vulnerable Older People's Plan)	42

Annexes	43
Annex A: Membership and Terms of Reference of the Leadership Alliance for the Care of Dying People (LACDP)	44
Annex B: Responses to Individual Panel Recommendations	47
Annex C: Priorities for Care of the Dying Person	76
Annex D: Priorities for Care of the Dying Person – Duties and Responsibilities of Health and Care Staff	80
Annex E: Priorities for Care of the Dying Person – Implementation Guidance for Service Providers and Commissioners	93
Annex i	101
Annex ii	102
Annex iii	103
Annex F: Terms of Reference for the Independent Review of the Liverpool Care Pathway	105
Annex G: Glossary of terms	106
Annex H: End of life care in existing training for professionals	112
Annex I: Spiritual Care Assessment Tool Based on FICA approach	138
Annex J: Report of rapid review on guidance on end of life care commissioned by the Leadership Alliance	140
Appendix A	162
Annex K: Terms of Reference and Membership of the LACDP Clinical Advisory Group	164
Annex L: Terms of Reference and Membership of the LACDP Guidance, Education and Training Advisory Group	166

Executive summary

This document sets out the approach to caring for dying people that health and care organisations and staff caring for dying people in England should adopt in future. The approach should be applied irrespective of the place in which someone is dying: hospital, hospice, own or other home and during transfers between different settings.

The approach has been developed by the Leadership Alliance for the Care of Dying People (LACDP), a coalition of 21 national organisations concerned to ensure high quality, consistent care for people in the last few days and hours of life.¹ The Alliance was established following an independent review of the Liverpool Care Pathway for the Dying Patient (LCP), which reported in July 2013.² The LCP was an approach to care developed during the 1990s, based on the care of the dying within the hospice setting, with the aim of transferring best practice to other settings. The review panel found evidence of both good and poor care delivered through use of the LCP and concluded that in some cases, the LCP had come to be regarded as a generic protocol and used as a tick box exercise. Generic protocols are not the right approach to caring for dying people: care should be individualised and reflect the needs and preferences of the dying person and those who are important to them.

The review panel recommended that use of the LCP should be phased out by July 2014; the Minister for Care and Support agreed this recommendation.³ This document sets out the approach that should be taken in future in caring for all dying people in England, irrespective of whether organisations were previously using the LCP.

The approach focuses on achieving five Priorities for Care. These make the dying person themselves the focus of care in the last few days and hours of life and exemplify the high-level outcomes that must be delivered for every dying person. The way in which the Priorities for Care are achieved will vary, to reflect the needs and preferences of the dying person and the setting in which they are being cared for. This approach is not, in itself, new. Where good care for dying people has been and continues to be given, it is typified by looking at what that care is like from the perspective of the dying person and the people who are important to them and developing and delivering an individualised plan of care to achieve the essentials of good care. Many health and care organisations and staff are already doing this and in some cases, as the review panel found, used the LCP to help them do so. However in other places, the LCP was associated with standardised treatment and care, carried out irrespective of whether that was right for the particular person in the particular circumstances. In some cases, the delivery of standardised treatment and care caused unnecessary distress and harm to dying people and those who were important to them. The risk of this continuing to happen is not tenable. Hence, the new approach set out in this document will replace the LCP.

¹ Listed at Annex A.

² See *More Care, Less Pathway. A Review of the Liverpool Care Pathway*, at: <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

³ See Commons Hansard 15 July 2013 Cols 62-64 WS

Priorities for Care of the Dying Person

The Priorities for Care are that, when it is thought that a person may die within the next few days or hours..

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

The variations in care for dying people found by the review panel highlight that where change is needed, it is in the practice of particular local organisations and staff. The role of national organisations is to require, encourage and support that change. In some instances where organisations are delivering poor care to dying people, the issue is not just about care in the last few days and hours of life. The Francis Inquiry⁴ into the events at Mid Staffordshire NHS Foundation Trust highlighted an organisational culture that tolerated poor standards and a disengagement from managerial and leadership responsibilities. Where these sorts of failings occur it is very likely that their manifestation in poor standards of care will include poor standards of care for dying people. The programme of action being taken in response to the findings of the Francis Inquiry will, therefore, be a key element in ensuring consistent, high quality care for people in the last days and hours of life.

In addition, the 21 organisations in the Leadership Alliance for the Care of Dying People are committed, as appropriate to their individual roles, to requiring, encouraging and supporting the changes local organisations and individual staff need to make to deliver the five Priorities for Care of the Dying Person consistently for everyone in the last few days and hours of life in England. As well as setting out the five Priorities for Care of the Dying Person in detail, this document sets out what the members of the Leadership Alliance will do to require, encourage and support their adoption and delivery. Annex B relates these actions to the recommendations for national organisations made by the LCP review panel. The document is accompanied by a separate commitment statement and call to action by Alliance members. This sets out their collective and individual commitments to ensuring that all care given to people in the last days and hours of life in England:

- is compassionate;
- is based on and tailored to the needs, wishes and preferences of the dying person and, as appropriate, their family and those identified as important to them;

⁴ See www.midstaffspublicinquiry.com

- includes regular and effective communication between the dying person and their family and health and care staff and between health and care staff themselves;
- involves assessment of the person's condition whenever that condition changes and timely and appropriate responses to those changes;
- is led by a senior responsible doctor and a lead responsible nurse, who can access support from specialist palliative care services when needed; and
- is delivered by doctors, nurses, carers and others who have high professional standards and the skills, knowledge and experience needed to care for dying people and their families properly.

Nothing less will do.

Background

The Liverpool Care Pathway

1. The LCP was an approach to care developed during the 1990s, based on the care of the dying within the hospice setting, with the aim of transferring best practice to other settings. The LCP provided guidance on a range of different aspects of care, including: comfort measures; anticipatory prescribing of medicines; discontinuation of interventions that were no longer necessary or in the patient's best interests; psychological and spiritual care; and care of the family (both before and after the patient's death).⁵ A range of support materials and guidance was available to support the use of the LCP: these included template documents; training for health and care staff; and arrangements for audit and evaluation about how the LCP had been used and its outcomes.

The Independent Review

2. Following concerns expressed particularly by families during 2012, the Minister for Care and Support commissioned an independent review of the LCP in January 2013, under the chairmanship of Baroness Julia Neuberger. The terms of reference for the review are at Annex F. The review received 483 submissions from members of the public, 91 from health and care professionals, some of whom also had experience of the LCP in their personal capacities, and 36 professional bodies and other organisations. Members of the review panel made visits to health providers that were using the LCP in a range of care settings. The panel held sessions in Leeds, London, Preston and Bristol, where they met 113 members of the public to hear their experiences directly from them.⁶ The panel published its report on 15 July 2013. Most of the panel's recommendations were for national organisations, reflecting the Panel's focus on creating strategic frameworks to deliver better care.

The Leadership Alliance for the Care of Dying People

3. In response to the panel's report, the 21 national organisations listed at Annex A came together to form the Leadership Alliance for the Care of Dying People. The starting point for the Alliance was the group of statutory/regulatory bodies to which the review panel addressed particular recommendations. This group invited other interested organisations, including charities, to develop, support and contribute to this work as members of the Alliance. The terms of reference and membership for the Leadership Alliance are at Annex A. The purpose of the Alliance was to take collective action to secure improvements in the consistency of care given in England

⁵ Ellershaw J, Wilkinson S: *Care of the Dying: A Pathway to Excellence*, 2nd Ed. Oxford: Oxford University Press, 2011, Introduction

⁶ See *More Care, Less Pathway: A Review of the Liverpool Care Pathway*, p. 13, paragraph 1.6 at: <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

to everyone in the last few days and hours of life and their families. Its objectives were to:

- support all those involved in the care of people who are dying in responding to the findings of the review; and
 - be the focal point for the system's response to the findings and recommendations of the LCP review.
4. The Alliance has now fulfilled these purposes and ceased to be as such. However, members of the Alliance, along with other bodies, will continue to work collectively to improve end of life care in England. This will include joint work to set and deliver future ambitions for end of life care. The joint working which has been done through the Alliance and which national organisations intend to do more widely to improve end of life care reflects the "national coalition" called for by the review panel. (Recommendation 39.)
 5. The key part of the Alliance's work was the development of Priorities for Care, intended as the basis of care for everyone in the last few days and hours of life, irrespective of whether that care is provided in a hospital, hospice, the person's home (including care homes) or another place. Alliance members are committed to taking forward the Priorities for Care and have already taken individual and collective action to implement the Priorities for Care, in response to the review panel's recommendations and more widely.
 6. The Alliance conducted widespread engagement on a draft version of the Priorities for Care (which were at that time called "outcomes and guiding principles"). The results of the engagement are reflected in the final version of the Priorities for Care.
 7. The Priorities for Care reinforce that the focus for care in the last few days and hours of life must be the person who is dying. They are all equally important to achieving good care in the last days and hours of life. Each supports the primary principle that individual care must be provided according to the needs and wishes of the dying person. To this end the Priorities are set out in sequential order. The Priorities are that, when it is thought that a person may die within the next few days or hours of life:
 - This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
 - Sensitive communication takes place between staff and the dying person, and those identified as important to them.
 - The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
 - The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
 - An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

8. The Priorities for Care are supported by:
 - duties and responsibilities of health and care staff to deliver the Priorities for Care (see Annex D);
 - implementation guidance for service providers and commissioners (see Annex E).
9. The Priorities for Care are relevant and accessible to everyone. The supporting documents are not alternative forms of the Priorities for Care. They are articulations of the Priorities for Care intended to make clear what individuals and organisations should do to deliver good care for dying people.

Acknowledgements

10. During this work, the Alliance received an immense amount of support from organisations and individuals. Alliance members are grateful to all those who have contributed, including:
 - those bereaved families and other individuals with experience of the care of dying people who attended workshops to discuss the draft “Outcomes and Guiding Principles”, including families and individuals who had previously given evidence to the review panel;
 - families and others with experience of receiving care for dying people who gave their views on-line and directly;
 - Help the Hospices, Macmillan Cancer Support, Marie Curie, Sue Ryder and the National Council for Palliative Care, who hosted and supported 12 regional workshops for individual family members and clinicians to discuss proposed “outcomes and guiding principles” for care in the last days and hours of life and how to take them forward;
 - Macmillan Cancer Support, for also funding a rapid review in relation to current advice on caring for people in the last few days and hours of life and Help the Hospices for supporting the analysis through the provision of a researcher;
 - health and care staff who attended the workshops, commented on the proposals on-line or otherwise put forward their views;
 - members of the Alliance’s Clinical Advisory Group and Guidance, Education and Training Advisory Group;
 - other individuals who attended additional meetings and workshops and contributed from their personal and professional experience; and
 - the Royal College of Physicians for providing the Secretariat to the Clinical Advisory Group.
11. Finally, Alliance members wish to thank the independent review panel members for their work in producing the report *More Care, Less Pathway*, and for their commitment to ensuring that dying people and their families receive the best care possible.

Priorities for Care of the Dying Person

12. Alliance members believe the starting point for ensuring excellent care for everyone in the last few days and hours of life should be a common description and understanding, between health and care staff and the dying person and those important to them and between staff themselves, of what such care looks like. This is in the form of five Priorities for Care of the Dying Person. Alliance members will monitor the situation as the Priorities for Care are implemented and expect to modify them in the light of feedback from dying people and their families and health and care staff, and as new research evidence becomes available. This will be done through an NHS England-initiated working group, which is being formed to support strategic work on the broader aspects of end of life care.
13. The Priorities for Care provide a new focus for caring for people in the last few days and hours of life, which involves assessing and responding to the holistic and changing needs of individual dying people and their families. Those providing such care, in whatever setting, including the person's home, will need to demonstrate (e.g. as part of CQC inspections) how they are achieving the Priorities for Care, not in a generic way, but by reference to the particular person. It will not be sufficient to demonstrate delivery of particular protocols or tools. Staff and service providers will need to be able to show that the Priorities for Care the Alliance has developed, through widespread engagement, are being met.
14. The Priorities for Care express the common principles of good palliative care. The duties and responsibilities of health and care staff to deliver them, which have also been set out by the Alliance, are consistent with standards of practice set out in GMC good practice guidance, *Treatment and care towards the end of life: good practice in decision-making*, the NMC's Code and competency standards for nursing practice, the HCPC's Standards of conduct, performance and ethics and the General Pharmaceutical Council's *Standards of conduct, ethics and performance*. (Panel recommendation 36 refers.)

Implementing the Priorities for Care

15. Key elements of the work Alliance members have done and will do to take forward the Priorities for Care of the Dying Person include:

- The Priorities for Care are aligned with the existing NICE Quality Standard for End of Life Care.
- NICE will take account of the Priorities for Care and accompanying Duties and Responsibilities of Health and Care Staff in drawing up a new Clinical Guideline on the care of dying adults, which it expects to publish in 2015.
- The Priorities for Care and the accompanying Duties and Responsibilities of Health and Care Staff and Implementation Guidance for Service Providers and Commissioners are informing and will continue to inform CQC's new approach to hospital inspections, under which end of life care will be one of eight core service areas to be inspected.
- They will also inform the inspection of end of life care in hospices, adult social care, community health services and general practice. They will also be taken into account as CQC undertakes a themed inspection focusing on end of life care, in 2014/15.
- The NHS Trust Development Authority will support NHS Trusts to implement the Priorities for Care and Implementation Guidance for Service Providers to enable them to provide high quality end of life care.
- The Priorities for Care and the Duties and Responsibilities of Health and Care Staff are aligned with the General Medical Council's good practice guidance, *Treatment and care towards the end of life: good practice in decision-making*, the Nursing and Midwifery Council's professional code of conduct, *The Code: Standards of conduct, performance and ethics for nurses and midwives*, the Health and Care Profession Council's *Standards of Conduct, Performance and Ethics* and the General Pharmaceutical Council's *Standards of Conduct, Ethics and Performance*, breach of any of which can endanger professional registration.
- The forthcoming reviews of professional standards by the Nursing and Midwifery Council, the General Pharmaceutical Council and the Health and Care Professions Council (HCPC) will consider whether nursing standards, standards for pharmacy professionals and standards for HCPC-registered professionals respectively need to be strengthened in the light of the development of the Priorities for Care and the Duties and Responsibilities of Health and Care Staff.
- The GMC will promote the Priorities for Care and the Duties and Responsibilities of Health and Care Staff as part of its work in 2014 to raise the profile of its guidance.

- Health Education England and other Alliance members will initiate work that guides health and care staff and educators in the use of the e-learning programme, e-ELCA⁷, as a resource to support education and training.
 - The Alliance has initiated work that will make existing advice to health and care staff on care for dying people, including the advice that already exists in relation to specific diseases and conditions, more accessible, through the creation of a central repository.
 - The National Institute for Health Research (NIHR) has commissioned updates of Cochrane Reviews of evidence on medically assisted nutrition and on medically assisted hydration for palliative care patients, and these were published by the Cochrane Collaboration in April 2014. The NIHR has also commissioned a mapping of evidence requirements flowing from the Priorities for Care.
 - The Alliance will use the outcomes from the results of the mapping and the recently established James Lind Alliance Priority Setting Partnership, which will work with families and others to find out what palliative and end of life care research is important to people who are likely to be within the last years of life, their families and those identified as important to the dying person, and the health and care staff who work with them, to inform the programme of future research around care for people in the last few days and hours of life.
16. Alliance members also agree with the foreword of the independent review panel's report and believe that it is essential that there should be a "proper National Conversation about dying". They take this to mean that everyone, members of the public, health and social care staff and the media should have opportunities to participate meaningfully in discussions about dying to raise awareness and understanding of this important part of life that everyone will experience, and to help ensure that people's care and experience is as good as it can be. Alliance members commit to working together and with all these groups to generate and promote this conversation.

⁷ e-ECLA (End of Life Care for All) is a series of over 150 highly interactive sessions of e-learning on end of life care, which aims to enhance the training and education of health and social care staff involved in delivering end of life care to people.

The Priorities for Care of the Dying Person

17. The Priorities for Care reinforce that the focus for care in the last few days and hours of life must be the person who is dying. They are all equally important to achieving good care in the last days and hours of life. Each supports the primary principle that individual care must be provided according to the needs and wishes of the dying person. To this end the Priorities are set out in sequential order.
18. If it is established that a person lacks capacity at the relevant time to make the relevant decision, then a decision must be taken in their best interests in accordance with the Mental Capacity Act 2005. The person making the decision must, if it is practicable and appropriate to do so, consult:
 - anybody named by the person as someone to be consulted on either the decision in question or similar issues;
 - anyone engaged in caring for the person, close relatives, friends or others who take an interest in the person's welfare;
 - any holder of a lasting power of attorney or enduring power of attorney; and
 - any deputy appointed by the court to make decisions for the person.

This is referred to below as a 'best interests decision'. Further guidance on how this decision should be made is provided in the Mental Capacity Act Code of Practice. If the person lacks capacity and there is a person with a registered lasting power of attorney who has the power to make the relevant decision, then the attorney should make the decision in the best interests of the person. It is also important to respect valid and applicable advance decisions.

Priority 1

This possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

19. When a person's condition deteriorates unexpectedly, and it is thought they may die soon, i.e. within a few hours or very few days, they must be assessed by a doctor who is competent to judge whether the change is potentially reversible or the person is likely to die. If the doctor judges that the change in condition is potentially reversible, prompt action must be taken to attempt this, provided that is in accordance with the person's wishes or in their best interests if it is established that they lack capacity to make the decision about treatment at that time. If the doctor judges that the person is likely to be dying, taking into account the views of others caring for the person, this must be clearly and sensitively explained to the person in a way that is appropriate to their circumstances (if conscious and they have not indicated that they would not wish to know), and their family and others identified as important to them. The person's views and preferences must be taken into account, and those important to them must be involved in decisions in accordance with the person's wishes. A plan of care must be developed, documented, and the person must be regularly reviewed to check that the plan of care remains appropriate and to respond to changes in the person's condition, needs and preferences.

Recognising 'dying'

20. Alliance members are concerned that there are misperceptions about the point at which a person becomes a 'dying person', at which treatment might end and care become palliative and about the level of certainty surrounding such judgements. Alliance members do not think that it is always possible or helpful to people who may be dying and their families to seek to make a definitive diagnosis of 'dying'. Care for people who are potentially in the last few days and hours should be a continuum, focusing on continually assessing their condition, needs and wishes and responding appropriately. However, professionals must make clear to the dying person and those who are important to them when it is thought that the person is likely to be dying and they should explain to them why they think this, what it is likely to entail and the uncertainties round this. Where a person's condition changes, this should be a 'trigger' for making decisions to change care and treatment (or review the position again later, e.g. when the senior clinician is next available). Even if it has been determined that someone may be dying, health and care staff must continue to offer them food and drink, provided eating and drinking would not harm the person. If the person wants this and needs help to eat and drink, health and care staff must provide that help.

21. The Alliance's approach creates a focus on recognition of patients who are clinically unstable and may not recover despite medical treatment, so that those patients and those important to them are as involved as much as possible in decisions being made about their care, rather than focusing on a 'diagnosis of dying', as occurred with the LCP. Alliance members themselves will adopt the approach of focusing on changes in the condition of someone who is likely to be dying, rather than diagnosing dying only. They will also stress the importance of ensuring that if someone is likely to be dying, this is clearly explained to the dying person (if conscious) and those important to them. They consider that this approach will deliver the intention behind the review panel's recommendation that definitions of time frames relating to end of life decision-making should be embedded firmly into the context of existing policies and programmes. (Panel recommendation 1 refers.)
22. The Alliance has considered the various prognostic tools that may help clinicians assess whether someone is in the last few days and hours of life, but has concluded that at the moment, there is insufficient evidence base for any specific tool to be endorsed by the Alliance (Panel recommendation 8 refers.)

Communicating about dying

23. The review panel noted that: "A common theme among respondents was that they were simply not told that their loved one was dying; this clearly contributed to a failure to understand that the patient was dying, compounded their distress and subsequently their grief, after what they perceived to have been a sudden death. It appears in these cases that conversations with relatives or carers to explain the diagnosis or prognosis had simply not taken place, or that doctors had used euphemisms such as 'making comfortable'. In other cases, discussions about the fact that the patient was regarded as dying took place hurriedly and inappropriately..."⁸
24. This is not acceptable practice. The Alliance's statement of the Duties and Responsibilities of Health and Care Staff includes that:
- "If the doctor judges that the person is likely to die soon, s/he must clearly and sensitively communicate this to the dying person (if conscious). This includes explaining when and how death might be expected to occur and the basis for that judgement, acknowledging and accepting any uncertainty about the prognosis, and giving the dying person the opportunity to ask questions. The same communication must take place with those important to the dying person and others involved in that person's care"; and*
- "The goals of treatment and care must be discussed and agreed with the dying person, involving those identified as important to them and the multidisciplinary team caring for the person. These discussions must be clearly documented and accessible to all those involved in the person's care, taking into account the person's wishes about sharing their confidential information. Doctors and nurses must acknowledge, accept and communicate uncertainty that exists about the prognosis."*

⁸ More Care, Less Pathway. A Review of the Liverpool Care Pathway, p. 24, paragraph 1.49, at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

Priority 2

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

25. Open and honest communication between staff and the person who is dying, and those identified as important to them, including carers, is critically important to good care. Clear, understandable and plain language must be used verbally and in all other forms of communication with the dying person and those important to them. If the dying person needs additional support to understand information, communicate their wishes or make decisions, these needs must be met. Communication must be regular and pro-active, i.e. staff must actively seek to communicate, not simply wait for the person or those important to them to ask questions. It must be two-way, i.e. staff must listen to the views of the person and those important to them, not simply provide information. It should be conducted in a way that maximises privacy. Communication must be sensitive, respectful in pace and tone and take account of what the dying person and those important to them want and feel able to discuss at any particular point in time. Staff must check the other person's understanding of the information that is being communicated, and document this.

26. The Alliance's statement of the duties and responsibilities of health and care staff includes that:

"Health and care staff must make time to talk with dying people, their families and those identified as important to them, including carers. They must listen, respond sensitively to their issues and concerns, provide information in a way that meets their communication needs and check that explanations and information are understood."

"The content and outcome of all discussions must be documented and accessible to all those involved in the person's care. This includes conversations about prognosis, goals of treatment and care plans at each point in time, and particular concerns that the person, their family and those identified as important to them have expressed."

(Panel recommendations 29, 30 and 31 refer.)

Priority 3

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

27. Individuals vary in the extent to which they wish to be involved in decisions about their own treatment, though most would want to make or influence decisions about the care they receive, and the way this is delivered. This includes day to day decisions about food, drink and personal care, as well as clinical and treatment decisions. Individuals also vary in the extent to which they wish their families and those important to them to be involved in decision-making. Sensitive communication is needed to ascertain the wishes of the dying person and their wishes must be respected. The person, and those important to them, must be told who is the senior doctor in the team who has responsibility for their treatment and care, whether in hospital or in the community, and the nurse leading their care. Where it is established that the dying person lacks capacity to make a particular decision, the decision made or action taken on their behalf must be in their best interests, and they should still be involved as far as possible in that decision.

Involvement of families in decision-making

28. The NHS Constitution pledges: “You have the right to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this. Where appropriate this right includes your family and carers.”⁹ The NHS Constitution Handbook includes more detail on what this right means and its legal underpinning.¹⁰
29. Involving families and carers in decisions about a dying person’s treatment and care can be a very difficult and sensitive area: as the review panel noted: “It is clear that one of the central issues causing difficulty [with the LCP] seems to be some misunderstanding and uncertainty over whether deciding to implement the LCP is a treatment decision that requires the patient’s consent (if the person has capacity) or requires the decision to be taken in the patient’s best interests (if the person lacks capacity). In some cases, relatives and carers incorrectly consider they are entitled to decide what treatment their relatives receive, and in others clinicians fail to seek consent or consult the relatives and carers in a ‘best interests’ assessment when they should.”¹¹ Alliance members agree that it should be made clear to dying people and those who are important to them whether they are being informed about, consulted about, involved in or taking particular decisions about treatment and care.

⁹ NHS Constitution, p. 9 www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf

¹⁰ NHS Constitution Handbook, pp. 70-71. www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/handbook-to-the-nhs-constitution.pdf

¹¹ *More Care, Less Pathway. A Review of the Liverpool Care Pathway*, p. 23, paragraph 1.44 at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

Professional responsibility for decisions about care and treatment

30. An area of particular concern to the review panel was decisions to withdraw or not to start potentially life-prolonging treatments. They were concerned about the timing of such decisions, including when they were made overnight. Where this happens, there is likely to be less scope to involve people whom the dying person has indicated they would like to be involved in such decisions. The review panel was also concerned that in some cases, such decisions were being taken by staff without the requisite training and competence. The Alliance's statement of the duties and responsibilities of health and care staff sets out that: "Doctors, nurses and other healthcare professionals must carefully consider which decisions need to be made on-the-spot to ensure the person's comfort and safety, and which can and must wait for a review of the person's condition by the senior doctor who has responsibility for the person's treatment and care (who may know the person better and/or have relevant competence and information to inform treatment decisions) or a clinician with the appropriate training and competence to whom the responsibility has been delegated".
31. This is consistent with and reinforces that, in line with the Government's response to the Francis Inquiry¹², every hospital patient should have the name of a responsible consultant/clinician and nurse above their bed. The Care Quality Commission will include the latter in its inspection of the quality of end of life care experienced by people in acute hospitals. (Panel recommendations 13 and 14 refer.)

Communicating professional responsibility for care and treatment

32. If the dying person does not know which professionals are in charge of their care at any point in time, it is very difficult for them to make clear how far they want to be involved in decisions about their treatment and care and then, insofar as they want, be involved in them. If people who are important to the dying person are to be involved in those decisions, they also need to know who the senior doctor responsible for the dying person's care and the lead nurse are, including when this changes, e.g. at the end and beginning of shifts. The review panel said: "From experiences described to the Review panel, it is clear that patients, their relatives and carers need to know better who is the senior responsible doctor in their care..."¹³ The Alliance's statement of the duties and responsibilities of health and care staff make it clear that the dying person and, as appropriate, those important to them, should always know who is in charge of the dying person's treatment and care. (Panel recommendations 14, 15, 26 and 27 refer.)

Capacity and advance decisions

33. Professionals must ensure that they comply with legal requirements in relation to representation or advocacy for people who lack capacity to consent. The Mental Capacity Act 2005 provides that in certain circumstances where the person lacks capacity to make a decision, arrangements for an independent mental capacity advocate, to represent and support the person, should be made. When considering

¹² See *Hard Truths The Journey to Putting Patients First - Volume Two of the Government Response to the Mid Staffordshire NHS Foundation Trust Public Inquiry: Response to the Inquiry's Recommendations*, p.195, at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/270103/35810_Cm_8777_Vol_2_accessible_v0.2.pdf

¹³ *More Care, Less Pathway. A Review of the Liverpool Care Pathway*, p.36, paragraph 2.9, at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

a person's capacity to make a particular decision, all practical steps to help the person to make a decision should be taken and it should be established whether the person has capacity. A person lacks capacity in relation to a matter if at the material time they are unable to make a decision for themselves in relation to a matter because of an impairment of, or a disturbance in the functioning of the mind or brain. A person is unable to make a decision for themselves if they are unable to understand the information relevant to the decision, retain that information, use or weigh that information as part of the process of making the decision or to communicate the decision (whether by talking, sign language or any other means).

34. Professionals must also ensure they respect advance decisions that are valid and applicable to the circumstances. Where there is a person with a registered lasting power of attorney to make the particular decision, then the attorney should make a best interests decision for the person. Professionals are held accountable for best interests decisions primarily through professional standards and regulation. (See response to Panel recommendation 32.)

Priority 4

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

35. Families and those important to the dying person, including carers, have their own needs which they, and others, can overlook at this time of distress. They are often tired, both physically and emotionally, and may be anxious and fearful, especially if they are the dying person's main caregiver at home. Even those who may appear to be coping well appreciate an acknowledgement that the imminent death of somebody they love is hard and that they have a role in ensuring that their loved one receives a good standard of care as they near the end of life. Where they have particular needs for support or information, these must be met as far as possible. Although it is not always possible to meet the needs or wishes of all family members, listening and acknowledging these can help. If a person who is dying lacks capacity to make a decision, the decision-making process should be explained to those people who are supporting the person and they should be involved as much as possible.

Priority 5

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

36. A plan for care and treatment must be developed to meet the dying person's own needs and wishes in relation to how their care should be managed and any treatment preferences they may want to express. This plan must include attention to symptom control (e.g. relief of pain and other discomforts) and the person's physical, emotional, psychological, social, spiritual, cultural and religious needs. The person must be supported to eat and drink as long as they wish to do so, and their comfort and dignity prioritised. There must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this. This plan of care must be documented so that consistent information about the person's needs and wishes is shared with those involved in the person's care and available at the time this information is needed.

Planning care

37. Unless a death is sudden and could not reasonably have been foreseen (for example if someone suffers a fatal injury), it is part of good care for a dying person to plan ahead as much as possible, if they wish this, involving them as much as possible and making best interests decisions for people who lack capacity. The care plan should be reviewed as circumstances, including the dying person's preferences, change. The care plan or, as a minimum, key elements of it, should be immediately available to health and care staff who are or might become involved in caring for the dying person, (including ambulance services, social care services and 'out-of-hours' general practitioners), so that the person's preferences are known and can be taken into account across the range of services they receive.
38. As noted above, some people will deteriorate and die unexpectedly and the Priorities for Care should be applied in such circumstances. However, in many cases people will already be receiving care and the care plan for their last few days and hours of life will be part of a planning process that started days, weeks, months or even years before. For example, people with long-term conditions and vulnerable older people should have care plans in place, if they so wish, well before the last few days and hours of life. The process of planning for dying should be part of these and other care planning processes, with the pace and timing of discussions about dying reflecting the person's and, where appropriate, their families' and friends' readiness to discuss particular aspects.

39. Where a person is being cared for by NHS or care staff, current arrangements strongly encourage the creation of a care plan. All the support materials the Alliance is aware of encourage health and care staff to ensure dying people and, as appropriate, their relatives and friends, are involved in the planning process. However, there is evidence, from the review of the Liverpool Care Pathway and elsewhere, that plans for the last few days and hours of life are not always developed with the dying person and their loved ones, nor are they always transparent. Hence the Alliance's Priorities for the Care of the Dying Person make clear that there must be an individual plan of care. (Panel recommendation 38 refers.)

Food and drink

40. The review panel noted that most of the submissions it received from families that were critical of the LCP referred to hydration and nutrition. Food and drink can be important to people's comfort and psychological wellbeing, even where their physical needs for hydration and nutrition are met through other means.
41. The GMC guidance on *Treatment and care towards the end of life: good practice in decision-making 2010*¹⁴ sets out clearly the need for patients to be offered food and drink orally, provided that it would not harm them (e.g. by causing choking). Specifically, it includes: "All patients are entitled to food and drink of adequate quantity and quality and to the help they need to eat and drink. Malnutrition and dehydration can be both a cause and consequence of ill health, so maintaining a healthy level of nutrition and hydration can help to prevent or treat illness and symptoms and improve treatment outcomes for patients. The doctor must keep the nutrition and hydration status of the patients under review. The doctor should be satisfied that nutrition and hydration are being provided in a way that meets patients' needs, and that if necessary patients are being given adequate help to enable them to eat and drink." It also states: "The offer of food and drink by mouth is part of basic care (as is the offer of washing and pain relief) and must always be offered to patients who are able to swallow without serious risk of choking or aspirating food or drink. Food and drink can be refused by patients at the time it is offered, but an advance refusal of food and drink has no force." Detailed guidance on assessing and meeting people's hydration and nutrition needs is also part of the guidance. Failure to follow the guidance may call into question a doctor's fitness to practise and endanger their registration. (Panel recommendation 17 refers.)
42. Similarly, the essential skills clusters for nutrition and fluid management as set out in the NMC's Standards for pre-registration education¹⁵ have the effect that registered nurses must be able to assess and monitor nutritional and fluid status and, in partnership with patients and their carers, formulate an effective plan of care to ensure people receive adequate food and fluid. This includes identifying when nutritional status worsens or there are signs of dehydration and acting appropriately to correct these. They must also ensure that appropriate assistance is available to enable people to eat and drink and to ensure that people unable to take food by mouth receive adequate fluid and nutrition to meet their needs. In April 2014, the NMC published the standards for nursing practice, including the essential skills clusters on hydration and nutrition, as a separate document from the education standards, so that they are more easily accessible and to make it clear that they apply to all nurses, not just student nurses.¹⁶ Nurses who fail to comply with the NMC

¹⁴ *Treatment and care towards the end of life: good practice in decision-making 2010*, p.52, available at: www.gmc-uk.org/End_of_life.pdf_32486688.pdf

¹⁵ http://standards.nmc-uk.org/Documents/Annexe3_%20ESCs_16092010.pdf

¹⁶ The NMC's *Standards for Competence for Registered Nurses (2014)* document is available on the NMC website at: www.nmc-uk.org/Documents/Standards/Standards%20for%20competence.pdf

Code: Standards of conduct, performance and ethics, may call into question their fitness to practise and endanger their registration. There are similar duties on other health and care professionals and pharmacists. (Panel recommendations 18, 20 and 21 refer.)

Use of sedatives and pain relief

43. The review panel found a mixed picture in relation to the use of sedatives and pain relief, with some examples of exemplary and appropriate management. However, the panel also took evidence that opiate pain killers and tranquillisers had been used inappropriately and was concerned that, in some cases, these drugs were given as a matter of course, rather than from a need for symptom control. The panel noted that the previous focus of work on symptom management at the end of life had been based on patients with advanced cancer in hospices who were inevitably going to die in days to weeks, with no chance of recovery. The panel suggested that new research was needed on the use of drugs at end of life, and in particular on the extent to which sedative and analgesic drugs themselves contribute to reduced consciousness, and perceived reduction of appetite and thirst.
44. The Alliance is concerned that such research would not address directly the issue of ensuring that pain killers and tranquillisers are given appropriately for symptom relief, rather than as a matter of course. It also notes that what drugs do is well-known – it is the way in which they are used that can lead, amongst other effects, to reduced consciousness. (Panel recommendation 24 refers.)
45. A particular area of concern for the independent review panel was the use of syringe drivers with sedative drugs. (Panel recommendation 23 refers.) Syringe drivers are used typically when a person is unable to take medication orally. They are pumps, which provide regular doses of the particular drug. The review panel noted that, in some cases where syringe drivers were initiated, patients did not communicate again. This was distressing for families who had not been made aware that a syringe driver was going to be used, nor understood the effects of the drug being administered in such a way. The Alliance's statement of the duties and responsibilities of health and care staff includes that:

"All medications, including anticipatory medicines, must be targeted at specific symptoms, have a clinical rationale for the starting dose, be regularly reviewed, and adjusted as needed for effect."

"The reason for any intervention, including the use of a syringe driver, must be explained to the dying person and to those important to the dying person. Other than in exceptional circumstances, this should be done before it is used."

"The likely side effects of specific interventions, especially those that may make the person sleepy, must be discussed with the dying person to enable them to make informed decisions, and explained to those important to the dying person if the person wishes."

Advice from specialist palliative care teams

46. In many situations where people are in the last days and hours of life, the health staff caring for them will find it helpful to seek advice from palliative care teams. Hence Priority for Care 5 includes: “There must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this.” The Alliance’s implementation guidance for service providers and commissioners includes that service providers must: “Work with commissioners and specialist palliative care professionals to ensure adequate access to specialist assessment, advice and active management. ‘Adequate’ means that service providers and commissioners are expected to ensure provision for specialist palliative medical and nursing cover routinely 9am - 5pm seven days a week and a 24 hour telephone advice service. Where this service does not already exist, service providers and commissioners should formulate an action plan and commit to provision of such services within defined timelines. This should ensure the provision of specialist cover over 24 hours, including face to face assessment in the exceptional circumstances where this is necessary.” (Panel recommendation 33 refers.)

Documenting treatment and care

47. It is part of professional practice that health and care staff keep clear and accurate records about all treatment and care given. The Priorities for Care do not cover this issue explicitly, because it is not specific to end of life care. However, the Review Panel received reports of incomplete and wrongly completed forms in relation to care given on the Liverpool Care Pathway. (Panel recommendation 7 refers.)
48. For nurses and midwives, the NMC Code currently states that nurses must:
- “Keep clear and accurate records
- You must keep clear and accurate records of the discussions you have, the assessments you make, the treatment and medicines you give, and how effective these have been.
 - You must complete records as soon as possible after an event has occurred.
 - You must not tamper with original records in any way.
 - You must ensure any entries you make in someone’s paper records are clearly and legibly signed, dated and timed.
 - You must ensure any entries you make in someone’s electronic records are clearly attributable to you.
 - You must ensure all records are kept securely.”¹⁷
49. Where these requirements are breached deliberately, as would be the case if a nurse or midwife sought to falsify records, this would be a disciplinary breach and could be cause for referral to the Nursing and Midwifery Council. The NMC’s consultation on the draft revised Code was launched in mid-May 2014 and will run until mid-August 2014. The revised Code will be published in December 2014. It will consider the issue of falsification of records further in this context, with a view to

¹⁷ See the NMC Code, p. 6 at: www.nmc-uk.org/documents/standards/the-code-A4-20100406.pdf

making it even clearer that falsifying documents for any reason, not just to deflect criticism of a failure of care for a dying person, is a serious fitness to practise matter.

50. The NMC frequently reminds people on their register that they must adhere to the Code and that falsification of records is a serious breach and may result in a referral and investigation into their fitness to practise. Details of the outcomes of hearings are published on the NMC website. A number of hearings have related to the falsification of records for which a sanction was applied. Where there are concerns that nurses might have falsified records, these should be raised with the NMC.
51. Similarly, *Good Medical Practice, 2013* (GMP 2013)¹⁸ makes clear that doctors must keep clear and accurate records and that any documents they write or sign must not be false or misleading. GMP 2013, published in March 2013 and updated in April 2014, was sent to all doctors on the Medical Register. It reminds doctors that serious or persistent failures to follow the guidance will place their registration at risk. The GMC's guidance to panellists who consider doctors' fitness to practise says: "Dishonesty, especially where persistent and/or covered up, is likely to result in erasure". The GMC continues to deliver a programme of work to promote the advice in GMP 2013, which is described in the GMC commitment statement that accompanies this document.
52. The HCPC's Standards of Conduct, Performance and Ethics require registrants to "keep accurate records" (standard 10); and "behave with honesty and integrity" to ensure that their behaviour does not damage the public's confidence in the registrant or their profession (standard 13).¹⁹ Behaviour contrary to these standards would be cause for referral to the HCPC and dishonesty is an issue considered very seriously by its fitness to practise panels. The HCPC will continue its ongoing engagement with those on its Register to ensure that these expectations are explored and understood. As part of its forthcoming review of its Standards of Conduct, Performance and Ethics, the HCPC will consider strengthening its expectations of registrants with reference to their responsibility to identify and be open about failures in care, and to take steps to put right any failures. The HCPC will consider strategies for the promotion and dissemination of its new standards as part of this review.
53. The GPhC's standards of Conduct, Ethics and Performance state that registrants must keep full and accurate records of the professional services they provide in a clear and legible format (standard 1.8) and be honest and trustworthy (Principle 6).²⁰ GPhC will consider the issue of falsification of records further in the context of its forthcoming review of the standards of Conduct, Ethics and Performance.
54. In response to the Francis Report²¹, the Government announced that the existing professional duty of candour on individuals will be strengthened through changes to professional guidance and codes²². The General Medical Council, the Nursing and Midwifery Council, Health and Care Professions Council and other professional regulators are working to agree consistent approaches to candour and reporting of errors, including a common responsibility across doctors and nurses, and other health professions, to be candid with patients when mistakes occur, whether serious or not, and clear guidance that professionals who seek to obstruct others in raising concerns or being candid would be in breach of their professional responsibilities. The

¹⁸ See *Good Medical Practice, 2013*, paragraph 71, available at: www.gmc-uk.org/guidance/news_consultation/20477.asp

¹⁹ See HCPC Standards of Conduct, Performance and Ethics, pp13-14 which is available online at: www.hpc-uk.org/aboutregistration/standards/standardsofconductperformanceandethics

²⁰ See GPhC Standards of Conduct, Ethics and Performance, p8, p14 which is available online at: www.pharmacyregulation.org/standards/conduct-ethics-and-performance

²¹ www.midstaffspublicinquiry.com/report

²² *Hard Truths: the journey to putting patients first. Volume One of the Government Response to the Mid Staffordshire NHS Foundation Trust Public Inquiry*, Executive summary, paragraph 15 – available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/270368/34658_Cm_8777_Vol_1_accessible.pdf

Professional Standards Authority will advise and report on progress with this work.

55. The NHS standard contract for 2014/15 includes a duty of candour in relation to patient safety. In addition, the Government has recently consulted on the proposal to introduce a statutory duty of candour as a CQC registration requirement in secondary legislation. This will also be a major step towards implementing a key recommendation from the Francis Report. The registration requirement will require all CQC registered providers to inform people if they believe treatment or care has caused significant harm, and provide an explanation and, where appropriate, an apology. CQC will decide when to take enforcement action for a failure to meet the duty of candour, including whether to bring a prosecution. Providers will be expected to establish the duty throughout their organisation.

Phasing out the LCP

56. Insofar as the LCP provided an approach to those caring for people in the last few days and hours of life, the Priorities for Care and the supporting documents will take its place. (Panel recommendation 3 refers). In order to implement the Priorities for Care effectively, organisations and staff will want to use alternative support materials, including easy-to-use reference documents and prompts; and templates for records. In future, these should be consistent with and support achievement of the Priorities for Care. Leaders of organisations or groups of organisations in individual localities will want to consider and advise their staff and organisations what support materials are most appropriate for their particular circumstances.
57. In developing its programme of action in response to the report by the independent panel, the Alliance has spent considerable time debating the pros and cons of developing either a single, recommended set of support materials, or a process for endorsing such products. This would save organisations having to develop their own materials and potentially 're-invent the wheel'. However, one of the key issues with the LCP was the way in which some organisations and health and care staff came to regard it as an end in itself, rather than using it to pro-actively engage with the needs of individual patients and their families. Alliance members therefore consider that a key part of ensuring effective care for all people in the last few days and hours of life is that organisations work out for themselves, using the Priorities for Care and the supporting documents, how they can deliver the best outcomes for dying people and their families, bearing in mind their own particular circumstances. The Alliance is also very conscious of the fact that in some cases, the effectiveness of different support materials will depend on the setting in which care for the dying person takes place.
58. Ideally, all the various organisations in a particular locality from whom a person in the last few days and hours of life might receive services would work out together how to deliver the best care. This would include hospitals, hospices, 'out-of-hours' GP services, ambulance services, social care, voluntary care services and others. They may want to consider using or developing particular support materials. There might be scope for some of these to be used across service providers (e.g. forms in relation to preferences about care and treatment). In many cases, however, the care will need to be supported by different support materials, depending on the setting in which the care takes place. Whilst the support materials are important, it is the way they are used and the other elements that contribute to the care of dying people coming together which are important in delivering appropriate care to individual patients. It is how - not whether - particular support materials are used which should be assessed.

Education, training and professional development

59. The issues raised by the review panel's report require substantial action on education, training and professional development. It is clear from the report that some staff caring for dying people do not have the skills and knowledge required to deliver care to high standards; and in some cases, they are not putting into practice the values that underpin such care.
60. Particular members of the Alliance have specific responsibilities for ensuring that initial training²³ for particular groups of staff equips them to carry out their roles effectively. This document describes action Alliance members have taken and will take to ensure this happens. Individual providers of health and care are responsible for ensuring their staff have the experience and competence they need to do their jobs well. This includes making time and other resources available for staff to undergo professional development. Staff themselves have responsibilities to ensure that they have the necessary skills to do their jobs and to keep those skills up-to-date. This document also describes action Alliance members have taken and will take to support service providers and individual health and care staff to deliver their responsibilities in relation to education and training on caring for dying people.

Training for doctors

61. Many of the competencies that are needed to deliver effective care for people in the last few days and hours of life are generic: i.e. they are also relevant to caring for other people. The Shape of Training Review, which reported to the GMC on 29 October 2013, stressed that future postgraduate curricula would need to encompass the generic professional capabilities that all doctors should possess (or be able to develop) to ensure the delivery of good quality care across all specialties. The GMC is working with the Academy of Medical Royal Colleges to identify what these are. They will include some fundamental areas of practice such as the need to communicate effectively, empathise, lead, follow and be diligent and conscientious as well as those more related to end of life care such as partnership and team working.
62. Further support for doctors' ongoing professional development is available through a document being produced by the Specialty Advisory Committee for Palliative Medicine of the Royal College of Physicians, the Joint Royal Colleges Postgraduate Training Board and the Association for Palliative Medicine of Great Britain and Ireland. This outlines how physicians training in a range of medical specialties can gain the required competences in palliative care. (Panel recommendation 10 refers to training for doctors.)

²³ Including post-graduate training required for qualification.

Ongoing education and training for all health and care staff

63. Alliance members are clear that all staff who have contact with dying people must have the skills to do this effectively and compassionately. This includes clinical and support staff (e.g. porters, reception staff and ward clerks.) Those organisations that deliver such care have the prime responsibility for ensuring that the people they employ are competent to carry out their roles effectively, including facilitating and funding ongoing professional development, where this is appropriate. The Alliance's Implementation Guidance for Service Providers and Commissioners includes advice to help those organisations ensure they are carrying out their responsibilities to ensure staff have the necessary training and skills in this area. This advice includes desired characteristics of programmes of education and training for staff who care for people in the last days and hours of life. The desired characteristics include taking an educational approach which employs evaluation methods that can demonstrate achievement of outcomes and, ideally, extend beyond the immediate end of the training course or event. The Alliance is creating a mechanism for sharing practice, and enabling evidence of its effectiveness, to be shared. The Alliance intends that those who fund, commission or provide training for health and care staff should use the 'desired characteristics' it has developed and its mechanism for sharing good practice, to help them develop specifications for specific training, education, professional development and learning packages that include care in the last few days and hours of life. On content, the Alliance's advice includes that such education and training cover:

- Specific attention to the topics of nutrition and hydration: assessment, discussion and shared decision-making with the person (where possible), and those important to them and other health and care team members.
- Symptom management: assessment, communication and shared decision-making wherever possible about use of medication (including route of delivery), physical measures (including repositioning) and safe and accurate prescribing.
- Communication skills, including empathy and recognising emotional response to stress and distress, discussing uncertainty, conversations about limits of treatment including 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR), withholding and withdrawing treatment, preferred place of care and death, etc.

(Panel recommendations 11, 16, 19 and 22 refer.)

64. Alliance members consider there is scope for those arranging training for health and care staff who care for dying people and their families to make greater use of Health Education England's e-Learning for Health e-learning programme on end of life care (e-ELCA). e-ELCA²⁴ is a library of over 150 highly interactive sessions of e-learning on end of life care, which aims to provide a resource for enhancing the training and education of health and care staff involved in delivering end of life care to people. The sessions are arranged in four core modules (advance care planning; assessment; communications skills; and symptom management, comfort and wellbeing), with three additional modules (social care, bereavement and spirituality) and one 'integrating learning' module which helps to consolidate and apply understanding in different situations.

²⁴ Further information on End of Life Care for All (e-ELCA) is available at: www.e-lfh.org.uk/projects/end-of-life-care

65. Despite its high regard, soundings taken by the Alliance suggest that the use of e-ELCA to support education and training remains patchy in some parts of England. The Alliance notes that the breadth of e-ELCA can make it difficult for busy practitioners to make choices and that its potential to be used as part of a blended approach to learning is not fully realised. Hence, it will seek to provide guidance on factors that maximise the effectiveness of e-ELCA. GMC will consider the possibility of including information about e-ELCA in its wider work to enable doctors to identify and access learning opportunities on end of life care; and its work to promote its guidance on *Treatment and care towards the end of life: good practice in decision-making, 2010*²⁵.
66. Individual Alliance members are keen to run joint education and training days throughout England to support care in the last few hours and days of life. For example, the RCGP, Marie Curie, Macmillan and the GMC are exploring the possibility of a collaboration to deliver one-day educational workshops on excellent personalised care and symptom control in 2014. The RCP is also considering plans to produce a toolkit on care for people in the last few days and hours of life to identify current problems and suggest ways of improving quality.
67. Training for the assessment and meeting of spiritual needs of dying people, their relatives and carers in any setting can be accessed from chaplaincy departments. Training can support the use of a variety of approaches, including FICA (The acronym FICA refers to: F - Faith and Belief, I - Importance, C - Community and A - Address in Care). Further details of this are at Annex I.

Assessment and evaluation of training, education and learning to support health and care staff caring for dying people

68. The Alliance has produced Implementation Guidance for Service Providers and Commissioners. This states that education and training programmes for care in the last hours of life should take an educational approach which includes how to apply learning to practice and evaluation methods that can demonstrate achievement of outcomes and will, ideally, extend beyond the immediate end of the training course or event. (Panel recommendation 22 refers.)
69. Health Education England will work with stakeholders to influence training curricula as appropriate, although the content and standard of clinical training is ultimately the responsibility of the professional bodies. Education and training of the existing workforce is primarily an employer responsibility. (Panel recommendation 35 refers.)

²⁵ Available at: www.gmc-uk.org/End_of_life.pdf_32486688.pdf

Advice

Terminology relating to death

70. In the national End of Life Care Strategy (2008), the term 'end of life care' was defined as the last year of life. However, for some people, including health and care staff, the term 'end of life' is understood to mean the last few days of life, in other words when death appears to be imminent. The Alliance agrees that this terminology is confusing. The Social Care Institute for Excellence, the National Council for Palliative Care and NHS England have undertaken a joint piece of work to generate and facilitate understanding about the terms 'palliative care' and 'end of life care' with the aim of developing greater clarity in the use of these terms.
71. In the meantime, the Alliance has agreed a glossary of terms in relation to care in the last few days and hours of life. This is at Annex G.

Terminology relating to guidance

Pathways

72. The term 'pathway' is used widely in health and care. For example, NICE (National Institute for Health and Care Excellence) Pathways are interactive topic-based diagrams which aim to provide users with a way to quickly view and navigate all NICE guidance recommendations on a particular topic. A NICE Pathway starts with a broad overview of a topic and allows the user to explore NICE recommendations and advice in increasing detail. Relevant topics are linked together forming a network of NICE information. A NICE Pathway provides a useful starting point for new users to a topic while giving specialists easy access to NICE recommendations. NICE Pathways do not provide a comprehensive management pathway for individual patient care.
73. A 'clinical pathway' generally refers to a standardised set of actions aiming to optimise care for a particular clinical problem, in line with evidence or guidelines. The process of dying should not be regarded as a "clinical problem" and hence the development or use of clinical pathways for the last few days and hours of life can cause confusion.
74. A 'care pathway' has been defined broadly as "a set of quality measures that together describe a care pathway for a particular population or group of patients." As the review panel noted, the Marie Curie Palliative Care Institute Liverpool (MCPCIL) described care pathways differently i.e. "a care pathway is a complex intervention for the mutual decision-making and organisation of care processes for a well-defined group of patients during a well-defined period."²⁶
75. The review panel went on to say that: "Due to ... [a] lack of clarity, the LCP is being perceived by some of its users – doctors and nurses – not as a document, nor as a

²⁶ See <https://lcp.mcpcil.org.uk/modules/page/page.aspx?pc=registrationint>

guideline, but most frequently as a set of instructions and prescriptions, that is to say a protocol.”²⁷

NICE

76. NICE uses the term ‘protocol’ in the context of research. The glossary on the NICE website defines a protocol as “A plan or set of steps that defines how something will be done. Before carrying out a research study, for example, the research protocol sets out what question is to be answered and how information will be collected and analysed.”²⁸
77. NICE uses the terms ‘guidelines’ and ‘guidance’ interchangeably, with specific definitions depending on the type of guideline / guidance it is discussing. At their most generic, they can be defined as: “evidence-based recommendations on the most effective and cost-effective treatment and care of people with specific diseases and conditions, and recommendations for populations and individuals on interventions that can help prevent disease or improve health.” The definition used in the NICE accreditation manual is “systematically developed statements to guide decisions about appropriate health and social care to improve individual and population health and wellbeing.”²⁹ NICE does not use the terms ‘standard operating procedures’ or ‘best practice models’.

General Medical Council (GMC), Nursing and Midwifery Council (NMC), Health and Care Professions Council (HCPC), General Pharmaceutical Council (GPhC)

78. The GMC publishes a range of guidance in fulfilment of its regulatory duties. This includes guidance for providers of undergraduate and postgraduate education and training and continuing professional development; guidance for its fitness to practise decision-makers; and guidance to doctors on the professional values and standards of ethical practice expected of all those on the medical register.³⁰
79. The NMC is required to establish standards of education, training, conduct and performance for nurses and midwives and to ensure maintenance of those standards. The NMC sets the standards for pre-registration nursing and midwifery education programmes and these contain the minimum requirements by which programme providers determine the programme content, learning outcomes and assessment. They also contain the competency standards for nursing and midwifery practice. These standards must be achieved by all students completing those programmes and are the standards which must be maintained by nurses and midwives on the NMC register. In addition, nurses and midwives must adhere to the standards of conduct, performance and ethics, known as “The Code”. The Code sets out in broad terms the standards of conduct and performance which society and the profession expect of nurses and midwives throughout their careers. The Code applies to all registered nurses and midwives, regardless of their role, their specialty, grade or area of work. Failure to comply with the Code may bring a nurse or midwife’s fitness to practise into question and endanger their registration. The NMC may also publish guidance where there is evidence that guidance is required to set out how the standards set out in the Code should be met. For example, NMC has recently published updated guidance on raising concerns for nurses and midwives.³¹

²⁷ See *More Care, Less Pathway. A Review of the Liverpool Care Pathway*, p.16, paragraph 1.18, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

²⁸ www.nice.org.uk/website/glossary/glossary.jsp?alpha=p

²⁹ www.nice.org.uk/media/886/95/NICEAccreditationProcessManual.pdf

³⁰ Details of GMC guidance are available on the GMC website at: www.gmc-uk.org

³¹ See NMC Code at: www.nmc-uk.org/documents/standards/the-code-A4-20100406.pdf

80. The HCPC is required to establish and maintain standards of education, training, conduct and performance for the professions it regulates, in order to protect the public. One such set of standards is the HCPC's standards of conduct, performance and ethics, which set out the behaviour expected from professionals on the HCPC Register. To help registrants meet these standards, the HCPC produces guidance, such as its guidance on confidentiality.³²
81. The GPhC regulates pharmacists, pharmacy technicians and registered pharmacies. One of the ways by which it does this is to set the standards of conduct, ethics and performance for pharmacy professionals. The GPhC also produces guidance to assist pharmacy professionals in meeting the standards of conduct, ethics and performance. Guidance covers topics such as consent and raising concerns.³³

The Alliance's approach to terminology

82. The Alliance agrees with the review panel that there is a lack of clarity about the status of different documents relating to care for people in the last few days and hours of life. It also agrees with the review panel's recommendation that it is not appropriate to use the term 'pathway' in relation to care for people in the last few days and hours of life, because of the possible concern that if someone was on a pathway for those approaching the end of life, the treatment and care they received would be 'standardised', rather than personalised. The Alliance has produced a glossary which includes definitions of, amongst other things, 'clinical pathways', 'protocols', 'standard operating procedures', 'guidelines/ guidance' and 'best practice models'.³⁴ Alliance members, will respect these definitions, and in relation to care in the last few days and hours of life, will reserve the terms 'guidance/ guidelines', as well as 'quality standards' for use by NICE and the professional regulators (GMC, NMC, HCPC and GPhC), who will continue to produce regulatory guidance on how professional standards should be achieved. The only exception will be that the Alliance has produced implementation guidance for service providers and commissioners on delivering the Priorities for Care of the Dying Person. (Panel recommendation 2 refers.)

Extent of existing guidance relevant to care in the last few days and hours of life

83. In response to the review panel's report, the Alliance commissioned a rapid review of existing guidance on caring for people in the last few days and hours of life. The report of the review is at Annex J. Its key findings include:
- there is extensive existing advice on caring for people who are approaching the end of their lives, including technical guidance relating to caring for people with diabetes, heart failure, neurological conditions, Parkinson's disease, advanced kidney diseases and dementia;
 - much of the advice is robust, developed by reputable sources; but
 - some of this advice is difficult to find and it is not in a single standard format.
84. Specific Alliance members will therefore undertake work to make particular advice, including that on specific disease groups, more easily accessible. The NHS will work

³² See HCPC *Standards of Conduct, Performance and Ethics* at: www.hpc-uk.org/aboutregistration/standards/standardsofconductperformanceandethics

³³ See GPhC *Standards of Conduct, Ethics and Performance* at: www.pharmacyregulation.org/standards/conduct-ethics-and-performance

³⁴ The Alliance's Glossary of Terms can be found below at Annex G.

with organisations with an interest in specific diseases and conditions to consider whether new advice is needed. (Panel recommendation 37 refers.)

85. The main current NICE guidance in relation to dying people is *Improving supportive and palliative care for adults with cancer*, published in 2004. NICE is currently developing new Guidance on the management of care for dying adults which it hopes to publish in 2015. It will also, a little later, update its existing guidance on palliative care and end of life service guidance as part of its ongoing surveillance and updating programme. The new guidance on the organisation of services for people who are dying will update some parts of the cancer service guidance on supportive and palliative care. NICE also intends, shortly, to develop separate guidance for End of Life Care in children. Its recently redrafted Quality Standard on End of Life Care will be revised following the publication of this new Guidance.
86. In the meantime, the NICE Quality Standard sets out what care and treatment for dying people should seek to achieve, as do the Alliance's Priorities for Care. (Panel recommendation 12 refers.)

Advice on decision-making

87. The GMC guidance on decision-making for doctors can be found in *Treatment and care towards the end of life: good practice in decision-making*, in place since May 2010.³⁵ It is highly regarded and plays an important role in establishing the principles of good practice in this area. During 2014, the GMC's work to promote improved standards of patient care will be prioritising activities to raise awareness of the guidance, especially the advice on oral nutrition and hydration, advance care planning and decision-making around cardiopulmonary resuscitation (CPR), as set out in its commitment statement. For nurses, the competency standards for nursing practice are stated within the Standards for Pre-registration nursing education.³⁶ Nursing practice and decision-making is one of the four domains within the standards for all nurses. This includes decision-making required in caring for people who are dying either as a consequence of old age or due to progressive or terminal illness and providing therapeutic nursing interventions to people, their families and carers. In April 2014, as part of the review of the Code and developing guidance for revalidation, the NMC published these standards for nursing practice separately to the pre-registration education standards, so nurses, patients and the public can access them more easily.³⁷ (Panel recommendation 13 refers.)
88. As part of developing the revised Code, the NMC will consider whether it should include specific guidance on caring for people at the end of life, including specific guidance about decision-making in relation to such care. In doing so, it will take account of the findings of the "rapid review" on guidance carried out on behalf of the Alliance, responses to public consultation and the impact of any system-wide guidance on this subject that may be issued by the Alliance or any other cross-regulatory bodies. The review of the Code will strengthen requirements in the areas of decision-making and end of life care on a more general basis for all nurses and midwives. It will also reinforce the NMC's position on the nurse's professional duty of candour, as will the guidance the NMC is working on alongside the GMC and other healthcare regulators on the professional duty of candour. (Panel recommendations 13 and 34 refer.)

³⁵ www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

³⁶ <http://standards.nmc-uk.org/Pages/Welcome.aspx>

³⁷ The NMC's *Standards for Competence for Registered Nurses* (2014) document is available on the NMC website at: www.nmc-uk.org/Documents/Standards/Standards%20for%20competence.pdf

Implementing the new Priorities for Care

Inspection and regulation

89. The Care Quality Commission (CQC) consulted on proposals to make significant changes to its inspection approach in 2013. The new inspection approach is being implemented in 2014 and will examine whether the service is safe, effective, caring, responsive to people's needs and well-led for all the sectors they regulate. This includes acute hospitals, primary care, adult social care, hospices and community health services.
90. This new approach to inspection is designed to get to the heart of people's experience of care. The role of health and care staff cuts across the five domains of care³⁸ and the role of health professionals in planning and delivery of care will be a key component of the judgements CQC inspection teams make. For example, in considering whether the care delivered is effective, inspection teams will look for evidence that services, treatment and care are delivered by qualified, competent staff who are supported in their development and in their role. In terms of end of life care, this will mean inspection teams consider the role health and care staff play in care in the last few days and hours of life as well as care provided after death, including the support provided to bereaved families and carers.
91. The introduction of the new approach has started with the acute sector, led by the Chief Inspector of Hospitals. All inspections of acute hospitals under the new approach include an inspection of end of life care services as one of eight core service areas which the inspection team routinely consider. (See response to panel recommendation 40.) Inspections look at palliative and end of life care across the hospital and are not limited to specialist services. Inspection teams gather views from people who use services, their families, carers and advocates; observe care; interview key members of the senior management team and staff at all levels; and may visit certain services out of hours and unannounced. Inspections of community health services under the new approach include a specific focus on end of life care.
92. CQC's Chief Inspectors of Adult Social Care and General Practice are also incorporating end of life care services in the inspection approach in their sectors. The proposed approach to inspection of care homes includes end of life care as a key inspection area. In inspecting services which deliver end of life care in any setting, CQC will review whether people receive care in line with the Alliance's Priorities for Care. CQC inspections of particular hospitals and care homes will include whether care is delivered by qualified, competent staff, who are supported in their development and in their roles. CQC inspection teams will gather views from people who use services and their families, carers and advocates. (Panel recommendation 4 refers.)

³⁸ The NHS Outcomes Framework, which sets out the high-level national outcomes that the NHS should be aiming to improve, is structured around the following five domains:

- Domain 1: Preventing people from dying prematurely;
- Domain 2: Enhancing the quality of life for people with long-term conditions
- Domain 3: Helping people to recover from episodes of ill-health or following injury
- Domain 4: Ensuring that people have a positive experience of care; and
- Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm

93. The Care Quality Commission also undertakes thematic work on prioritised topics across the sectors it regulates in addition to its regulation of registered providers of care. Thematic work enables CQC to look at the quality of care across registered providers and sectors, and to focus on integrated care and the patient's journey through services by listening to what users, carers and staff say about care quality.
94. CQC will undertake a themed inspection focusing on end of life care in 2014/15, and will publish a national report presenting its findings. The themed inspection is in addition to the ongoing programme of inspections of hospitals, care homes, hospices, GPs and community services, which will reflect end of life care as a priority, and it will build on the inspection programme. The themed inspection topic will focus on an area with significant implications for people's experience of care at the end of life, and where CQC can use its unique position as the regulator of health and social care to achieve the maximum impact. The scope of the inspection will include all settings where people experience care at the end of their lives, and will consider issues such as integration, inequity, vulnerabilities and access across the whole community. (See response to panel recommendation 41.)
95. The CQC works closely with Monitor and the NHS Trust Development Authority to identify where improvement is needed, whilst ensuring their approaches are coordinated and that regulatory activity is not duplicated. Hence, if the CQC has a concern about the quality of care being delivered at an NHS foundation trust or if a foundation trust is failing to meet its registration requirements, it will inform Monitor, and the two organisations will work together to ensure that appropriate and joined-up regulatory action is taken. If CQC has a concern about the quality or safety of care provided by an NHS trust, it will inform and work closely with NHS TDA.
96. For NHS trusts, the NHS Trust Development Authority has included in its Planning Guidance 2014-15 an expectation that the forthcoming recommendations from the Alliance will be adopted and it will use the Priorities for Care and the three supporting statements as part of the process to support NHS Trusts to deliver high quality end of life care.

Commissioning

97. The review panel recommended that "payments 'per person implemented on the LCP, or equivalent approach' should cease." Alliance members agree that such financial incentives are inappropriate. In a written statement to Parliament on 15 July 2013,³⁹ the Minister for Care and Support "said: "I am asking NHS England to work with clinical commissioning groups to implement this [recommendation] immediately." There are no longer any such national incentives and NHS England agrees that any such payments from clinical commissioning groups should cease. (Panel recommendation 25 refers.)
98. NHS England and the NHS Commissioning Assembly have also jointly established a 'Task and Finish Group' to look at how to embed the Alliance's Priorities for Care within commissioning processes. (See response to panel recommendation 42.)

³⁹ Commons Hansard, 15 July 2013, Col 64WS.

Organisational leadership and governance

99. Local leadership will be an important part of securing improvements in the overall care of people in the last few days and hours of life and ensuring that the Alliance's proposed Priorities for Care are successfully implemented and embedded. Across England, thousands of different organisations are responsible for providing that care. Each one of them needs to have leadership that is committed to ensuring that those people to whom it provides services who are dying receive high-quality, compassionate care, focused on the needs of the dying person and their family. As many of those who are in the last few days and hours of life receive services from a range of local providers, a powerful driver for improving services in a particular locality could be for relevant service providers to come together with a common goal of providing excellent, seamless services for people approaching the end of their lives. The Alliance calls on local organisations to commit to the Priorities for Care.
100. The Minister for Care and Support wrote to the chairs and chief executives of individual NHS Trusts and NHS Foundation Trusts on 15 July 2013 about the report of the independent review into the Liverpool Care Pathway. Amongst other things, he asked them to appoint a Board member with the responsibility for overseeing any complaints about end of life care and for reviewing how end of life care is provided.
101. CQC's new inspection approach looks at whether a service is well-led, and specifically includes end of life care in acute hospitals. Inspection teams will look at whether individuals at all levels are clear about their responsibilities and how effectively they are held to account. Individual responsibility for end of life care at board level is integral to this. CQC is also undertaking a themed inspection focused on end of life care in 2014/15 (see paragraph 91). This will focus on people's experience of end of life care across sectors and develop understanding of why some groups of people experience poor care. In carrying out this review, CQC will consider governance and leadership issues. (Panel recommendation 28 refers.)

A priority for NHS England in the Mandate

102. The current Mandate to NHS England includes five priority areas, one of which is ensuring that people have a positive experience of care. Within this, improving the experience of care for people at the end of their lives is identified as one of the nine areas where progress will be expected. Progress will be measured by assessing bereaved carers' views on the quality of care given to their relatives in the last three months of life through an annual survey. There are a number of questions which relate specifically to the last two days of life.
103. This is an important area and so the Government will continue to keep under review the need to include anything further in the annual refresh of the NHS England Mandate and the second edition which will run from April 2015. (Panel recommendation 43 refers.)

Research

104. The independent panel that reviewed the Liverpool Care Pathway included in its report: “Dying is not only a physical event – it is the conclusion of a life defined in its nature, content and connections within a society and its cultures that are every bit as important as the mechanism of how dying happens.”⁴⁰ The Alliance agrees. In order for health service research to develop and evaluate effective ways by which people who are dying and their families can be supported, there needs to be greater understanding of how people who are dying, and their relatives and carers, experience care at the end of life; and greater understanding of the social and health effects of different experiences of dying on individuals and on their families.
105. In October 2013, the James Lind Alliance⁴¹ launched a Priority Setting Partnership to find out what palliative and end of life care research is important to people who are likely to be within the last years of life, their families, and the staff who work with them. The partnership means that people directly affected will get the chance to have their say in setting research priorities for palliative and end of life care. The partnership has been initiated by Marie Curie Cancer Care, and is co-funded by the National Institute for Health Research (NIHR), the Economic and Social Research Council (ESRC), the Medical Research Council (MRC), charities, and the Devolved Administrations. The aim of the partnership is to ensure that future research brings the greatest possible benefit to people at the end of life, and their carers and families, by identifying what questions are of the greatest importance to them. Over 20 organisations – who can reach people with palliative and end of life care needs and life-limiting illnesses, and also families, carers, doctors, nurses and social care staff – have pledged their support. Members of the Alliance for the Care of Dying People who are also members of the James Lind Alliance Priority Setting Partnership are: the Department of Health, Macmillan Cancer Support, Marie Curie Cancer Care, NICE and the Royal College of Nursing.
106. The NIHR has commissioned through the Pain, Palliative and Supportive Care Cochrane Review Group a ‘mapping’ review of the evidence requirements flowing from the Priorities for Care.
107. The Priority Setting Partnership on palliative and end of life care research and the conclusions of the ‘mapping’ Cochrane Review will help set the research agenda for the next few years. It will be a key part of taking forward work to develop understanding of the experience that both dying people and their families have. Some research questions will be relevant to NIHR, but other questions that are social science-based may be more relevant to the Economic and Social Research Council (ESRC) than NIHR. (Panel recommendation 6 refers.)

⁴⁰ *More Care, Less Pathway. A Review of the Liverpool Care Pathway.* p. 18, paragraph 1.25.

⁴¹ The James Lind Alliance is a non-profit making initiative which was established in 2004. It brings patients, carers and clinicians together to identify and prioritise the top 10 uncertainties or ‘unanswered questions’ that they agree are the most important about the effects of particular treatments.

108. The Alliance understands that dying people and their families would often like more certainty about the process of dying and what is likely to happen. The NIHR has issued a call for research proposals on prognostic models for people with advanced cancer. The closing date for outline proposals under this call was 29 August 2013. Work continues on developing a proposal of sufficient quality to justify funding. The NIHR will review continuing needs for research in the light of the coverage offered by any successful proposal. (Panel recommendation 9 refers.)
109. NIHR has discussed the review panel's findings and its recommendation for further research into the biology of dying with the Medical Research Council, whose responsibilities include basic and translational medical research. Their joint conclusion is that it would be more effective to initiate research into the biology of dying once there is a better understanding of the societal and cultural context, reflecting the fact that the physical, psychological and emotional processes involved in dying cannot be separated. (Panel recommendation 5 refers.)

Transforming Primary Care (Vulnerable Older People's Plan)

110. Following engagement last year on proposals for a Vulnerable Older People's Plan, the Government published Transforming Primary Care, in April 2014, which sets out its plans for primary care to become more proactive, personalised and joined up, in particular for those people with the most complex needs. These plans focus on making care and support planning more person-centred and proactive, ensuring health professionals consider people's needs and goals holistically, and improving information sharing between health and care staff. These principles are relevant to many of the issues identified by the review panel. The Alliance's Priorities for Care set out in more detail what treatment and care for people in the last few days and hours of life should be like, consistent with and reinforcing the plans set out in Transforming Primary Care. (Panel recommendation 44 refers.)

Annexes

Annex A:
Membership and Terms of Reference of the Leadership Alliance for the Care of Dying People (LACDP)

Annex B:
Responses to Individual Review Panel Recommendations

Annex C:
Priorities for Care of the Dying Person

Annex D:
Priorities for Care of the Dying Person – Duties and Responsibilities of Health and Care Staff

Annex E:
Priorities for Care of the Dying Person – Implementation Guidance for Service Providers and Commissioners

Annex F:
Terms of reference for the Independent Review of the Liverpool Care Pathway

Annex G:
Glossary of terms

Annex H:
End of life care in existing training for professionals

Annex I:
FICA approach to assessing spiritual care needs

Annex J:
Report of rapid review on guidance on end of life care commissioned by the Leadership Alliance

Annex K:
Terms of Reference and Membership of the LACDP Clinical Advisory Group

Annex L:
Terms of Reference and Membership of the LACDP Guidance, Education and Training Advisory Group

Annex A:

Membership and Terms of Reference of the Leadership Alliance for the Care of Dying People (LACDP)

Terms of reference:

The immediate objectives of the Alliance are to:

- support all those involved in the care of people who are dying to respond to the findings of the review; and
- be the focal point for the system's response to the findings and recommendations of the LCP review.

Amongst other things, the Alliance is:

- developing advice for professionals on individual care plans and other arrangements in place of the LCP;
- considering how health and social care can best address the recommendations in the review about the accountability and responsibility of individual clinicians, out-of-hours decisions, nutrition and hydration and communication with the patient and their relatives or carers; and
- engaging with patients, carers, the public and clinicians as part of developing a set of desired outcomes and guiding principles that will describe what high quality care for people should look like in the last days and hours of life no matter where they are being looked after.

Membership:

Organisation	Member	Position in organisation
	Dr Bee Wee (Chair)	National Clinical Director, End of Life Care, NHS England
Care Quality Commission	Kate Birrell	Regulatory Policy Officer Strategy and Intelligence Directorate - Better Regulation
College of Health Care Chaplains	Rev Meg Burton	Organising Professional Committee
Department of Health	Jacqueline Naylor	Lead policy advisor
General Medical Council (GMC)	Sharon Burton	Head of Standards and Ethics (with Mark Dexter, Head of Policy (Education), GMC)
General Pharmaceutical Council	Priya Warner	Head of Standards and Fitness to Practise Policy
Health and Care Professions Council	Selma Elgaziari	Policy officer
Health Education England	Wendy Russell	Head of Policy and Operations
Monitor	Catherine Pollard	Pricing Development and Integrated Care Director
National Institute for Health Research (NIHR)	Dr David Cox	Deputy Director, Research Finance, & Programmes
NICE (National Institute for Health and Care Excellence)	Professor Gillian Leng	Deputy Chief Executive, Director of Health and Social Care
NHS England	Susan Swientozielskyj	Head of Long Term Conditions, Nursing Directorate
NHS Improving Quality	Claire Henry to March 2014, thereafter, Anita Hayes	Claire Henry: Head of Improvement Programmes for Long-term conditions and end of life care Anita Hayes: Programme Director, End of Life Care
NHS Trust Development Authority	Jacqueline McKenna	Deputy Director of Nursing

Nursing and Midwifery Council (NMC)	Carmel Lloyd to 31 January 2014, thereafter Yasmin Becker	Carmel Lloyd: Standards Development Manager, Continued Practice Directorate Yasmin Becker: Assistant Director of Revalidation and Standards
Public Health England	Professor Julia Verne BSc, MBBS, MSc. PhD, FFPH	Director for Knowledge & Intelligence (South West) and Clinical Lead - National End of Life Care Intelligence Network.
Representing the Marie Curie Cancer Care/ Help the Hospices/ NCPCC Strategic Partner Programme "consortium"	Dr Jane Collins	Chief Executive, Marie Curie Cancer Care
Representing the Sue Ryder/ NCF/ VODG Strategic Partner Programme "consortium"	Dr John Hughes	Medical Director, Sue Ryder
Representing the Richmond Group of Health Charities	Mike Hobday	Director of Policy and Research, Macmillan Cancer Support
Royal College of GPs	Dr Dennis Cox to 1 January 2014, thereafter Dr Peter Nightingale	
Royal College of Nursing	Amanda Cheesley	Long Term Conditions Adviser
Royal College of Physicians	Dr Anita Donley	Clinical Vice President

Annex B:

Responses to Individual Panel Recommendations

Rec. no.	Theme	
1	Terminology	<p>NHS England should work speedily to issue clear definitions of time frames relating to end of life decision-making, and these definitions should be embedded firmly into the context of existing policies and programmes so that there is no room for doubt.</p> <p>Accepted in part.</p> <p>NHS England believes that matters related to end of life decision-making are for the dying person themselves, clinical staff and civil society, not government bodies. Alliance members now use the terms 'dying', 'in the last days to hours of life' or 'in the last few days and hours of life' when referring to people whose death is expected within hours or up to two/three days. The Priorities for Care documents refer throughout to the 'last few days and hours of life'.</p> <p>Alliance members have also agreed the definition, which reflects current common usage, that: "Patients are 'approaching the end of life' when they are likely to die within the next 12 months" and will use the term 'end of life' in this way.</p> <p>The background to this recommendation was: "The review panel is concerned that, in settings where there is little or no input from a specialist palliative care team – whether in hospitals or the community – it might be all too easy to misinterpret a doctor's statement about the patient being now at the 'end of life' and for the LCP to be initiated inappropriately". The Priorities for Care are devised to be appropriate "when it is thought that a person may die within the next few days or hours" i.e. they will support good care even if someone is not, in fact, dying.</p> <p>The Alliance has produced a glossary of terms used in end of life care, which also includes terms such as 'palliative care' and 'specialist palliative care'.</p>

2	<p>NHS England and the National Institute for Health and Care Excellence should review urgently the terms they are using to define clinical ‘pathways’, as opposed to protocols, standard operating procedures, guidelines, guidance, and best practice models.</p> <p>Accepted.</p> <p>The Alliance has produced a glossary (included at Annex G of the system-wide response) which includes definitions of, amongst other things, ‘clinical pathways’, ‘protocols’, ‘standard operating procedures’, ‘guidelines/ guidance’ and ‘best practice models’.</p> <p>Alliance members will respect these definitions and in relation to care in the last few days and hours of life will reserve the terms ‘guidance/ guidelines’, as well as ‘quality standards’, for use by NICE and the professional regulators. The Alliance has produced implementation guidance for service providers and commissioners on delivering the Priorities for Care of the Dying Person. Alliance members will, through their ongoing work, promote the adoption by all health and care staff of the definitions in the glossary.</p>
3	<p>The name ‘Liverpool Care Pathway’ should be abandoned, and within the area of end of life care, the term ‘pathway’ should be avoided. An ‘end of life care plan’ should be sufficient for both professionals and lay people.</p> <p>Accepted.</p> <p>Use of the ‘Liverpool Care Pathway’ will be phased out by 14 July 2014. Whenever someone is in the last few days and hours of life, care must be focused around achieving the five Priorities for Care, one of which explicitly requires an individual plan of care and treatment for those in the last few days and hours of life to be delivered. The plan must be developed to meet the dying person’s own needs and wishes in relation to how their care should be managed and any treatment preferences they may want to express. The plan must include attention to symptom control and the person’s physical, emotional, psychological, social, spiritual and religious needs and provide for the person to be supported to eat and drink as long as they wish to do so and for their comfort and dignity to be prioritised.</p> <p>The Alliance does not refer to such plans as ‘end of life’ care plans, in line with the usage of the term ‘end of life care’ set out in its response to recommendation 1 (and included in the glossary it has produced).</p> <p>Alliance members do not think that ‘clinical pathways’ as defined in its glossary (i.e. “a standardised set of actions aiming to optimise care for a particular clinical problem, in line with evidence or guidelines”) are</p>

		<p>appropriate for care in the last few days and hours of life and they will not issue or endorse any 'clinical pathways' in relation to such care.</p> <p>CQC's new inspection approach will be introduced from October 2014. CQC's inspection of end of life care will reflect the Priorities for Care and the action taken by the provider to respond to the review of the LCP.</p>
4	Evidence base	<p>The CQC, in collaboration with the Health Quality Improvement Partnership, should conduct fully independent assessments of the role of healthcare professionals in end of life care in England, focusing on the outcomes and experience of care, as reported by patients, their relatives and carers, as well as the quality of dying.</p> <p>Accepted.</p> <p>CQC inspections will include checking whether care is delivered by qualified, competent staff, who are supported in their development and in their roles. CQC inspection teams will gather views from people who use services and their families, carers and advocates.</p>
5		<p>The National Institute for Health Research fund should fund research into the biology of dying.</p> <p>Not accepted at this stage.</p> <p>Alliance members consider that new research in relation to end of life care should focus initially on developing a better understanding of the experience that dying people and their families have; and what matters to them. This work will be carried out through the James Lind Partnership, which brings together patients, carers and clinicians to identify the top ten uncertainties or unanswered questions that they agree are most important to them in a particular area of treatment or care. If this work identifies research into the biology of dying as a priority, the appropriate funding bodies for such research will be approached after that. It is expected that the James Lind Alliance Priority Setting Partnership will have completed its work by early 2015.</p>
6		<p>The National Institute for Health Research fund should fund research into the experience of dying. Research priorities must extend also to systematic, qualitative and mixed methods research into communication in the patient and relative or carer experience.</p> <p>Still being considered.</p>

		<p>NIHR and ESRC will consider this recommendation in the light of conclusions reached by the James Lind Alliance Priority Setting Partnership (see response to Recommendation 5) and research questions identified through the Cochrane 'mapping' review (see response to Recommendation 9). Both these exercises will have been completed by early 2015.</p> <p>NIHR and ESRC will take the outcomes of these exercises into account in deciding the appropriate response: this might be targeted topics for research commissioning, or a more broadly-based highlighting of research needs. Only once the priority topics for research are established, can the most relevant methodological approaches be identified.</p>
7	Falsification of documentation	<p>Clinicians should be reminded by their registration bodies that the deliberate falsification of any document or clinical record, in order to deflect future criticism of a failure of care, is contrary to GMC and NMC guidelines, and therefore a disciplinary matter.</p> <p>Accepted in principle.</p> <p>The NMC's standards on record keeping are currently contained both within the NMC Code and stand-alone guidance on record keeping.⁴² As part of the current review of the Code, NMC is strengthening those elements within the Code that deal with record keeping. It will therefore be made even clearer in the revised Code that falsifying documents for ANY reason, not just to deflect criticism of a failure of care for a dying person, is a serious disciplinary matter. Once the revised Code has been issued – which is anticipated to take place in December 2014 - NMC will consider whether any changes are required to the underpinning stand-alone guidance on record keeping. This will be part of its thorough review of standards and guidance which is scheduled to take place in 2015-16. When the revised Code is launched, there will be accompanying literature that will highlight any changes of content and emphasis in the revised Code – NMC will ensure that this includes reference to record keeping and falsification of documents. As part of communicating to nurses and midwives the requirements of the revised Code, NMC will emphasise this area as appropriate.</p> <p>GMC will continue work to raise awareness of the advice in Good medical practice (2013)⁴³ around doctors' responsibilities to be open and honest when things go wrong with a patient's care; to keep clear, accurate records; and to comply with systems set up to promote patient safety and improvements to healthcare services.</p> <p>The health and care regulatory bodies expect to publish in the summer, for consultation, a joint statement on the responsibilities of medical and nursing staff to be candid with patients when things go wrong with their care.</p>

⁴² For NMC Code, see: www.nmc-uk.org/documents/standards/the-code-A4-20100406.pdf

⁴³ See www.gmc-uk.org/guidance/good_medical_practice/20463.asp

		<p>The HCPC is clear that healthcare professionals must not knowingly falsify any record of treatment or care given. It articulates the need for registrants to keep clear and accurate records and to act with honesty and integrity in its standards of conduct, performance and ethics.⁴⁴ The HCPC will continue its ongoing programme of engagement with those on its Register to ensure that expectations in these standards are explored and understood. The HCPC is currently reviewing these standards and will consider strengthening its expectations of registrants with reference to their responsibility to identify and be open about failures in care as part of its working group for the review later this year. Promotion of the new standards and further dissemination strategies will also be considered as part of this review.</p> <p>GPhC standards require registrants to be honest and keep full and accurate records of the professional services they provide in a clear and legible form and the GPhC takes seriously allegations that records have been falsified.⁴⁵ The GPhC intends to review its core standards in 2014/15 and will consider whether further changes to its core standards are needed, as part of that review.</p>
8	Diagnosis of dying - prognostic tools	<p>NHS England and Health Education England should collaborate to promote:</p> <ul style="list-style-type: none"> the use of evidence-based prognostic tools, including awareness of their limitations; <p>Not accepted.</p> <p>This is not a role for NHS England.</p> <p>Alliance members share the concerns of families, the panel and others that some people were placed on the LCP when they were not dying and hence that the treatment and care they received may not have been appropriate. The Priorities for Care are devised to be appropriate “when it is thought that a person may die within the next few days or hours” i.e. they will support good care even if someone is not, in fact, dying. In particular, the Priorities provide for regular assessments to assess whether the person is still thought to be dying and whether the plan of care remains appropriate. Under this approach, there is no definitive ‘diagnosis’ of dying. The approach makes provision for uncertainty about whether someone is dying and supports professionals in managing that uncertainty and communicating about it with the person and those who are important to them.</p> <p>The approach is consistent with the fact that existing prognostic indicators are based on clinical experience and intended to guide practice in recognising when a condition has reached an advanced, progressive stage. NHS England and Health Education England consider that the evidence base for them is insufficient to recommend their use as ‘prognostic tools’.</p>

⁴⁴ See www.hcpc-uk.org/aboutregistration/standards/standardssofconductperformanceandethics

⁴⁵ See GPhC Standards at: www.pharmacyregulation.org/standards/conduct-ethics-and-performance

	<p>In line with the approach taken in the Priorities for Care, Alliance members are not clear that if the evidence base for a particular prognostic tool or tools to diagnose dying improves significantly in future, it will necessarily be helpful to promote their use.</p> <ul style="list-style-type: none"> • evidence-based education and competency based training, with regular refresher modules, for all professionals working with people approaching the end of their lives, both in the use of prognostic tools and in explanation to patients and relatives or carers of how they are used and the unavoidable uncertainties that accompany an individual's dying. <p>Accepted in part.</p> <p>Alliance members agree that there is a pressing need to ensure that health and care staff are trained and competent to explain to dying people and those who are important to them the uncertainties around dying and judgements that someone may be in the last few days and hours of life. The Alliance has included in its publication 'Priorities for Care: implementation guidance for service providers and commissioners' that providers and commissioners must "require and enable health and care staff to acquire and maintain the necessary competences for delivering the Priorities for Care of the dying person, commensurate with the individual's role and responsibility, by providing protected learning time and resources for education and training, as part of induction, continuing professional development and regular updates." The Alliance's suggested core components of education and training for those caring for dying people (which are part of its "Priorities for Care: implementation guidance for service providers and commissioners") include communication and managing uncertainty.</p> <p>CQC inspections will seek assurance that providers require and enable health and care staff involved in caring for dying people to undertake education and training appropriate to their role.</p>
<p>9</p>	<p>The National Institute for Health Research should fund research on improving, where possible, the accuracy of prognostic tools for the last weeks to days of life. This would cover, for example, the accuracy of prognostication where that is possible, suitably configured, mixed method trials of different forms of care during dying, specific interventions, such as hydration and nutrition, and symptom control measures.</p> <p>Accepted.</p> <p>NIHR has issued a call for research proposals on prognostic models, including prognostic tools, for people with advanced cancer. Work continues on developing a proposal of sufficient quality to justify funding. NIHR will review the need for commissioning further research on prognostic tools after January 2015, when the James Lind Alliance Priority Setting Partnership has identified the uncertainties or</p>

	<p>unanswered questions that are most important to dying people, their carers and clinicians, and when the Cochrane 'mapping' review (see immediately below) is complete. (See response to Recommendation 6).</p> <p>The NIHR has commissioned through the Pain, Palliative and Supportive Care Cochrane Review Group a 'mapping' review of the evidence requirements flowing from the Priorities for Care.</p> <p>NIHR has also commissioned updates of Cochrane Reviews of evidence on medically assisted nutrition and on medically assisted hydration for palliative care patients and these were published by the Cochrane Collaboration in April 2014. Work began on a Cochrane Review of evidence on the impact of morphine, fentanyl, oxycodone or codeine for cancer pain on patient consciousness, appetite and thirst in March 2014 and will be completed by August 2014. The Cochrane Reviews are being led by the Pain, Palliative and Supportive Care group of the Cochrane Library.</p>
10	<p>The General Medical Council should review whether adequate education and training is currently provided at undergraduate and postgraduate levels to ensure competence. It should also consider how, given its recently increased responsibilities for specialist training and enhanced role in continuing professional development, it can ensure that practising doctors maintain and improve their knowledge and skills in these areas.</p> <p>Accepted.</p> <p>The GMC accepts this recommendation. It has reviewed how the training for doctors provided at undergraduate and postgraduate level equips them to address uncertainty and dying, as well as other aspects of caring for people in the last few days and hours of life. Details of this are at Annex H.</p> <p>In preparing medical students for their future role as doctors, the GMC will continue to set the standards and outcomes for undergraduate medical education and training. At present the standards and outcomes are set out in the GMC document Tomorrow's Doctors. The outcomes for graduates in Tomorrow's Doctors require that students at the point of graduation must be able to: 'Contribute to the care of patients and their families at the end of life, including management of symptoms, practical issues of law and certification and effective communication and team working.'</p> <p>In June 2014, the GMC and the Medical Schools Council will jointly write to all Deans of Medical Schools reminding them of the need to ensure that the curricula they set should equip students effectively to support the care for dying people.</p> <p>The curricula developed by the medical royal colleges and faculties and approved by the GMC for postgraduate medical education - including the</p>

		<p>Foundation Programme and specialty training – will continue to set out the education and training which trainee doctors must undertake in relation to the care of dying people.</p> <p>As part of its drive to strengthen curricula, the GMC is working with the Academy of Medical Royal Colleges to enhance the coverage of skills that are generic to all specialty training and relevant to the care of people in the last days of life. The aim is to develop, by the end of 2014, a framework for ‘generic professional capabilities’ which focuses on areas such as shared decision-making, effective communication and team working.</p> <p>In 2014, the GMC will also be publishing advice to help doctors access guidance and other learning opportunities on end of life care, that support doctors’ continuing professional development.</p>
11	Diagnosis of dying – communicating uncertainty	<p>The National Institute for Health Research should as a matter of priority fund research into the development and evaluation of education and training methods and programmes addressing uncertainty and communication when caring for the dying.</p> <p>Still being considered.</p> <p>NIHR is not the organisation responsible for ensuring there is appropriate research on the effectiveness of training and development.</p> <p>Instead, HEE will consider whether it should seek to get research on this area funded through the Department of Health Policy Research Programme. It will also work with stakeholders to influence training curricula as appropriate, acknowledging that the content and standard of clinical training is ultimately the responsibility of the professional bodies.</p> <p>Existing evidence on the effectiveness of particular education and training methods and programmes addressing the uncertainty around dying and developing communication skills that are relevant to the last days and hours of life include:</p> <ul style="list-style-type: none"> • The previous National End of Life Care Programme carried out work in 12 pilot sites on communications in end of life care. The pilots carried out a training needs analysis, reviewed existing provision and benchmarked it against national competences. They then used a needs-based approach to develop new training plans. Key findings from the pilots included that three factors reduced the effectiveness of training of communications in end of life care: lack of opportunity to apply skills in practice; training not being relevant to participants’ roles; and training which does not match the prior knowledge and skills of participants.

		<ul style="list-style-type: none"> • Evaluation of the GP Pilot Project, carried out by Dying Matters in 2011, showed that workshops on communicating about the end of life, supported by a reminder list for GPs and specific communications materials for patients, transformed the confidence of GPs in talking to patients about dying and hence improved end of life care. RCGP promotes resources produced by Dying Matters, including about communicating on the end of life. <p>NHS Improving Quality is investigating options for information exchange and knowledge sharing about effective practice in care and in training and development for people in the last few days and hours of life, including evaluation information. This would contribute towards better understanding of what training and development is effective.</p>
12	Guidance on diagnosis of dying	<p>Clear guidance should be issued by the National Institute of Health and Care Excellence on:</p> <ul style="list-style-type: none"> • diagnosis and who should ultimately be responsible for diagnosing that someone is beginning to die • the necessity for multidisciplinary decision-making • the usefulness or otherwise of laboratory and other biological evidence • the importance of case notes review for diagnosis • how any uncertainty about whether a patient is in the active process of dying should be taken into account in the clinical management of the patient, in different healthcare settings. <p>Accepted.</p> <p>NICE is currently developing new Guidance on the management of care for dying adults which it hopes to publish in 2015. Later, it will update its existing guidance on palliative care and end of life service guidance as part of our ongoing surveillance and updating programme. The Quality Standard on End of Life Care will be revised following the publication of this new guidance. In preparing the guidance and Quality Standard, NICE will consider how best to respond to the specific issues referred to in this recommendation.</p>
13	Good practice guidance for nurses on decision-making	<p>As a matter of urgency the Nursing and Midwifery Council should issue for nurses guidance on good practice in decision-making in end of life care, equivalent to that issued by the General Medical Council for doctors.</p>

		<p>Accepted in part.</p> <p>As part of the review of the Code, which will include extensive public consultation on all elements of the current Code and the opportunity for comments to be made on a draft version of the proposed revised Code, NMC will strengthen the standards that relate to decision-making as it applies to all nurses and midwives on the register, in whichever areas they work, not just end of life care. This consultation exercise began in May 2014 and will run to August 2014, and the revised Code will be published in December 2014.</p> <p>In the meantime, the NMC published, in April 2014, the existing, generic competency standards for decision-making in a more accessible form⁴⁶. This will make access to current competency standards on decision-making simpler for all those who wish to access them, including members of the public.</p>
14	Decisions to initiate an end of life care plan out of hours	<p>Every patient diagnosed as dying should have a clearly identified senior responsible clinician accountable for their care during any 'out of hours' period. Unless it is unavoidable, urgent, and is clearly in the patient's best interests, the decision to withdraw or not to start a life-prolonging treatment should be taken in the cool light of day by the senior responsible clinician in consultation with the healthcare team. The practice of making such decisions in the middle of the night, at weekends or on Bank Holidays, by staff that do not have the requisite training and competence, should cease forthwith.</p> <p>Accepted.</p> <p>For hospital patients, including those who are dying, clarification of who is the responsible consultant/clinician during 'out of hours' is part of work being carried out by the Academy of Royal Medical Colleges, following the Government's response to the Francis Inquiry⁴⁷, which stated that every hospital patient should have the name of a responsible consultant and nurse above their bed. The Academy is producing key principles with worked examples on how the principle of all hospital patients having a named consultant who is responsible for their care can be implemented in a way that sustains professional support.</p> <p>Current arrangements mean that for patients being cared for in the community, a dying person's registered or named GP is responsible for their care during surgery hours, with this responsibility delegated to the GP's deputising service during any 'out of hours' period.</p> <p>The Alliance's document 'Priorities for Care of the Dying Person – Duties and Responsibilities of Health and Care Staff' includes:</p>

⁴⁶ The NMC's *Standards for Competence for Registered Nurses* (2014) document is available on the NMC website at: www.nmc-uk.org/Documents/Standards/Standards%20for%20competence.pdf

⁴⁷ *Hard Truths: the journey to putting patients first. Volume One of the Government Response to the Mid Staffordshire NHS Foundation Trust Public Inquiry* https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/270368/34658_Cm_8777_Vol_1_accessible.pdf

“The person whose condition has deteriorated unexpectedly must be assessed by a doctor who is competent to judge whether the person’s change in condition is potentially reversible or they are likely to die in the next few hours or few days.”

“If the doctor judges that the person is likely to die soon, s/he must clearly and sensitively communicate this to the dying person (if conscious). This includes explaining when and how death might be expected to occur and the basis for that judgement, acknowledging and accepting any uncertainty about the prognosis, and giving the dying person the opportunity to ask questions. The same communication must take place with those important to the dying person and others involved in that person’s care. The responsibility for communicating this information may be delegated by the doctor to another clinician who has the appropriate training and competence.

The decision must be reviewed at the next available opportunity by a senior clinician within the person’s care team who is competent to assess whether the person has reached the stage where they are dying. The views of the wider multi-professional team must be taken into consideration in making this assessment.

The goals of treatment and care must be discussed and agreed with the dying person, involving those identified as important to them and the multidisciplinary team caring for the person. These discussions must be clearly documented and accessible to all those involved in the person’s care, taking into account the person’s wishes about sharing their confidential information. Doctors and nurses must acknowledge, accept and communicate uncertainty that exists about the prognosis.”

“Doctors, nurses and other healthcare professionals must carefully consider which decisions need to be made on-the-spot to ensure the person’s comfort and safety, and which can and must wait for a review of the person’s condition by the senior doctor who has responsibility for the person’s treatment and care (who may know the person better and/or have relevant competence and information to inform treatment decisions) or a clinician with the appropriate training and competence to whom the responsibility has been delegated.”

“Clinical teams must give the dying person, their families and those important to them the name of the Senior Doctor in the team who has overall responsibility for providing appropriate treatment and care for the dying person, and explain how that responsibility is handed over in times of absence or change in care arrangements or settings. This must be clearly documented and accessible to all those involved in the person’s care.”

“The dying person’s senior doctor is responsible for ensuring that adequate information is available to support decision-making by those involved in caring for the person when the senior doctor is not available.”

	<p>Alongside the Priorities for Care, Alliance members are taking action, described elsewhere in this document, to ensure that professionals who make decisions about the treatment and care of people who are thought to be dying are competent to make those decisions. Taken together, these actions and the Priorities for Care, should address any instances of decisions to withdraw or not to start a life-prolonging treatment being taken by staff without the requisite training and competence. Alliance members agree with the panel that staff who are not competent to take such decisions, must not do so.</p>
15	<p>The General Medical Council, the Health and Care Professions Council and the Nursing and Midwifery Council should ensure their professional standards clearly place the responsibility for such decisions on the senior responsible clinician, and they should take steps to emphasise how clinicians will be held to account against these standards. Furthermore, NHS England must ensure that appropriate systems are in place, with adequate levels of staffing to deliver these arrangements in practice. And CQC and Monitor should ensure their inspection regimes focus on this important aspect of the patient experience.</p> <p>Accepted in part.</p> <p>The Alliance has set out the duties and responsibilities of health and care staff for meeting the needs of a dying person at all times of the day or night, including the role of the senior responsible doctor.</p> <p>The GMC's guidance on Good Medical Practice makes clear that doctors have responsibilities for ensuring the continuity and safety of a patient's care. This includes ensuring appropriate arrangements for the hand over and delegation of care; the safe transfer of patients between healthcare providers and between health and social care providers and checking that a named clinician or team has taken over responsibility when their role in providing a patient's care has ended.⁴⁸ Failure to follow the GMC guidance may call in question a doctor's fitness to practise. A fitness to practise case that raises issues about a doctor's practice in relation to the care of a dying patient can take into account the advice set out in the Responsibilities document.</p> <p>The NMC's review of its Code for nurses will result in a greater emphasis being put on decision-making for all nurses and midwives, whilst ensuring that they work within the scope of their practice and the limits of their competence. The consultation exercise on the new Code began in May 2014 and will run to August 2014. The revised Code will be published in December 2014. When the revised Code is launched, there will be accompanying literature that will highlight any changes of content and emphasis in the revised Code – the NMC</p>

⁴⁸ *Good medical practice (2013)*, paragraph 44. Available at: www.gmc-uk.org/guidance/good_medical_practice/continuity_care.asp

		<p>will ensure that this includes reference to decision-making. In the meantime, the NMC has published, in April 2014, the existing, generic competency standards for decision-making in a more accessible form.⁴⁹ This will make access to current competency standards on decision-making simpler for all those who wish to access them, including members of the public.</p> <p>The HCPC's standards of conduct, performance and ethics require registrants to act only within the limits of their knowledge, skills and experience and to make referrals to more appropriately trained colleagues where appropriate. In line with these standards, the HCPC would expect registrants to refer decisions to withdraw or not to start a life-prolonging treatment to a senior responsible clinician.</p> <p>Expectations in the standards of conduct, performance and ethics are explored with registrants as part of an ongoing programme of communication. The HCPC will highlight these expectations with reference to care of the dying as part of its promotion of the Priorities of Care highlighted in its individual commitment statement.</p> <p>The Chief Nursing Officer for England and the National Quality Board have set out expectations of commissioners and providers in relation to getting nursing, midwifery and care staffing right so they can deliver high quality care and the best possible outcomes for their patients.⁵⁰</p> <p>CQC's new approach to hospital inspections from October 2014 will include reviewing how decisions are made regarding the care of patients who are dying. The detail of the inspection methodology in hospitals, including specific lines of enquiry, are being consulted on (from April 2014 onwards), and will be finalised by October 2014. Inspections will review whether the optimum staffing levels and skill-mix is sustained at all times of day and night to support safe, effective and compassionate care and levels of staff wellbeing.</p>
16	Training in shared decision-making	<p>The Review panel is deeply concerned that the GMC guidance is clearly not always being followed in the care of the dying, and recommends that the Royal Colleges review the effectiveness of any training in shared decision-making that they provide, examining the extent to which it closely reflects the professional standards in GMC and NMC guidance and required competencies in this area, with a view to ensuring continued competence is maintained across the education and training spectrum from undergraduate teaching and learning through to continued professional development.</p> <p>Accepted.</p> <p>The RCP will review its education and training in shared decision-making against professional standards including those of the GMC.</p>

⁴⁹ The NMC's *Standards for Competence for Registered Nurses* (2014) document is available on the NMC website at: www.nmc-uk.org/Documents/Standards/Standards%20for%20competence.pdf

⁵⁰ *How to ensure the right people, with the right skills are in the right place at the right time: A guide to nursing, midwifery and care staffing capacity and capability* - available on the NHS England website at: www.england.nhs.uk/wp-content/uploads/2013/11/nqb-how-to-guid.pdf

		<p>The RCGP has stressed the importance of shared decision-making in its curriculum covering GP consultations. A GP must negotiate a shared understanding of the problem and its management with patients, so that they are empowered to look after their own health; and achieve meaningful consent to a plan of management by seeing the patient as a unique person in a unique context. The RCGP will continue to review its education and training in shared decision-making against professional standards including those of the GMC.’</p> <p>HEE developed two e-learning sessions on shared decision-making in 2012 in partnership with AQuA⁵¹. The resource provides guidance on what Shared Decision Making (SDM) is and how to implement it in practice. It also provides resources to help health professionals learn the required skills. A web-based training and assessment package designed for pharmacy professionals supports the development of consultation and shared decision-making skills.</p>
17	Nutrition and hydration	<p>The General Medical Council should review its guidance on supporting oral nutrition and hydration to consider whether stronger emphasis could be given to this issue.</p> <p>Accepted in part.</p> <p>The GMC has reviewed the guidance set out in paragraphs 109-111 of Treatment and care towards the end of life: good practice in decision-making and concluded that it gives the right emphasis to ensuring people who are dying have their hydration and nutrition needs met, including being offered food and drink orally. However, the guidance is not always put into practice. Hence in 2014, as part of its programme of work to raise awareness of the guidance and supporting online resources, the GMC will use all its available channels to vigorously promote its use, focusing especially on the advice on oral nutrition and hydration. In particular, in 2014, it will deliver a coordinated programme of work to raise awareness and use of this guidance and vigorously promote its use by the profession. It will prioritise this within the work programme of its Regional Liaison Service in England, and teams in Scotland, Wales and Northern Ireland, collaborating with the NMC, RCN and other organisations as opportunities arise.</p>

⁵¹ AQuA (Advancing Quality Alliance) is a membership health improvement organisation. Its role is to stimulate innovation, spread best practice and support local improvement in health and in the quality and productivity of health services. Details of AQuA online resources are on the NHS England website at: www.england.nhs.uk/ourwork/pe/sdm/resources/aqua

18		<p>The Nursing and Midwifery Council should urgently produce guidance for nurses on supporting oral nutrition and hydration.</p> <p>Accepted.</p> <p>The NMC agrees that there should be guidance for nurses on supporting oral nutrition and hydration. Its Standards for Pre-Registration Nursing Education already contain such guidance.</p> <p>The NMC will raise awareness of the Code, its competency standards and essential skills clusters on nutrition and fluid management through its programme of work on revalidation and review of the Code in 2014. The proposed draft Code is being consulted on between May and August 2014 and will be published in December 2014. When the revised Code is launched, there will be accompanying literature that will highlight any changes of content and emphasis in the revised Code – NMC will ensure that this includes references to nutrition and hydration.</p> <p>NMC has also raised awareness by publishing as a separate document, in April 2014, the standards for nursing competency (including the essential skills cluster on hydration and nutrition) so that they are more easily accessible by nurses, patients and families.⁵² The foreword to this document and the accompanying publicity on NMC's website highlighted in particular the sections on end of life care, hydration and nutrition and the fact that the document was published in response to the recommendations of the LCP panel's report.</p>
19		<p>All staff in contact with patients should be trained in the appropriate use of hydration and nutrition at the end of life and how to discuss this with patients, their relatives and carers.</p> <p>Accepted.</p> <p>The Alliance's recommended core content for education and training on the care of dying people, which are included in its "Priorities for Care: implementation guidance for service providers and commissioners", include nutrition and hydration and refer specifically to discussion and shared decision-making on this with the person (where possible), those important to them and other health and care team members. Alliance members will include these aspects in any education and training on care for dying people that they fund, commission or deliver in future.</p>

⁵² The NMC's *Standards for Competence for Registered Nurses* (2014) document is available on the NMC website at: www.nmc-uk.org/Documents/Standards/Standards%20for%20competence.pdf

20		<p>There should be a duty on all staff to ensure that patients who are able to eat and drink should be supported to do so.</p> <p>Accepted.</p> <p>There is already a duty on doctors and registered nurses to support patients to eat and drink, where this is desired and not harmful, through the GMC guidance on doctors' responsibilities in this area and the NMC's Code and competency standards for nursing practice, breach of either of which could endanger a professionals' registration. GMC and NMC will take specific action to make doctors and registered nurses aware of their responsibilities in this area (see responses to recommendations 17 and 18).</p> <p>The Chief Nursing Officer will write to all nurses when the Priorities for Care are published, drawing attention to them and reminding nurses of their duty to support dying people who wish to eat and drink to do so.</p> <p>The HCPC expects this behaviour of professionals as part of their duty to promote, protect and act in the best interests of their service users, outlined in its standards of conduct, performance and ethics. Failure to act in accordance with these standards could endanger a registrant's registration. The HCPC will continue with its current communication programme with registrants to ensure that these standards are explored and understood and will communicate these expectations further as part of its promotion of the Priorities for Care.</p>
21		<p>Failure to support oral hydration and nutrition when still possible and desired should be regarded as professional misconduct.</p> <p>Accepted.</p> <p>See responses to recommendations 17, 18 and 20, including on how the regulator's guidance is used when it considers a doctor's actions through its fitness to practise process.</p>
22		<p>Specialist services, professional associations and the Royal Colleges should run and evaluate programmes of education, training and audit about how to discuss and decide with patients and relatives or carers how to manage hydration at the end of life.</p> <p>Accepted in part.</p> <p>On education and training, see response to recommendation 19 above with regard to education and training. The NMC will be evaluating its pre-registration nursing education standards in 2015-16 and this will include evaluation of the effectiveness of current training on end of life care and associated areas such as communication skills, nutrition and hydration.</p>

23	Sedation and pain relief	<p>Before a syringe driver is commenced, this must be discussed as far as possible with the patient, their relatives or carer, and the reasoning documented.</p> <p>Accepted.</p> <p>The Alliance's 'Priorities for Care of the Dying Person: Duties and Responsibilities of Health and Care Staff' include:</p> <p>"Health and care staff must give the dying person the information they need or are asking for in a way they can understand, and the support they need to make informed decisions about treatment options.</p> <p>The dying person's wishes about the extent to which families and those important to them are involved in discussing their treatment and care must be respected and supported."</p> <p>"The reason for any intervention, including the use of a syringe driver, must be explained to the dying person and to those important to the dying person. Other than in exceptional circumstances, this should be done before it is used.</p> <p>The likely side effects of specific interventions, especially those that may make the person sleepy, must be discussed with the dying person to enable them to make informed decisions, and explained to those important to the dying person if the person wishes."</p> <p>"The content and outcome of all discussions must be documented and accessible to all those involved in the person's care. This includes conversations about prognosis, goals of treatment and care plans at each point in time, and particular concerns that the person, their family and those identified as important to them have expressed."</p>
24		<p>New research is needed on the use of drugs at end of life, and in particular on the extent to which sedative and analgesic drugs themselves contribute to reduced consciousness, and perceived reduction of appetite and thirst.</p> <p>Accepted.</p> <p>NIHR has recently commissioned the Cochrane Pain, Palliative and Supportive Care Group to conduct a review on the impact of morphine, fentanyl, oxycodone and codeine on patient consciousness, appetite and thirst in cancer patients. This is likely to be completed by August 2014.</p> <p>The review will enable new research to be more clearly focused on the unanswered research questions.</p>

25	Financial incentives	<p>Payments ‘per patient implemented on the LCP, or equivalent approach’ should cease.</p> <p>Accepted.</p> <p>Alliance members agree that such financial incentives are inappropriate. There are no longer any such national incentives and NHS England agrees that any such payments from clinical commissioning groups would also be inappropriate and should cease.</p>
26	Accountability	<p>A named consultant or GP, respectively, should take overall responsibility for the care of patients who are dying in hospital or the community.</p> <p>Accepted.</p> <p>The Government’s response to the Francis Inquiry made clear that every hospital patient should have the name of a responsible consultant above their bed.</p> <p>Current arrangements mean that for patients being cared for in the community, a dying person’s registered or named GP is responsible for their care during surgery hours, with this responsibility delegated to the GP’s deputising service during any ‘out of hours’ period.</p>
27		<p>The name of a registered nurse responsible for leading the nursing care of the dying patient should be allocated at the beginning of each shift. This nurse will be responsible also for communicating effectively with the family, checking their understanding, and ensuring that any emerging concerns are addressed.</p> <p>Accepted.</p> <p>The Government’s response to the Francis Inquiry made clear that every hospital patient should have the name of a responsible nurse above their bed.</p> <p>The Alliance’s “Priorities for Care: implementation guidance for service providers and commissioners” sets out that providers of health and care services must put in place local governance arrangements so that the nurse leading the care of the dying person at any one time, including during each shift if the person is in hospital or care home, is identified to the person and those important to them; and that the name of the relevant nurse is documented. CQC’s new inspection approach (subject to consultation) reviews whether people receive care which is caring, and this includes whether dying people and their families know who the named nurse or key worker responsible for their care is.</p>

28		<p>The boards of healthcare providers providing care for the dying give responsibility for this to one of its members – preferably a lay member whose focus will be on the dying patient, their relatives and carers – as a matter of urgency. This is particularly important for acute hospitals.</p> <p>Accepted.</p> <p>The Minister for Care and Support wrote to all chairs and chief executives of NHS Trusts and NHS Foundation Trusts on 15 July 2013 about the report of the independent review into the Liverpool Care Pathway. Amongst other things, he asked them to appoint a Board member with the responsibility for overseeing any complaints about end of life care and for reviewing how end of life care is provided.</p> <p>The NHS TDA has asked NHS trusts how far they are complying with this and all NHS Trusts have confirmed they have appointed a Board member with responsibility for end of life care.</p> <p>CQC new inspections of NHS trusts include, as part of assessing whether services are well led, looking at Board level responsibility for end of life care.</p> <p>CQC’s themed inspection on end of life care, to be carried out during 2014/15, will consider governance and leadership issues.</p>
29	Documenting an end of life care plan	<p>Guidance should specify that the senior clinician writes in the patient’s notes a record of the face to face conversation in which the end of life care plan was first discussed with the patient’s relatives or carers. The record of that conversation must include the following:</p> <ul style="list-style-type: none"> • That the clinician explained that the patient is now dying and when and how death might be expected to occur. • If the family or carers do not accept that the patient is dying, the clinician has explained the basis for that judgement. • That the relatives or carers had the opportunity to ask questions. <p>Accepted.</p> <p>The Alliance’s “Priorities for Care of the Dying Person: Duties and Responsibilities of Health and Care Staff” includes:</p> <p>“If the doctor judges that the person is likely to die soon, s/he must clearly and sensitively communicate this to the dying person (if conscious). This includes explaining when and how death might be expected to occur and the basis for that judgement, acknowledging and accepting any uncertainty about the prognosis, and giving the dying person the opportunity to ask questions. The same communication must take place with those important to the dying</p>

		<p>person and others involved in that person’s care. The responsibility for communicating this information may be delegated by the doctor to another clinician who has the appropriate training and competence.</p> <p>The decision must be reviewed at the next available opportunity by a senior clinician within the person’s care team who is competent to assess whether the person has reached the stage where they are dying. The views of the wider multi-professional team must be taken into consideration in making this assessment.</p> <p>The goals of treatment and care must be discussed and agreed with the dying person, involving those identified as important to them and the multidisciplinary team caring for the person. These discussions must be clearly documented and accessible to all those involved in the person’s care, taking into account the person’s wishes about sharing their confidential information. Doctors and nurses must acknowledge, accept and communicate uncertainty that exists about the prognosis.”</p> <p>“The content and outcome of all discussions must be documented and accessible to all those involved in the person’s care. This includes conversations about prognosis, treatment goals and care plans at each point in time, and particular concerns that the person, their family and those identified as important to them have expressed.”</p>
30		<p>A shared care folder, kept at the hospital bedside and designed for communication between patients, relatives and the staff, should be introduced, supported by training for staff on how to use it.</p> <p>Accepted in principle.</p> <p>The Alliance agrees that there must be clear arrangements for sharing key information about the individual’s care, treatment and preferences between staff and that individual. The Priorities for Care include that:</p> <p>“Sensitive communication takes place between staff and the dying person and those identified as important to them.”</p> <p>In line with its general approach that care must be individualised, the Alliance wants to ensure that the wishes of the dying person about how they would like information to be shared, and with whom, are respected. The concept of a folder or diary shared between the dying person, those important to them and staff is included in the Alliance’s “Priorities for Care: duties and responsibilities of health and care staff” as a suggestion for helping to enhance communication about the person’s needs, wishes and views, as other recording mechanisms such as CDs or DVDs for those with visual impairment.</p>

31		<p>There should be better integration in the community between LCP or other similar documentation and the existing system of shared care folders, so that the care provided by relatives and carers (professional or otherwise) is noted, and their contribution is incorporated into documentation.</p> <p>Accepted.</p> <p>The Alliance's "Priorities for Care: Duties and Responsibilities of Health and Care Staff" include:</p> <p>"Where the person's family or those identified as important to them are involved in the care of the dying person, their observations and judgements must be taken into account as part of the ongoing discussion and planning of care."</p> <p>"The content and outcome of all discussions must be documented and accessible to all those involved in the person's care. This includes conversations about prognosis, goals of treatment and care plans at each point in time, and particular concerns that the person, their family and those identified as important to them have expressed."</p> <p>"The context makes clear that family or others cannot access or be provided with information that the patient would not wish to be shared with them. Use of the LCP itself is due to be phased out by July 2014."</p>
32	Independent advocacy	<p>For each patient on an end of life care plan that has no means of expressing preferences and no representation by a relative or carer, views on their care should be represented by an independent advocate, whether appointed under the Mental Capacity Act 2005, a chaplain, or an appropriate person provided through a voluntary organisation. This applies to people of whatever age who lack capacity.</p> <p>Accepted in part.</p> <p>Organisations must appoint independent Mental Capacity Advocates (IMCAs) where this is provided for in the Mental Capacity Act 2005; and take account of any relevant Lasting Power of Attorney for health and welfare decisions and any advance decision to refuse treatment. This covers all serious medical treatment.</p> <p>The Priorities for Care of the Dying Person: Duties and Responsibilities for health and care staff includes:</p> <p>"Staff must operate within the legal framework provided by the Mental Capacity Act 2005 and its Code of Practice.⁵³ The Act makes clear who can take decisions in which situations, and how they should go about this. Anyone who works with or cares for an adult</p>

⁵³ The Mental Capacity Act 2005 and the MCA Code of Practice (with accompanying guides for staff and members of the public) are available at: www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

		<p>who lacks capacity must comply with the MCA when making decisions or acting for that person. The Act sets out 5 statutory principles that must guide decisions, including requirements that staff ensure that those who may lack capacity to decide are empowered to make as many decisions for themselves as possible and that any decision made, or action taken, on their behalf is made in their best interests.</p> <p>If an Advance Decision to Refuse Treatment exists and is valid and applicable (within the terms of the Act and Code), it must be followed. Individuals who have been nominated by the dying person to be involved in decisions and those who hold Lasting Powers of Attorney (LPA) relating to health and welfare issues must be involved in decisions. Those who hold a registered LPA for health and welfare may have legal authority under the terms of the LPA to make the decision on behalf of the dying person.”</p> <p>The Alliance’s “Priorities for Care: implementation guidance for service providers and commissioners” includes that service providers and employers must: “ensure that health and care staff are aware of the role of advocates as an independent voice (formal and informal), including when this is required under the Mental Capacity Act, offer this to patients and families and enable advocates to be utilised where necessary”.</p>
33	Availability of palliative care support	<p>Funding should be made available to enable palliative care teams to be accessible at any time of the day or night, both in hospitals and in community settings, seven days a week.</p> <p>Accepted.</p> <p>The Alliance’s implementation guidance for service providers and commissioners includes that service providers must: “Work with commissioners and specialist palliative care professionals to ensure adequate access to specialist assessment, advice and active management. ‘Adequate’ means that service providers and commissioners are expected to ensure provision for specialist palliative medical and nursing cover routinely 9am - 5pm seven days a week and a 24 hour telephone advice service. Where this service does not already exist, service providers and commissioners should formulate an action plan and commit to provision of such services within defined timelines. This should ensure the provision of specialist cover over 24 hours including face to face assessment in the exceptional circumstances where this is necessary.”</p> <p>In the next stage of their work the NHS Services, Seven Days a Week Forum will make proposals for improving the interfaces between hospitals and community, primary and social care organisations at weekends. This will improve responsiveness and ensure that unnecessary hospital admissions are prevented, and that discharges are safe and timely.</p>

34	Guidance for nurses in end of life care	<p>As part of its work to review the Nursing and Midwifery Code in preparation for revalidation, and as a matter of priority the Nursing and Midwifery Council should provide guidance for nurses caring for people at the end of life. This should encompass the good practice guidance on decision-making recommended in paragraph 1.42 (see recommendation 13).</p> <p>Not accepted.</p> <p>NMC's Council decided in September 2013 not to issue separate guidance on this matter but instead to consider this recommendation as part of the ongoing review of the Code. The review of the Code will strengthen requirements in the area of end of life care on a more general basis for all nurses and midwives. It is anticipated that the revised Code will be issued in December 2014.</p> <p>The revised Code will incorporate the principles behind the "Priorities for Care" – inclusion within the Code will automatically make adherence to these principles the personal responsibility of all registrants. This will make a difference to patients as it will be clear to all registrants that the principles behind the "Priorities for Care" are integral to their practice and cannot be ignored without running the risk of jeopardising their registration.</p> <p>NMC will publicise the "Priorities for Care: duties and responsibilities of health and care staff" via its website, drawing the attention of all registrants and interested stakeholders and members of the public to them and their importance.</p>
35	Education in care for the dying	<p>Health Education England should pay particular attention to the pressing need for more evidence-based education in all settings that care for the dying in its work to improve workforce planning to ensure sufficient staff are trained with the right skills in the right locations to enable healthcare providers to deliver their commissioning plans.</p> <p>Accepted.</p> <p>Health Education England will work with stakeholders to develop and influence education and training as appropriate. Through Health Education England's e-Learning for Health (eLfh), the e-ECLA programme and modules on shared decision-making have been developed to support the care of the dying.</p> <p>The content and standard of clinical training is ultimately the responsibility of the healthcare regulators working with professional bodies; continuing professional development of the existing workforce is primarily an employer responsibility. However, Health Education England will seek to influence stakeholders.</p>

		<p>Health Education England supports the recommendations for developing the future workforce and will engage with other organisations to take this recommendation forward. The first workforce plan for England for 2014/15 was published in 2013. Future workforce planning will take into account a life-course approach.</p>
36	Guidance	<p>A series of guides and alerts should be developed that reflect the common principles of good palliative care and link directly to the General Medical Council’s and Nursing and Midwifery Council’s guidance (when the latter is developed). Implementation of this guidance should be the personal responsibility of clinicians.</p> <p>Accepted.</p> <p>The Alliance’s “Priorities for Care: Duties and Responsibilities for Health and Care Staff” provide clear guidance on the approach that is to replace the LCP. The content of the document reflects the principles of good care for dying people and, as appropriate, good palliative care.</p> <p>The duties and responsibilities document is aligned with the GMC guidance, Treatment and care towards the end of life: good practice in decision-making, the NMC Code of Practice, the HCPC’s Standards of conduct, performance and ethics and the GPhC’s Standards of conduct, ethics and performance.</p> <p>The NMC’s revised Code will incorporate the principles behind the “Priorities for Care” – inclusion within the Code will automatically make adherence to these principles the personal responsibility of all registrants. This will make a difference to patients as it will be clear to all registrants that the principles behind the “Priorities for Care” are integral to their practice and cannot be ignored without running the risk of jeopardising their registration.</p> <p>NMC will publicise the “Priorities for Care: Duties and Responsibilities of Health and Care Staff” via its website, drawing the attention of all registrants and interested stakeholders and members of the public to them and their importance.</p> <p>The HCPC will promote the Priorities of Care as articulated for health and care professionals and related HCPC expectations by providing information and alerts on its website, in its newsletters aimed at registrants and education providers and through established links with the professional bodies of each of the professions it regulates.</p>

37		<p>In addition to the core driving palliative care philosophy common to all the guidance, there would be elements of technical guidance specific to certain disease groups. They should be designed to be readily adapted for local use to meet the needs of individuals.</p> <p>Accepted.</p> <p>The Alliance carried out a rapid review of guidance which is now available. Guidance on caring for people, including dying people, with some specific diseases and conditions, e.g. renal disease, diabetes and chronic obstructive pulmonary disease, already exists. The NHS will continue to work on developing existing and new guidance with specialist societies and charitable organisations which specialise in relevant disease groups. There is not currently robust, universal evidence about the effect of particular treatments and interventions in particular circumstances. The 'Cochrane' reviews commissioned by NIHR (see response to recommendation 9) will address this to a significant extent.</p>
38	End of life care plan	<p>Use of the Liverpool Care Pathway should be replaced within the next six to 12 months by an end of life care plan for each patient, backed up by condition-specific good practice guidance.</p> <p>Accepted.</p> <p>The Alliance has developed an approach (set out in the Priorities for Care and associated documentation) that should be applied to all care for people in the last few days and hours of life and which will support service providers and professionals in ensuring the LCP is phased out by July 2014. The approach covers both expected and unexpected dying: the "Duties and Responsibilities of Health and Care Staff" document includes explicitly that: "Families and those close to the dying person will require additional support if the death has been unexpected or if it occurs after a very short deterioration".</p> <p>This approach is underpinning CQC inspections and will be reflected in the new NICE guideline for Care of the Dying Adult. CQC will ask providers how they have considered and acted on the recommendations of the review of the Liverpool Care Pathway, and will review the planning of care for dying people during inspections.</p> <p>One of the Priorities for Care focuses on an 'individual plan of care' – the Alliance has chosen to use this term rather than an 'end of life care' plan to avoid the confusion about the use of the term 'end of life care' which the independent review highlighted.</p>

		<p>As noted in the response to recommendation 37, the Alliance has made information about existing disease-specific guidance available.</p>
39	<p>A system-wide, strategic approach to improving care for the dying</p>	<p>The system needs a coalition of regulatory and professional bodies with NHS England, along with patient groups, setting clear expectations for a high standard of care for dying patients – care that will also meet the important and sometimes neglected needs of their relatives and carers. Working together strategically, such a coalition should lead the way in creating and delivering the knowledge base, the education training and skills and the long term commitment needed to make high quality care for dying patients a reality, not just an ambition. As a minimum, this would entail close co-operation between the GMC, NMC, the Royal Colleges, the CQC, NHS England and NICE.</p> <p>Under this approach, the GMC and NMC would take the lead with the Royal Colleges, HEE and NHS England in:</p> <ul style="list-style-type: none"> • Providing any additional good practice guidance, building on the standards set out in the GMC guidance on treatment and care towards the end of life • Reviewing whether current education and training standards adequately address care of the dying; setting requirements based on agreed levels of competence in the care of dying patients; and quality assuring the outcomes and effectiveness of teaching and learning. • Setting relevant standards for continuing professional development, for all clinicians (generalist and specialists) who have a role in caring for dying patients and their relatives or carers. And, where appropriate, encouraging or facilitating the development of relevant resources or programmes for continuing professional development. <p>As part of this coalition, the CQC would collaborate with patient groups in defining what good quality end of life care services should look like and then inspect against those standards.</p> <p>Accepted in principle.</p> <p>The organisations proposed by the panel, along with others, came together to form the Leadership Alliance for the Care of Dying People, which has created the platform for the sort of coalition described by the panel.</p> <p>The ‘founding’ organisations in the Alliance were CQC, DH, GMC, HEE, NHS England, NHS IQ, NICE, and NMC. They agreed to invite various other organisations to be members.</p>

		<p>The Alliance collectively has gone beyond the 44 recommendations in this report and set high expectations about how the system needs to work together to provide a good experience of care for the dying person and those important to them. Following engagement with the public and professionals, it has articulated the Priorities for Care of the dying person, and set out the duties and responsibilities of health and care staff, and requirements of service providers and commissioners to achieve these. Members of the Alliance will work through their respective networks to influence the quality of care locally, and to check on this through the normal inspection and regulatory mechanisms. For example, NHS England will work with local commissioners through its regional and local area teams, the Strategic Clinical Networks, Clinical Senates and the NHS Commissioning Assembly. CQC's inspection framework will be aligned with the Priorities for Care (see responses to recommendations 40 and 41 for further details).</p> <p>Individual Alliance members have set out in commitment statements that accompany this document how they will take forward the Priorities for Care and the work begun by the Alliance. Alliance members will also continue to work through various networks, including those listed above. Where collaboration between Alliance members is useful, e.g. on education and training, and on research and evidence, those Alliance members will come together to work on these strands. The working group, which is being formed to support the strategic work on the broader aspects of end of life care (i.e. not only the last days of life) will coordinate and oversee these strands of work. Alliance members commit to meeting in May 2015, to stock-take progress on their responses to the review panel's recommendations.</p>
40	Hospital inspections	<p>End of life care should be incorporated urgently into the hospital inspection programme of the newly announced Chief Inspector of Hospitals.</p> <p>Accepted.</p> <p>CQC inspections of acute hospitals will include an inspection of end of life care services as one of eight core service areas which the inspection team will always look at. From October 2014, CQC's inspection framework will incorporate the Priorities for Care. Inspections of end of life care in acute hospitals will include all services provided throughout the hospital relating to the care given to all patients approaching, during and after the end of their life. This includes end of life care on any ward or service, provision and access to specialist palliative care and support, bereavement and mortuary services provided. The inspection team will review the quality of end of life care under the five domains of safe, effective, caring, responsive and well-led care.</p>

		<p>CQC has developed an approach to inspection of care homes and domiciliary care services which incorporates the principles of good end of life care. There will be a linked approach to inspection of hospices and hospice-at-home services. In community health services, the proposed inspection approach includes end of life care delivered in the community as one of four core services which will always be inspected. CQC's inspections of primary care services will review the quality of care for different population groups, and will review end of life care as part of provision of good quality care for these groups. Each inspection approach is subject to consultation from April 2014, and will be implemented from October 2014, with exact timing dependent on the sector.</p>
41	Thematic review of end of life care	<p>The Care Quality Commission should carry out a thematic review within the next 12 months, of how dying patients are treated across the various settings, from acute hospitals to nursing and care homes, as well as hospice and the community.</p> <p>Accepted.</p> <p>CQC started thematic activity focusing on end of life care across settings in March 2014 and will publish a national report presenting its findings by March 2015. The thematic activity in end of life care will focus on inequalities experienced by people in end of life care, in particular the barriers which prevent some people from receiving good quality, joined up care at the end of life. The thematic work will look at the experience of priority groups including people with non-cancer diagnoses or multiple co-morbidities, people from black and minority ethnic communities; lesbian, gay, bisexual, and transgender communities; and people with particular vulnerabilities such as dementia, mental health needs or learning disabilities. CQC will take a phased approach to the work to ensure that the most effective methods are used. In the first phase the thematic work will build on existing data sources to look at geographic variation in end of life care, and CQC will request information from commissioners about local arrangements for end of life care. In the second phase it is planned to case track people's experience of end of life care, and to analyse the findings of initial inspections of end of life care across sectors. In the final phase, CQC will work with stakeholders to review the findings and identify recommendations to encourage improvement. The thematic activity is a significant piece of work for CQC, and it involves multiple projects and stakeholders. Based on experience from previous thematic work, a timescale of 12 months to deliver the work is realistic. In addition to this, the planned work will use evidence from inspections under CQC's new inspection approach, which will be available in late 2014.</p>

42	Commissioning	<p>Using its full powers and mindful of its general duties, NHS England should work with clinical commissioning groups to address what are clearly considerable inconsistencies in the quality of care for the dying, to drive up quality by means of considerably better commissioning practices than persist at present.</p> <p>Accepted.</p> <p>NHS England and the NHS Commissioning Assembly have established a joint group to look at how to embed the Alliance's Priorities for Care within commissioning processes. NHS England will ensure that the requirements for the implementation of the Priorities of Care are in place across the services for which it has direct commissioning responsibility.</p>
43	Mandate to NHS England	<p>The Government should set improved quality of care for the dying as a priority for NHS England in the next Mandate.</p> <p>Accepted in part.</p> <p>The Government believes that care for dying people is core business for the NHS and will consider how best to cover this in future Mandates to the NHS. In the meantime, the Government will continue to measure progress on improving end of life care by assessing bereaved carers' views on the quality of care given in the last three months of life.</p>
44		<p>Given the very strong links between the vulnerability of older people and the quality of care for the dying, the Review panel further recommends that the vulnerable older people's plan include a strand on care for the dying, and that NHS England's contribution to it be specified also as a priority in the NHS Mandate.</p> <p>Accepted in part.</p> <p>Transforming Primary Care set out the Government's plans for improving primary care, in particular for those people with the most complex needs. A core component of this is the Proactive Care Programme, which will provide over 800,000 people with the most complex needs, including vulnerable older people, high risk patients and patients needing end-of-life care who are at risk of unplanned admission to hospital, with a proactive and personalised programme of care and support, tailored to their needs and views. If it is thought that anyone, including someone whose care has been supported by the Proactive Care Programme, may die in the next few days and hours of life, the Priorities for Care will apply and the Government expects care to be delivered in accordance with them.</p>

Annex C:

Priorities for Care of the Dying Person

Priorities for Care of the Dying Person

Caring for people who are close to death demands compassion, kindness and a skilled application of knowledge. This document sets out five Priorities for Care in the last few days and hours of life. There are corresponding documents which set out:

- duties and responsibilities of health and care staff who are involved in the care of dying people; and
- implementation guidance for service providers and commissioners who have a responsibility to ensure that health and care staff have the right education, training and support to achieve these priorities.

The Priorities are all equally important to achieving good care in the last few days and hours of life. Each supports the primary principle that individual care must be provided according to the needs and wishes of the person. To this end, the Priorities have been set out below in sequential order.

The principles of palliative and end of life care apply from a much earlier point in a person's life-limiting illness. Advance care planning, symptom control, rehabilitation to maximise social participation, and emotional and spiritual support are all important in helping the individual to live well until they die. This document deals specifically with the priorities for care when a person is imminently dying, i.e. death is expected within a few hours or very few days.

If it is established that a person lacks capacity at the relevant time to make the relevant decision, then a decision must be taken in their best interests in accordance with the Mental Capacity Act 2005. The person making the decision must, if it is practicable and appropriate to do so, consult:

- anybody named by the person as someone to be consulted on either the decision in question or similar issues;
- anyone engaged in caring for the person, close relatives, friends or others who take an interest in the person's welfare;
- any holder of a lasting power of attorney or enduring power of attorney; and
- any deputy appointed by the court to make decisions for the person.

This is referred to below as a 'best interests decision'. Further guidance on how this decision should be made is provided in the Mental Capacity Act Code of Practice.⁵⁴ If the person lacks capacity and there is a registered person with a lasting power of attorney who has the power to make the relevant decision, then the attorney should make the decision in the best interests of the person. It is also important to respect valid and applicable advance decisions.

⁵⁴ The Mental Capacity Act Code of Practice can be found on the Ministry of Justice website at: www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

When it is thought that a person may die within the next few days or hours...

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

All health and care staff who care for dying patients must ensure that they are aware of and follow up to date guidance and local best practice. They must recognise that the evidence on which this is based will continue to evolve, so a commitment to lifelong learning is fundamental.

Priority 1

The possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Expanded explanation:

When a person's condition deteriorates unexpectedly, and it is thought they may die soon, i.e. within a few hours or very few days, they must be assessed by a doctor who is competent to judge whether the change is potentially reversible or the person is likely to die soon, i.e. within a few hours or days. If the doctor judges that the change in condition is potentially reversible, prompt action must be taken to attempt this, provided that is in accordance with the person's wishes or in their best interests if it is established that they lack capacity to make the decision about treatment at that time. If the doctor judges that the person is likely to be dying, taking into account the views of others caring for the person, this must be clearly and sensitively explained to the person in a way that is appropriate to their circumstances (if conscious and they have not indicated that they would not wish to know), and their family and others identified as important to them. The person's views and preferences must be taken into account, and those important to them must be involved in decisions in accordance with the person's wishes. A plan of care must be developed, documented, and the person must be regularly reviewed to check that the plan of care remains appropriate and to respond to changes in the person's condition, needs and preferences.

Priority 2

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

Expanded explanation:

Open and honest communication between staff and the person who is dying, and those identified as important to them, including carers, is critically important to good care. Clear, understandable and plain language must be used verbally and in all other forms of communication with the dying person and those important to them. If the dying person needs additional support to understand information, communicate their wishes or make decisions, these needs must be met. Communication must be regular and proactive, i.e. staff must actively seek to communicate, not simply wait for the person or those important to them to ask questions. It must be two-way, i.e. staff must listen to the views of the person and those important to them, not simply provide information. It should be conducted in a way that maximises privacy. Communication must be sensitive, respectful in pace and tone and take account of what the dying person and those important to them want and feel able to discuss at any particular point in time. Staff must check the other person's understanding of the information that is being communicated, and document this.

Priority 3

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

Expanded explanation:

Individuals vary in the extent to which they wish to be involved in decisions about their own treatment, though most would want to make or influence decisions about the care they receive, and the way this is delivered. This includes day to day decisions about food, drink and personal care, as well as clinical and treatment decisions. Individuals also vary in the extent to which they wish their families and those important to them to be involved in decision-making. Sensitive communication is needed to ascertain the wishes of the dying person and their wishes must be respected. The person, and those important to them, must be told who is the senior doctor in the team who has responsibility for their treatment and care, whether in hospital or in the community, and the nurse leading their care. Where it is established that the dying person lacks capacity to make a particular decision, the decision made or action taken on their behalf must be in their best interests, and they should still be involved as far as possible in that decision.

Priority 4

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

Expanded explanation:

Families and those important to the dying person, including carers, have their own needs which they, and others, can overlook at this time of distress. They are often tired, both physically and emotionally, and may be anxious and fearful, especially if they are the dying person's main caregiver at home. Even those who may appear to be coping well appreciate an acknowledgement that the imminent death of somebody they love is hard and that they have a role in ensuring that their loved one receives a good standard of care as they near the end of life. Where they have particular needs for support or information, these must be met as far as possible. Although it is not always possible to meet the needs or wishes of all family members, listening and acknowledging these can help. If a person who is dying lacks capacity to make a decision, the decision-making process should be explained to those people who are supporting the dying person and they should be involved as much as possible.

Priority 5

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Expanded explanation:

A plan for care and treatment must be developed to meet the dying person's own needs and wishes in relation to how their care should be managed and any treatment preferences they may want to express. This plan must include attention to symptom control (e.g. relief of pain and other discomforts) and the person's physical, emotional, psychological, social, spiritual, cultural and religious needs. The person must be supported to eat and drink as long as they wish to do so, and their comfort and dignity prioritised. There must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this. The plan of care must be documented so that consistent information about the person's needs and wishes is shared with those involved in the person's care and available at the time this information is needed.

Annex D:

Priorities for Care of the Dying Person – Duties and Responsibilities of Health and Care Staff

Priorities for Care of the Dying Person

Duties and Responsibilities of Health and Care Staff

Caring for people who are close to death demands compassion, kindness and a skilled application of knowledge. This document sets out Five Priorities for Care in the last few days and hours of life. It also sets out the Duties and Responsibilities of Health and Care Staff to ensure the Priorities are achieved when they are involved in the care of dying people.

The Priorities are all equally important to achieving good care in the last few days and hours of life. Each supports the primary principle that individual care must be provided according to the needs and wishes of the person. To this end, they have been set out below in sequential order.

When it is thought that a person may die within the next few days or hours...

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Health and care staff who are involved in the care of dying people have duties and responsibilities as set out in this document. These are aligned with professional regulatory guidance and relevant legal requirements, including the obligations on staff set out in the Mental Capacity Act 2005 (the MCA) and its supporting Code of Practice.⁵⁵ Health and care staff will need the appropriate education and training to enable them to recognise and deliver these responsibilities in practice. Their employers and the system in which such staff work must support them in doing this. There is corresponding implementation guidance which sets out the requirements for commissioners and service providers to enable staff to deliver the five Priorities for Care and includes advice for educators.

⁵⁵ The Mental Capacity Act Code of Practice can be found on the Ministry of Justice website at: www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act.

This document deals specifically with the priorities for care when a person is imminently dying, i.e. death is expected within a few hours or very few days. However, it should be noted that, for people living with life-limiting illness, the general principles of good palliative and end of life care (reflected in the Duties and Responsibilities) apply from a much earlier point. Advance care planning, symptom control, rehabilitation to maximise social participation, and emotional and spiritual support are all important in helping any individual to live well until they die.

The Duties and Responsibilities relate to care and treatment decisions made when a person has capacity to decide and when someone lacks capacity to make a particular decision. Anyone who works with or cares for an adult who lacks capacity to make a decision must comply with the Mental Capacity Act 2005 when making decisions or acting for that person. The Act makes clear who can take decisions in which situations, how they should go about this, who they must consult and involve, and the legal principles that they must apply to ensure that decisions are within the law. The Duties and Responsibilities statements take account of the requirements in the Mental Capacity Act and its Code of Practice, in particular the obligation on staff and others to make decisions in the 'best interests' of the person who lacks capacity to decide.⁵⁶

As with other areas of practice, all health and care staff who care for dying people must ensure that they are aware of, and follow, up-to-date guidance and local best practice. They must recognise that the evidence on which good care is based will continue to evolve, so a commitment to lifelong learning is fundamental.

Priority 1

The possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Expanded explanation:

When a person's condition deteriorates unexpectedly, and it is thought they may die soon, i.e. within a few hours or very few days, they must be assessed by a doctor who is competent to judge whether the change is potentially reversible or the person is likely to die. If the doctor judges that the change in condition is potentially reversible, prompt action must be taken to attempt this, provided that is in accordance with the person's wishes or in their best interests if it is established that they lack capacity to make the decision about treatment at that time. If the doctor judges that the person is likely to be dying, taking into account the views of others caring for the person, this must be clearly and sensitively explained to the person in a way that is appropriate to their circumstances (if conscious and they have not indicated that they would not wish to know), and their family and others identified as important to them. The person's views and preferences must be taken into account, and those important to them must be involved in decisions in accordance with the person's wishes. A plan of care must be developed, documented, and the person must be regularly reviewed to check that the plan of care remains appropriate and to respond to changes in the person's condition, needs and preferences.

⁵⁶ See also the 'Reminder about the law on capacity' in the 'Generic good practice reminders' section of this document, below.

To achieve this:

1. The person whose condition has deteriorated unexpectedly must be assessed by a doctor who is competent to judge whether the person's change in condition is potentially reversible or they are likely to die in the next few hours or few days.
2. If it is clear that reversing the deterioration in a person's condition is possible their consent to treatment must be sought including discussion of the benefits, burdens and risks. If it is established that the person lacks capacity at that time to make the decision about treatment, a decision must be taken about whether providing treatment would be in their best interests, following the requirements of the Mental Capacity Act and related Code of Practice.
3. If the doctor judges that the person is likely to die soon, s/he must clearly and sensitively communicate this to the dying person (if conscious). This includes explaining when and how death might be expected to occur and the basis for that judgement, acknowledging and accepting any uncertainty about the prognosis, and giving the dying person the opportunity to ask questions. The same communication must take place with those important to the dying person and others involved in that person's care. The responsibility for communicating this information may be delegated by the doctor to another clinician who has the appropriate training and competence.
4. The decision must be reviewed at the next available opportunity by a senior clinician within the person's care team who is competent to assess whether the person has reached the stage where they are dying. The views of the wider multi-professional team must be taken into consideration in making this assessment.
5. The goals of treatment and care must be discussed and agreed with the dying person, involving those identified as important to them and the multidisciplinary team caring for the person. These discussions must be clearly documented and accessible to all those involved in the person's care, taking into account the person's wishes about sharing their confidential information. Doctors and nurses must acknowledge, accept and communicate uncertainty that exists about the prognosis.
6. If it is established that the dying person lacks capacity to make decisions about the goals of treatment and care, the goals must be discussed and agreed with any holder of a lasting power of attorney to make healthcare decisions on the person's behalf and discussed with those identified as important to them, with the aim of reaching a consensus on what future treatment and care would be in the person's best interests.
7. The dying person must be reviewed by a senior clinician within the person's care team at least daily thereafter – or sooner if there is an unanticipated change in the person's condition – to assess whether they are still likely to be dying (given the uncertainties of prognosis), and if the plan of care remains appropriate. The senior clinician may delegate this responsibility to another clinician who has appropriate training and competence but will remain accountable for the overall care of the dying person.
8. The senior clinician must consider whether involvement of a specialist would be helpful if there is uncertainty whether or not the person is dying.
9. Doctors, nurses and other health and care staff responsible for the person's care must seek out opportunities to communicate about any deterioration or change in the dying person's condition with those identified as important to that person.

Priority 2

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

Expanded explanation:

Open and honest communication between staff and the person who is dying, and those identified as important to them, including carers, is critically important to good care. Clear, understandable and plain language must be used verbally and in all other forms of communication with the dying person and those important to them. If the dying person needs additional support to understand information, communicate their wishes or make decisions, these needs must be met. Communication must be regular and proactive, i.e. staff must actively seek to communicate, not simply wait for the person or those important to them to ask questions. It must be two-way, i.e. staff must listen to the views of the person and those important to them, not simply provide information. It should be conducted in a way that maximises privacy. Communication must be sensitive, respectful in pace and tone and take account of what the dying person and those important to them want and feel able to discuss at any particular point in time. Staff must check the other person's understanding of the information that is being communicated, and document this.

To achieve this:

1. Health and care staff must make time to talk with dying people, their families and those identified as important to them, including carers. They must listen, respond sensitively to their issues and concerns, provide information in a way that meets their communication needs and check that explanations and information are understood.
2. All relevant discussions must be in simple, appropriate, straight forward language without using euphemisms.
3. Sensitive communication includes the need for health and care staff to respect the wishes of people who have made it clear that they do not wish to have open conversations about their condition or what is happening to them.
4. Health and care staff must ask the person who they want to be contacted and with whom they wish information about their condition to be shared. They must also ask if there are specific individuals with whom they do not wish information to be shared. This must be clearly recorded and shared with all who care for the person particularly if they move between care settings, e.g. hospital to home.
5. Health and care staff have legal duties and ethical responsibilities to protect confidential information about a patient. Professional and other guidance set out the circumstances in which confidential information can be shared with the person's family and others. Within those guidelines, health and care staff must recognise and address the communication and information needs of the dying person's family and others identified as important to them. Where there is no record to the contrary and the person does not have capacity to give consent, it is reasonable to assume that they would want their family and those important to them to be informed about their condition and prognosis.

6. The content and outcome of all discussions must be documented and accessible to all those involved in the person's care. This includes conversations about prognosis, goals of treatment and care plans at each point in time, and particular concerns that the person, their family and those identified as important to them have expressed.
7. Difficult conversations must not be avoided but must be carried out sensitively, recognising that communication is an on-going process and not a one-off event.
8. When it has been established that a dying person lacks capacity to make a particular decision, the Mental Capacity Act requires that any decision made is in the best interests of the dying person. It also sets out who can make decisions about the person's health and welfare. What this means in practice, for the role of family members and others important to the dying person, should be explained in clear, understandable language by health and care staff involved in the care of the dying person.
9. Assumptions must not be made about the frequency of communication that might be acceptable to the person, their families and those important to them. Staff must check this with them.
10. The way in which information about the person's needs, wishes and views can be shared with those identified as important to them and staff, must be discussed with the person, so that the method used is in accordance with individual preferences. For example, shared information folders or diaries may be a helpful way of enhancing communication for some. Those who have visual impairment may prefer to use other means for conveying their wishes, e.g. using a CD or DVD.
11. When the dying person is being cared for at home, the named GP, senior responsible doctor or named nurse responsible for the person's care must ensure that families and carers of the dying person are given clear, reliable and consistent information about how to seek urgent help when this is needed, including who to ring, what number(s) to use at any time of day or night, and what key information they should provide that will facilitate the most appropriate response. This must include information about what to do when the person dies.
12. As soon as possible after the death of the person, and depending on the family's wishes, a health care professional should offer to attend the person to ensure their body is appropriately cared for and the immediate practical and emotional needs of those present and those important to the person are attended to.

Priority 3

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

Expanded explanation:

Individuals vary in the extent to which they wish to be involved in decisions about their own treatment, though most would want to make or influence decisions about the care they receive, and the way this is delivered. This includes day to day decisions about food, drink and personal care, as well as clinical and treatment decisions. Individuals also vary in the extent to which they wish their families and those important to them to be involved in decision-making. Sensitive communication is needed to ascertain the wishes of the dying person and their wishes must be respected. The person, and

those important to them, must be told who is the senior doctor in the team who has responsibility for their treatment and care, whether in hospital or in the community, and the nurse leading their care. Where it is established that the dying person lacks capacity to make a particular decision, the decision made or action taken on their behalf must be in their best interests, and they should still be involved as far as possible in that decision.

To achieve this:

1. Clinical teams must give the dying person, their families and those important to them the name of the senior doctor in the team who has overall responsibility for providing appropriate treatment and care for the dying person, and explain how that responsibility is handed over in times of absence or change in care arrangements or settings. This must be clearly documented and accessible to all those involved in the person's care.
2. The name of the nurse responsible for leading the care of the dying person must also be given to the person and those important to them with an explanation of how this responsibility is handed over. This must be clearly documented and accessible to all those involved in the person's care.
3. Health and care staff must give the dying person the information they need or are asking for in a way they can understand, and the support they need to make informed decisions about treatment options.
4. All decisions must involve consideration of the potential benefits, burdens and risks of treatment (or non-treatment) for the individual person. Individuals must be supported to make informed decisions as much as possible and to the extent they wish.
5. The dying person's wishes about the extent to which families and those important to them are involved in discussing their treatment and care must be respected and supported.
6. Health and care staff must understand the difference between explaining what is going on (including any decisions made); seeking the person's consent for specific interventions or actions; and consulting the person's family and those important to them about making a best interests decision.
7. The dying person should be given all the help and support they need to make a decision before anyone concludes that they cannot make their own decision. Any actions taken or decisions made on behalf of someone who lacks capacity must be done in their best interests, after considering what is known about their preferences (and any relevant and valid advance decision to refuse medical treatment), and wherever possible still involving them in making the decision.
8. Doctors, nurses and other healthcare professionals must carefully consider which decisions need to be made on-the-spot to ensure the person's comfort and safety, and which can and must wait for a review of the person's condition by the senior doctor who has responsibility for the person's treatment and care (who may know the person better and/or have relevant competence and information to inform treatment decisions) or a clinician with the appropriate training and competence to whom the responsibility has been delegated.
9. The starting point of communication between health and care staff and the family and those important to the person must be that all parties wish to act in

the person's best interests. Differences in opinion, about how to work towards agreement on what would be best for the dying person, must be discussed openly and additional advice sought, including a second opinion, where there is a continuing difference of opinion or if additional reassurance would be helpful.

10. The dying person's senior doctor is responsible for ensuring that adequate information is available to support decision-making by those involved in caring for the person when the senior doctor is not available.
11. If a healthcare professional is considering withdrawing or not starting a potentially life-prolonging but burdensome treatment, because it is not considered clinically appropriate in managing the person's care, they must explore in a sensitive way how willing the dying person might be to know about and discuss this or whether they would prefer that this is discussed with those identified as important to them.
12. If there is a continuing difference of opinion about the treatment or care of a dying person, or if additional reassurance about a decision would be helpful, health and care staff must consider obtaining a second opinion and getting support to facilitate communication to reach a consensus, for example from a social worker, advocacy worker or a chaplain or faith community leader, especially if the difference of opinion is expressed in relation to religious beliefs or concerns. If significant disagreement remains, staff must seek advice on applying to the court for an independent ruling and inform the dying person (and those important to them) as early as possible.

Priority 4

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

Expanded explanation:

Families and those important to the dying person, including carers, have their own needs which they, and others, can overlook at this time of distress. They are often tired, both physically and emotionally, and may be anxious and fearful, especially if they are the dying person's main caregiver at home. Even those who may appear to be coping well appreciate an acknowledgement that the imminent death of somebody they love is hard and that they have a role in ensuring that their loved one receives a good standard of care as they near the end of life. Where they have particular needs for support or information, these should be met as far as possible. Although it is not always possible to meet the needs or wishes of all family members, listening and acknowledging these can help. If a person who is dying lacks capacity to make a decision, the decision-making process should be explained to those people who are supporting the dying person and they should be involved as much as possible.

To achieve this:

1. Health and care staff must regularly assess and address (if possible) the needs of families and those important to the dying person, and offer information about getting access to other sources of help and support.
2. Health and care staff in in-patient facilities must ensure families are welcome and enabled to spend time with the dying person to the extent that they and the dying person wish.

3. Family or important others who wish to participate in caring for the dying person in an in-patient facility must be supported by staff to do so, e.g. by showing them simple practical techniques, but assumptions must not be made about their ability or wish to do so.
4. In some situations, the dying person, or their family or carer may be more skilled at performing certain tasks than the health and care staff. Their expertise must be acknowledged and they must be supported to continue performing these tasks while they remain willing and able to do so.
5. Where the person's family or those identified as important to them are involved in the care of the dying person, their observations and judgements must be taken into account as part of the ongoing discussion and planning of care.
6. Health and care staff must acknowledge that the needs of the dying person, their families and those important to them may differ. Differences must be acknowledged and addressed in a sensitive way. For example, children and elderly people important to the dying person may have particular needs for practical and emotional support that require careful consideration by health and care staff.
7. Some families do not wish to talk openly about death and dying. This must be respected but health and care staff must find a sensitive way to remain clear in their communication, and to avoid euphemisms.
8. If the dying person is in hospital or another institution, staff must pay attention to the wellbeing of families and those important to the dying person by showing them where the toilets are located, where to make drinks, how they can rest, etc.
9. Health and care staff must offer information and explanations to the dying person's family and those important to them, including carers, to prepare them for what happens when a person is close to death, whether the death is occurring at home or in an institution.
10. When a person is imminently dying, the responsible nurse or other healthcare professional must check with the dying person's family and those important to them about how they would best wish to be supported. Some prefer to be left alone; others prefer a staff member to briefly check in with them every now and then; others may need more support. Importantly, they need to know where staff are if they are needed.
11. The family and those important to the dying person, including carers, may have their own spiritual and religious needs which may, or may not, be similar to that of the dying person. Staff must involve chaplains or relevant religious leaders if the family and those important to the person want this.
12. When a person has died, the wellbeing of the bereaved family and carers must be considered, and health and care staff must ensure adequate support is available for their immediate needs. They must be allowed time with the deceased person, if they wish, without being put under pressure.
13. Families and those important to the dying person will require additional support if the death has been unexpected or if it occurs after a very short deterioration, for example help to understand post mortem, coroners' and death certification procedures, and to have their questions answered.

Priority 5

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Expanded explanation:

A plan for care and treatment must be developed to meet the dying person's own needs and wishes in relation to how their care should be managed and any treatment preferences they may want to express. This plan must include attention to symptom control (e.g. relief of pain and other discomforts) and the person's physical, emotional, psychological, social, spiritual, cultural and religious needs. The person must be supported to eat and drink as long as they wish to do so, and their comfort and dignity prioritised. There must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this. The plan of care must be documented so that consistent information about the person's needs and wishes is shared with those involved in the person's care and available at the time this information is needed.

To achieve this:

Planning care

1. Health and care staff must offer the dying person the opportunity to discuss, record and update their wishes and preferences as part of individualised care planning. Ideally, this planning should have started earlier in the illness and the plan updated as the situation changes. The extent to which the dying person wishes to be involved in developing a plan of care must be respected; so must their wishes about who else to involve in these discussions.
2. Where a nominated friend/family member has been identified by the dying person to take part in care planning, they must be involved in the preparation of the plan of care.
3. Health and care staff must take account of and give weight to the views, beliefs and values of the person in agreeing the plan of care. If it is established that a dying person lacks capacity to make particular decisions and their wishes and views about future care cannot be ascertained, then the decisions made must be in the person's best interests. The observations and judgements of those involved in the person's care (formal and informal) must be taken into account in ongoing discussions and planning of care.
4. The individual plan of care must be agreed, communicated, adhered to and regularly reviewed, with the person and, if they agree, those important to them.

Assessment

5. The person's physical, emotional, psychological, spiritual, cultural and religious needs must be assessed to formulate personalised plans to address these needs, in discussion with the dying person and, if they wish, their family or those important to them.
6. Assessment must be conducted with respect for personal privacy and dignity. Aids to communication that the person normally uses, e.g. spectacles, hearing aids, dentures, must be used.

7. The frequency of review and how the person's comfort is monitored, including the use of assessment tools, must be individualised and agreed with the person and, if it is established that the person lacks capacity to make decisions about these matters, the decisions made must be in the person's best interests.
8. Health and care staff must ensure that important assessments of a patient's condition, capacity to decide, or treatment and care needs (e.g. swallowing) are conducted openly and family and others important to the dying person are provided with clear explanations and involved where that may provide helpful information about the dying person to ensure an effective assessment is made, provided this does not delay attending to the dying person's needs.
9. Health and care staff must ensure that disagreement about the outcome of assessments are swiftly acknowledged and acted upon, creating opportunity for discussion, reflection and allowing alternative opinions. If there is significant disagreement about a person's capacity to make a decision, which has not been resolved through informal, local procedures, staff must seek advice about obtaining a ruling from the court (as required by the Mental Capacity Act).

Food and drink

10. The dying person must be supported to eat and drink as long as they wish to do so and there is no serious risk of harm (for example through choking). However if there is likely to be a delay in assessing their ability to swallow safely, alternative forms of hydration must be considered and discussed with the person. Nursing and medical records on the assessment of intake must be kept.
11. If a dying person makes an informed choice to eat or drink, even if they are deemed to be at risk of aspiration, this must be respected.
12. If the dying person is unable to swallow, decisions about clinically assisted hydration and nutrition must be in line with the General Medical Council 2010 guidance *Treatment and care towards the end of life: good practice in decision-making* and relevant clinical guidelines.
13. Health and care staff must pay attention to the dying person's mouth care and other personal care needs to maintain their comfort and dignity.

Symptom control

14. All medications, including anticipatory medicines, must be targeted at specific symptoms, have a clinical rationale for the starting dose, be regularly reviewed, and adjusted as needed for effect.
15. The reason for any intervention, including the use of a syringe driver, must be explained to the dying person and to those important to the dying person. Other than in exceptional circumstances, this should be done before it is used.
16. The likely side effects of specific interventions, especially those that may make the person sleepy, must be discussed with the dying person to enable them to make informed decisions, and explained to those important to the dying person if the person wishes.
17. Health and care staff must ensure that medicines, equipment and other aids that can improve the dying person's comfort and dignity are obtained as soon as this is needed, or in anticipation of needs if the person is not in hospital.

18. If paramedical or ambulance staff are called to a dying person at home or in a care home because the person has symptoms, they must assess and wherever possible manage symptoms in accordance with the person's preferences and agreed care plans. This may include decisions about whether or not to transfer the dying person to hospital or another care facility. Where the dying person's preferences or care plan are not known or clear, ambulance clinicians must seek senior ambulance clinical advice and/or contact the GP/primary care out of hours provider if required to obtain urgent clinical advice first.
19. Clinical teams must refer to specialist palliative care for advice or assessment when the person's needs (or the needs of those important to them) are beyond their competency to provide for, or when initial measures have failed to provide adequate relief within at most 24 hours.

Spiritual and religious care

20. When specialist spiritual/religious support is identified as required, health and care staff must ensure that the dying person, and those important to them, have ready access to information about the available chaplaincy and/or spiritual care provision.
21. The chaplains must have information about local faith leaders to enable, where requested by the person, referral to church or faith community leaders.
22. Staff, must find out from the dying person, their family and those important to them, the details of any cultural or religious-specific requirements, including what constitutes respectful treatment of the body after death.

Co-ordinating care

23. Health and care staff must ensure they provide accurate and timely handover to teams taking over care, particularly regarding the person's wishes.
24. Adequate care planning information about the dying person must be available to ensure safe and appropriate clinical decisions are made regarding care and treatment, taking into account the individual's prior wishes, in the event that the dying person is unable to participate in the decision at the time.
25. If a dying person has to move between care settings, a clear emergency plan must be made and communicated so that action appropriate to the person's needs and preferences can be taken if their condition changes unexpectedly.
26. Where there is inadequate time to determine the person's wishes about, or suitability for, attempts at cardiopulmonary resuscitation, DNACPR (Do Not Attempt Cardio-pulmonary Resuscitation) documentation from another care setting or care provider should be taken into account, and followed where the healthcare professional making the decision is certain that s/he has sufficient information about the person to judge that the DNACPR is valid and applicable.

Generic good practice reminders:

1. Health and care staff must note that dying people who cannot communicate easily, either because their first language is not English or because they have a sensory, physical or mental impairment, will require additional time and assistance, and these staff must know how to seek specialist help, including an interpreter, or special aids if required.

2. The coordination of care requires a certain amount of information about the person to be shared. Staff must be aware of and follow relevant national and local guidelines for protecting and sharing information about the person, including understanding the circumstances in which they can rely on the person's implied consent to sharing information with those important to the person and health and care staff involved in providing care.
3. Staff must ensure that the person understands what information is being shared and how this will be used and shared.
4. Staff must be aware of, and manage, the potential risks caused by multiple sets of documentation.
5. Staff must draw on the experience and skill of the multidisciplinary team to undertake and reinforce discussions as necessary.
6. Staff must be aware of the role of advocates as an independent voice (formal and informal), offer an advocate to patients and families and utilise advocates where necessary.
7. Staff must consider the particular needs of families and those important to the dying person who may have specific disability or impairment; in discussion with families and those important to the dying person, staff should consider how to support them.

Reminder about the law on capacity

8. Staff must operate within the legal framework provided by the Mental Capacity Act 2005 (MCA) and its Code of Practice. The Act makes clear who can take decisions in which situations, and how they should go about this. Anyone who works with or cares for an adult who lacks capacity must comply with the MCA when making decisions or acting for that person. The Act sets out five statutory principles that must guide decisions, including requirements that staff ensure that those who may lack capacity to decide are empowered to make as many decisions for themselves as possible and that any decision made, or action taken, on their behalf is made in their best interests.
9. If an Advance Decision to Refuse Treatment exists and is valid and applicable (within the terms of the Act and Code), it must be followed. Individuals who have been nominated by the dying person to be involved in decisions and those who hold Lasting Powers of Attorney (LPA) relating to health and welfare issues must be involved in decisions. Those who hold a registered LPA for health and welfare may have legal authority under the terms of the LPA to make the decision on behalf of the dying person.⁵⁷

⁵⁷ Detailed advice about obligations of staff under the Act and Code is available on the website of the Ministry of Justice: www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

References:

- GMC 2010 guidance, *Treatment and care towards the end of life: good practice in decision-making* ⁵⁸
- Mental Capacity Act 2005 and the MCA Code of Practice (with accompanying guides for staff and members of the public) ⁵⁹
- *Standards of Conduct, Performance and Ethics*, HCPC (2008: updated 2012 to reflect name change) ⁶⁰

⁵⁸ www.gmc-uk.org/End_of_life.pdf_32486688.pdf

⁵⁹ www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

⁶⁰ www.hcpc-uk.org/publications/standards/index.asp?id=38

Annex E:

Priorities for Care of the Dying Person – Implementation Guidance for Service Providers and Commissioners

Priorities for Care of the Dying Person

Implementation Guidance for Service Providers and Commissioners

The NICE Quality Standard for End of Life Care (2011) describes what a high quality service for the last year of life should look like, and sets the context for this work, which focuses on care in the last few days and hours of life. Caring for people who are close to death demands compassion, kindness and a skilled application of knowledge. This document sets out the expectations for commissioners, service providers and employers to ensure that the five Priorities for Care of the dying person can be delivered in a safe, effective and person-centered way, whatever the care setting. Health and care staff who are involved in the care of dying people have duties and responsibilities, set out in a separate document, for achieving these priorities. They must be enabled and supported by their employers and the system in which they work, whether this is in the public, private or voluntary sector.

The principles of palliative and end of life care apply from a much earlier point in a person's life than is common practice currently. Advance care planning, symptom control, rehabilitation to maximise social participation, and emotional and spiritual support are all important in helping the individual to live well until they die. These processes are individually time consuming and complex, requiring time and skill to deliver. Identifying people with multiple conditions and/or frailty which may together limit life expectancy is a key step in beginning this process.

All health and care staff who care for dying people must ensure that they are aware of, and follow, guidance and local best practice. They should recognise that the evidence on which this is based will continue to evolve, so a commitment to lifelong learning and continuous improvement is fundamental.

The Priorities are all equally important to achieving good care in the last few days and hours of life. Each supports the primary principle that individual care must be provided according to the needs and wishes of the person. To this end, they have been set out below in sequential order.

Priorities for Care

When it is thought that a person may die within the next few days or hours...

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.

3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

An expanded explanation for each Priority for Care follows:

Priority 1

The possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Expanded explanation:

When a person's condition deteriorates, unexpectedly, and it is thought they may die soon, i.e. within a few hours or very few days, they must be assessed by a doctor who is competent to judge whether the change is potentially reversible or the person is likely to die. If the change in condition is potentially reversible, prompt action must be taken to attempt this, provided that is in accordance with the person's wishes or in their best interests if it is established that they lack capacity to make the decision about treatment at that time. If the doctor judges that the person is likely to be dying, this must be clearly and sensitively explained to the person in a way that is appropriate to their circumstances (if conscious and they have not indicated that they would not wish to know), and their family and others identified as important to them. The person's views and preferences must be taken into account, and those important to them must be involved in decisions in accordance with the person's wishes. A plan of care must be developed, documented and the person must be regularly reviewed to check that the plan of care remains appropriate and to respond to changes in the person's condition, needs and preferences.

Priority 2

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

Expanded explanation:

Open and honest communication between staff and the person who is dying, and those identified as important to them, including carers, is critically important to good care. Clear, understandable and plain language must be used verbally and in all other forms of communication with the dying person and those important to them. If the dying person needs additional support to understand information, communicate their wishes or make decisions, these needs must be met. Communication must be regular and proactive, i.e. staff must actively seek to communicate, not simply wait for the person or those important to them to ask questions. It must be two-way, i.e. staff must listen to

the views of the person and those important to them, not simply provide information. It should be conducted in a way that maximises privacy. Communication must be sensitive, respectful in pace and tone and take account of what the dying person and those important to them want and feel able to discuss at any particular point in time. Staff must check the other person's understanding of the information that is being communicated, and document this.

Priority 3

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

Expanded explanation:

Individuals vary in the extent to which they wish to be involved in decisions about their own treatment, though most would want to make or influence decisions about the care they receive, and the way this is delivered. This includes day to day decisions about food, drink and personal care, as well as clinical and treatment decisions. Individuals also vary in the extent to which they wish their families and those important to them to be involved in decision-making. Sensitive communication is needed to ascertain the wishes of the dying person and their wishes must be respected. The person, and those important to them, must be told who is the senior doctor in the team who has responsibility for their treatment and care, whether in hospital or in the community, and the nurse leading their care. Where it is established that the dying person lacks capacity to make a particular decision, the decision made or action taken on their behalf must be in their best interests, and they should still be involved as far as possible in that decision.

Priority 4

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

Expanded explanation:

Families and those important to the dying person, including carers, have their own needs which they, and others, can overlook at this time of distress. They are often tired, both physically and emotionally, and may be anxious and fearful, especially if they are the dying person's main caregiver at home. Even those who may appear to be coping well appreciate an acknowledgement that the imminent death of somebody they love is hard and that they have a role in ensuring that their loved one receives a good standard of care as they near the end of life. Where they have particular needs for support or information, these should be met as far as possible. Although it is not always possible to meet the needs or wishes of all family members, listening and acknowledging these can help. If a person who is dying lacks capacity to make a decision, the decision-making process should be explained to those people who are supporting the dying person and they should be involved as much as possible.

Priority 5

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Expanded explanation:

A plan for care and treatment must be developed to meet the dying person's own needs and wishes in relation to how their care should be managed and any treatment preferences they may want to express. This plan must include attention to symptom control (e.g. relief of pain and other discomforts) and the person's physical, emotional, psychological, social, spiritual, cultural and religious needs. The person must be supported to eat and drink as long as they wish to do so, and their comfort and dignity prioritised. There must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this. The plan of care must be documented so that consistent information about the person's needs and wishes is shared with those involved in the person's care and available at the time this information is needed.

Expectations of Commissioners, Service Providers and Employers

Commissioners, service providers and employers play specific roles in enabling and ensuring good care for the dying person. The requirements set out below should be read in the context of wider expectations set out in other publications about health and care provision, including the guide 'How to ensure the right people, with the right skills, are in the right place at the right time' published by the National Quality Board (see Annex (i) for detail on the expectations), the report 'Future Hospital' by the Royal College of Physicians and the current work on Transforming Urgent and Emergency Care Services led by NHS England. These references and additional useful links are set out in Annex (ii).

The main responsibility for delivering quality care lies with health and care staff, service providers and those who commission, fund and arrange local services. The Care Quality Commission monitors, inspects and regulates services to make sure they meet fundamental standards of quality and safety, including in end of life care. As part of its quality assurance process, the General Medical Council is able to identify how the education standards it sets are being met by all those involved with the organisation and delivery of medical education and training, including local education providers.

The Role of Commissioners

The details of what is required of service providers and employers to enable the five Priorities for Care of the dying person to be delivered are set out below. As part of their commissioning responsibility, Clinical Commissioning Groups, NHS England and Local Authorities must consider how these requirements are included in their contractual and service specification arrangements for end of life care, both in terms of service provision, and the necessary education and training for its workforce. Responsibility for the latter extends to the Local Education and Training Boards. The National Quality Board sets out the expectation that 'commissioners actively seek assurance that the right people, with the right skills, are in the right place at the right time within the providers with whom

they contract'.

Commissioners have a crucial role in influencing and expecting service providers and health and care employers to have leadership and governance arrangements in place that enable and ensure good quality care for people in their last days of life. Commissioners should also draw on the NICE Quality Standard for End of Life Care which includes a specific quality statement about care in the last days of life.

To achieve the Priorities for Care of the dying person, service providers and employers must:

Leadership, accountability and responsibility

1. Provide strong managerial leadership and a strong governance framework which prioritises care of dying people with Board level accountability.
2. Provide strong clinical and cultural leadership and implement a local policy which recognises that care of the dying person is a priority and the responsibility of all health and care staff, not just those working in specialist palliative care, as long as they have any contact with dying people and their families or those important to them.
3. Provide strong leadership and implement a local policy which recognises that all health and care staff, and the service providers they work for, have a responsibility to contribute to, and learn from, audit, evaluation and research that is necessary to continually improve the quality of care and the evidence base for care of dying people.

Education, training and support (see Annex (iii) for further details)

4. Provide mentorship, support and direct involvement from senior clinical staff in recognising when dying is likely in the next few days or hours, and in assessing and reviewing the dying person's needs and preferences.
5. Require and enable health and care staff to acquire and maintain the necessary competences for delivering the Priorities for Care of the dying person, commensurate with the individual's role and responsibility, by providing protected learning time and resources for education and training, as part of induction, continuing professional development and regular updates.
6. Require and support health and care staff to develop the high level of communication skills they need to communicate effectively with people and those important to them in the last days and hours of life, and with people who have been bereaved.
7. Ensure that health and care staff have access to locally agreed advice for palliative and end of life care based on current best available evidence.
8. Recognise that conversations about dying and death are difficult and health and care staff need support, and time and opportunity for reflection, if they are to continue to have resilience to do this in an effective and compassionate manner.
9. Recognise, through clearly defined support structures, teams and working patterns, that caring for the dying person requires ring fenced time and investment of emotional energy.
10. Work with commissioners to ensure access to an adequately resourced specialist palliative care workforce to provide leadership, education and training, including for pre-qualifying education, and support to non-specialist front-line health and care workers.

Culture of care and compassion

11. Promote and support an organisational culture which prioritises care, compassion, respect and dignity as fundamental to caring for dying people.
12. Ensure and enable care for a dying person to be delivered with consistency, compassion and effectiveness with clear local advice/requirements.
13. Ensure that food and drink is provided and the dying person supported to eat and drink if they wish to do so.
14. Ensure access to assessment for, and provision of, clinically assisted hydration where this is in the dying person's best interests and wanted by the person.
15. Implement and support mechanisms for feedback which facilitate service improvement.
16. Work with commissioners and specialist palliative care professionals to ensure adequate access to specialist assessment, advice and active management. 'Adequate' means that service providers and commissioners are expected to ensure provision for specialist palliative medical and nursing cover routinely 9am-5pm, seven days a week, and a 24 hour telephone advice service. Where this service does not already exist, service providers and commissioners should formulate an action plan and commit to provision of such services within defined timelines. This should ensure the provision of specialist cover over 24 hours including face to face assessment in the exceptional circumstances where this is necessary.
17. Ensure arrangements are in place for enabling a second opinion to be offered for the dying person's care where this is required, and that staff are aware of how to seek this.
18. Ensure that health and care staff know:
 - a. When and how to seek senior and/or specialist support in any aspect of assessment or delivering care and treatment when this is beyond their competence, including clinical, psychological, emotional, social, spiritual and/or religious support.
 - b. When to offer the services of an interpreter for dying people and their families who may not have English as their first language, (or other forms of communication support, such as signing) and ensure that such services are readily accessible.
 - c. How to find out about the specific needs of dying people, and those important to them, who have disability or impairments, and ensure that they can obtain any necessary aids, equipment or expert help as quickly as possible.
19. Ensure that health and care staff are aware of the role of advocates as an independent voice (formal and informal), including when this is required under the Mental Capacity Act, offer this to patients and families and enable advocates to be utilised where necessary.
20. Ensure that families and those important to the dying person, are welcomed and enabled to spend time with the dying person to the extent that they, and the dying person, wish, relaxing visiting times if necessary.

21. Ensure that families and carers who wish to participate in care are actively encouraged, enabled and empowered to do so, e.g. by being shown how to carry out tasks. But those who do not wish to do so must not be made to feel that they need to do so because of staffing levels.
22. Ensure that health and care staff understand that their duty of care to the dying person extends beyond death to the care of the deceased body and the administration of practical requirements (including death certification), and that they are supported to carry out these duties.
23. Ensure that when a person has died, the wellbeing of the bereaved family and those important to that person, including carers, is considered, and that adequate support is available according to their needs, including timely access to viewing the body of the deceased person.
24. Promote awareness of the impact of the dying person on other people in an institutional environment, e.g. other patients and residents in a care home, and other staff, and ensure that they are supported and kept appropriately informed.

Environment

25. Ensure there is suitable provision for making the environment sensitive to the needs of the dying person and those important to them, including dignity, privacy and suitable space for care and difficult conversations to take place.
26. Provide information and facilities to support families and those important to the dying person to spend time with them, including where and how to obtain food and drink for themselves, appropriate seating, etc.

Clinical governance and systems of care

27. Put in place local governance arrangements so that the senior doctor with overall responsibility for the dying person's care is identified to the person and those important to them.
28. Put in place local governance arrangements so that the nurse leading the care of the dying person at any one time, including during each shift if the person is in hospital or care home, is identified to the person and those important to them.
29. Ensure that there are explicit policies in place which require those delivering end of life care to document:
 - a. their decisions about drug treatments and interventions with justifications based on the needs and preferences of the individual as well as best practice;
 - b. the content and outcome of all discussions, including conversations about prognosis, decisions, treatment goals and care plans at each point in time, and any concern that the person, and those important to them, have expressed;
 - c. plans of care for the dying person which are current, reviewed and individualised, taking into account their needs and wishes, and adapted as required;
 - d. names of the senior doctor with overall responsibility for the dying person's care and the nurse leading the care of the dying person at any one time, are documented and accessible to those involved in the person's care.

30. Ensure that policies about care and treatment for the dying person, including food and drink, facilitate and support informed choices by the person.
31. Ensure ready access and availability of medicines and equipment at all times of day and night, including pharmaceutical advice when required. Where a delay may be anticipated, e.g. at weekends, these should be prescribed and delivered in advance if appropriate and the person and family agree.
32. Put in place arrangements to enable health and care staff to give families and carers clear, reliably and consistent information about how to seek urgent help when this is needed, including who to ring, what number(s) to use at any time of day or night, and what key information they should provide that will facilitate the most appropriate response, when the dying person is being cared for at home.
33. Ensure that there are clear and adequate mechanisms for handover within the organisation, and work in partnership across the health and care community to develop and maintain information sharing systems to enable coordinated care across organisational boundaries.
34. Ensure clear arrangements for transfers across settings by ambulance or other means if this is necessary, including clear agreements about timescale.

Annex (i)

Source: How to ensure the right people, with the right skills, are in the right place at the right time. A guide to nursing, midwifery and care staffing capacity and capability. National Quality Board (2013)

- Expectation 1: Boards take full responsibility for the quality of care provided to patients, and as a key determinant of quality, take full and collective responsibility for nursing, midwifery and care staffing capacity and capability.
- Expectation 2: Processes are in place to enable staffing establishments to be met on a shift-to-shift basis.
- Expectation 3: Evidence-based tools are used to inform nursing, midwifery and care staffing capacity and capability.
- Expectation 4: Clinical and managerial leaders foster a culture of professionalism and responsiveness, where staff feel able to raise concerns.
- Expectation 5: A multi-professional approach is taken when setting nursing, midwifery and care staffing establishments.
- Expectation 6: Nurses, midwives and care staff have sufficient time to fulfil responsibilities that are additional to their direct caring duties.
- Expectation 7: Boards receive monthly updates on workforce information, and staffing capacity and capability is discussed at a public Board meeting at least every six months on the basis of a full nursing and midwifery establishment review.
- Expectation 8: NHS providers clearly display information about the nurses, midwives and care staff present on each ward, clinical setting, department or service on each shift.
- Expectation 9: Providers of NHS services take an active role in securing staff in line with their workforce requirements.
- Expectation 10: Commissioners actively seek assurance that the right people with the right skills are in the right place at the right time within the providers with whom they contract.

Annex (ii)

- *How to ensure the right people, with the right skills, are in the right place at the right time. A guide to nursing, midwifery and care staffing capacity and capability.* National Quality Board, (2013): www.england.nhs.uk/wp-content/uploads/2013/11/nqb-how-to-guid.pdf
- *Future Hospital.* Royal College of Physicians, (2013): www.rcplondon.ac.uk/projects/future-hospital-commission
- *Transforming Urgent and Emergency Care Services.* NHS England, (2013): www.nhs.uk/NHSEngland/keogh-review/Pages/about-the-review.aspx
- RCGP commissioning guidance for EOLC: www.goldstandardsframework.org.uk/cd-content/uploads/files/Primary%20Care/EOLC%20Commissioning%20Guidance%20Final%20-Apr13.pdf
- *Commissioning guidance for specialist palliative care: helping to deliver commissioning objectives.* National Council for Palliative Care (2012) - Developed in collaboration with: Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care and Palliative Care Section of the Royal Society of Medicine: www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf

Annex (iii)

Recommendations on desired characteristics of education and training programmes for care in the last days of life – for use by those who commission, fund or procure such programmes for health and care staff involved in care of the dying person.

As a minimum, such education and training programmes should include:

Learning Objectives

These are high level objectives as they need to be adapted to suit the programme, its duration and format, and its intended learners. Depending upon role they should focus from awareness to application to complex assessment and decision-making. They should include:

By the end of the training programme, learners are able to:

- Describe how to assess and act upon the needs of a dying person: physical, psychological, emotional, social, spiritual, cultural, religious.
- Explain how to address the dying person's comfort, specifically in relation to food, fluids and symptoms.
- Discuss how to approach and implement individualised care planning including shared decision-making.
- Demonstrate how to communicate about dying with the person, and those who are important to them.
- Describe how to assess and act upon the needs of the dying person's family and those important to the person.
- Describe the importance of and act upon maintaining own and team resilience through reflective practice and clinical supervision.
- Demonstrate understanding of how Mental Capacity Act should be applied when the dying person lacks capacity.
- Demonstrate understanding of the impact of loss and grief, including how to support individuals who are bereaved.

Additionally, for clinicians:

- Describe how to recognise that dying may be imminent, assess reversibility, make appropriate decisions and plans for review, and communicate uncertainty

Content

- Assessing the person whose condition has changed, including how to gather information from that person and those important to them, and other health and care team members, make professional judgements about the potential reversibility of the condition (and if so, whether or not reversing the condition is the right thing to do) and take appropriate action, including seeking senior advice or second opinion if necessary.

- Assessing and discussing the physical, psychological, emotional and social needs of the dying person.
- Assessing and discussing the spiritual and/or religious needs of dying patients, and those important to them.
- Specific attention to the topics of nutrition and hydration: assessment, discussion and shared decision-making with the person (where possible), and those important to them and other health and care team members
- Symptom management: assessment, communication and shared decision-making wherever possible about use of medication (including route of delivery), physical measures (including repositioning) and safe and accurate prescribing.
- Assessing and addressing the needs of those important to the dying person, including in bereavement.
- Communication skills, including empathy and recognising emotional response to stress and distress, discussing uncertainty, conversations about limits of treatment including 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR), withholding and withdrawing treatment, preferred place of care and death, etc.
- Clarity in verbal and written handovers between professionals, and across shifts/duty periods and settings (e.g. community and hospital care) to ensure consistent care and communication with the person and those important to them.
- An appreciation that caring for people in the last days of life is not just about 'doing' or 'fixing' things. It is concerned with supporting the person and those that are important to them during the dying period.

Educational approaches

- Employer commitment to ensure the delivery of appropriate end of life education programmes to health and care workers.
- Employee commitment to attend and implement learning from end of life education programmes.
- Explicit learning outcomes which include how to apply learning to practice, and supports implementation of advice from the Leadership Alliance for the Care of Dying People.
- Teaching methods which include some element of experiential learning, and encourages reflective practice as part of continuing professional development, and life-long learning
- Evaluation methods which can demonstrate achievement of outcomes and ideally extend beyond the immediate end of the course/training event.

Annex F:

Terms of Reference for the Independent Review of the Liverpool Care Pathway

The Review's terms of reference were as follows:

'The review will:

- examine systematically the experience of patients and families of the use of the Liverpool Care Pathway
- examine the experience and opinions of health professionals about the use of the Liverpool Care Pathway
- examine hospital complaints about end of life care and in particular those about the Liverpool Care Pathway
- review the literature about the Liverpool Care Pathway in practice;
- consider the role of financial incentives in this area
- make recommendations about what steps can be taken to:
 - improve care
 - ensure that patients are always treated with dignity and are involved in decisions about their care wherever possible
 - ensure that carers and families are always properly involved in the decision-making process
 - restore public confidence.

The review will report to Department of Health Ministers and the NHS Commissioning Board with its conclusions and recommendations by summer of 2013.'

Annex G:

Glossary of terms

End of life	<p>Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:</p> <ul style="list-style-type: none"> (a) advanced, progressive, incurable conditions (b) general frailty and co-existing conditions that mean they are expected to die within 12 months (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition (d) life-threatening acute conditions caused by sudden catastrophic events. <p>In General Medical Council guidance the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.</p>
Care pathway	<p>A care pathway is: "anticipated care placed in an appropriate time frame, written and agreed by a multidisciplinary team."</p> <p>"It has locally agreed standards based on evidence where available to help a patient with a specific condition or diagnosis move progressively through the clinical experience."</p> <p>"It forms part or all of the clinical record, documenting the care given."</p> <p>"It facilitates and demonstrates continuous quality improvement. It includes patient milestones and clinical interventions noted on the day or stage that they are expected to occur."</p> <p><i>(Welsh National Leadership and Innovation Agency for Healthcare guide to integrated care pathways, 2005).</i></p>
Clinical pathway	<p>A standardised set of actions aiming to optimise care for a particular clinical problem, in line with evidence of guidelines.</p> <p><i>(King's Fund, 2012)</i></p>

NICE Pathways	<p>NICE Pathways are interactive topic-based diagrams which aim to provide users with a way to quickly view and navigate all NICE guidance recommendations on a particular topic. A NICE Pathway starts with a broad overview of a topic and allows the user to explore NICE recommendations and advice in increasing detail. Relevant topics are linked together forming a network of NICE information. A NICE Pathway provides a useful starting point for new users to a topic while giving specialists easy access to NICE recommendations. NICE Pathways do not provide a comprehensive management pathway for individual patient care.</p>
Protocols	<p>A plan or set of steps that defines how something will be done.</p>
Guidelines/ guidance	<p>NICE uses the term 'guidance'/'guidelines' interchangeably, to refer to evidence-based recommendations on the most effective and cost-effective treatment and care of people with specific diseases and conditions, and recommendations for populations and individuals on interventions that can help prevent disease or improve health.</p> <p>The professional regulators (GMC, NMC, HCPC and GPhC), produce regulatory 'guidelines'/'guidance' on how professional standards should be achieved.</p> <p>The LACDP has produced implementation 'guidance' for service providers and commissioners on delivering the Priorities for Care of the Dying Person.⁶¹</p> <p>Alliance members have agreed that they will not use the terms 'guidelines' or 'guidance' in relation to care in the last few days and hours of life other than in the three specific contexts described above.</p>
Standard operating procedures	<p>Detailed, written instructions to achieve uniformity of the performance of a specific function.</p> <p><i>(International Conference on Harmonisation(ICH))</i></p>
Best practice models	<p>A method or technique that has consistently shown results superior to those achieved with other means, and that is used as a benchmark. In addition, a 'best' practice can evolve to become better as improvements are discovered.</p>

⁶¹ The Priorities for Care of the Dying Person – Implementation Guidance for Service Providers and Commissioners can be found at: Annex E of *One Chance to Get it Right: improving people's experience of care in the last few days and hours of life*, the system-wide response to the Independent Review of the Liverpool Care Pathway.

Advance Care Planning (ACP)	<p>Advance care planning (ACP) is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. An ACP discussion might include:</p> <ul style="list-style-type: none"> • the individual's concerns and wishes, • their important values or personal goals for care, • their understanding about their illness and prognosis, • their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these. <p>(Advance Care Planning: A Guide for Health and Social Care Staff NHS End of Life Care Programme, Published February 2007, Revised August 2008.)⁶²</p>
Advance statement	<p>A statement that conveys a person's preferences, wishes, beliefs and values regarding their future care. The aim is to provide a guide to anyone who might have to make decisions in the person's best interest if that person has lost the capacity to make a decision.</p>
Advance Directive/ Advance Decision/ Advance Decision to Refuse Treatment (ADRT)	<p>This is a decision to refuse specified treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 (1) of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment.</p> <p>An advance decision to refuse treatment:</p> <ul style="list-style-type: none"> • can be made by someone over the age of 18 who has mental capacity; • is a decision relating to refusal of specific treatment and may also include specific circumstances; • can be verbal, but if an advance decision includes refusal of life-sustaining treatment, it must be in writing, signed and witnessed and include the statement 'even if life is at risk'; • will only come into effect if the individual loses capacity; • only comes into effect if the treatment and any circumstances are those specifically identified in the advance decision; • is legally binding if valid and applicable to the circumstances. <p>(<i>Capacity, care planning and advance care planning in life limiting illness</i> February 2012 - National End of Life Care Programme)⁶³</p>

⁶² See: www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf

⁶³ See: www.nhs.uk/resource-search/publications/eolc-ccp-and-acp.aspx

Best interests (in the context of patients lacking capacity to make a particular decision)	<p>Any decisions made, or anything done for a person who lacks capacity to make specific decisions, must be in the person's best interests. The Mental Capacity Act 2005 (England and Wales) sets out how a best interests decision should be made. Any staff involved in the care of a person who lacks capacity should make sure a record is kept of the process of working out the best interests of that person for each relevant decision, setting out:</p> <ul style="list-style-type: none"> • how the decision about the person's best interests was reached; • what the reasons for reaching the decision were; • who was consulted to help work out best interests; and • what particular factors were taken into account.
Equality Act 2010 – nine protected characteristics	<p>In accordance with the public sector equality duty (section 149 of the Equality Act 2010), public authorities must have due regard to the need to eliminate discrimination, harassment and victimisation and other conduct prohibited by the Act; advance equality of opportunity between people who share a protected characteristic and those who do not; foster good relations between people who share a protected characteristic and those who do not. These aims of the public sector equality duty apply to the following protected characteristics: age, disability, gender, gender reassignment, pregnancy and maternity, race, religion or belief, sexual orientation, and marriage and civil partnership (but only in regards to the aim of eliminating discrimination and harassment).</p>
Independent Mental Capacity Advocate (IMCA)	<p>If a person who lacks capacity has no close family or friends to support or represent them or no-one whom it is appropriate to consult, then an <i>Independent Mental Capacity Advocate</i> (IMCA) must be instructed and consulted regarding decision-making about serious medical treatment or about placement in hospital for longer than 28 days or a care home for longer than 8 weeks. The only exception is when an urgent decision is needed. An ICMA may be appointed in some other circumstances.</p>
Lasting Power of Attorney (LPA)	<p>An LPA is a statutory form of power of attorney created by the Mental Capacity Act 2005 (England and Wales). Anyone who has the capacity to do so may choose a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity. There are two types of LPAs: (a) for personal welfare (which includes healthcare and consent to medical treatment); and (b) for property and affairs.</p>

Mental capacity	<p>A person must be assumed to have mental capacity unless it is established that they lack capacity. An assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made, and not their ability to make decisions in general. Under the Mental Capacity Act 2005 (England and Wales), anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity:</p> <ul style="list-style-type: none"> • Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.) • If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made? <p>A person is unable to make a decision for himself if he is unable to understand the information relevant to the decision, retain that information, use or weigh that information as part of the process of making the decision or to communicate the decision (whether by talking, sign language or any other means).</p>
Palliative care	<p>Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:</p> <ul style="list-style-type: none"> • provides relief from pain and other distressing symptoms; • affirms life and regards dying as a normal process; • intends neither to hasten or postpone death; • integrates the psychological and spiritual aspects of patient care; • offers a support system to help patients live as actively as possible until death; • offers a support system to help the family cope during the patient's illness and in their own bereavement; • uses a team approach to address the needs of patients and their families; • enhances quality of life and may also positively influence the course of illness; • is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. <p>Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.</p> <p><i>(World Health Organisation)</i></p>

Specialist palliative care	<p>Specialist palliative care is the active, total care of patients with progressive, advanced disease and [of] their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training.</p> <p><i>(Tebbit, National Council for Palliative Care, 1999)</i></p>
Quality standards	<p>Alliance members have agreed that, to avoid confusion, they will avoid using the term 'quality standards' in relation to end of life care other than for NICE 'quality standards' and any 'quality standards' produced by the professional regulators (GMC, NMC, HCPC and GPhC) which describe how professional standards should be achieved.</p>
Spiritual care	<p>Spiritual care is that care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires.</p> <p><i>(NHS Education for Scotland, 2009)</i></p>

Annex H:

End of life care in existing training for professionals

End of life care in existing training for professionals

Contents

Section A

1. GMC's Education Standards
2. Postgraduate - Foundation and Specialty curricula and guidance
3. GMC ethical guidance - Treatment and care towards the end of life: good practice in decision making
4. Consensus syllabus for undergraduate palliative medicine for Great Britain and Ireland, 2006
5. NMC
6. National end of life qualifications
7. National Common Core Competences and Principles for End of Life Care

Section Bi - Summary of coverage of end of life care – including the underpinning competencies and outcomes - in the curriculum for doctors training in the Foundation Programme

Table of Foundation year 1 and 2 Outcomes

Section Bii - Coverage of end of life care in the curricula for postgraduate medical specialty education and training. (Specialty training takes place after Foundation training.)

1. General practice
2. Palliative medicine
3. Core Medical Training (CMT)
4. General (internal) medicine
5. Acute internal medicine Curriculum (AIM)
6. Broad Based Training
7. Geriatric medicine
8. Intensive care medicine (ICM)
9. Paediatric palliative care medicine
10. Medical oncology
11. Respiratory medicine
12. Cardiology

13. Guidance – Prolonged disorders of consciousness – national clinical guidelines

Glossary of terms for Section B

Section C - Some additional training programmes and resources for end of life care

Section A

Background on the coverage of end of life care in standards, guidance and in curricula for health and care staff

1. GMC's Education Standards

Tomorrow's Doctors, 2009 (standards and outcomes for undergraduate medical education)

Under the section which sets out the areas in which individuals will be expected to demonstrate that they can diagnose and manage clinical presentations, part 14j states that they must:

'Contribute to the care of patients and their families at the end of life, including management of symptoms, practical issues of law and certification, and effective communication and team working.'

Curricula for undergraduate medical education

Curricula for undergraduate medical education are set by the medical schools.

An overview of the coverage of end of life care in medical school curricula is provided.

The Foundation Programme

The standards for Foundation training are contained in the *Trainee Doctor*, published in 2011, including the outcomes for provisionally registered Foundation Year 1 doctors.

The 2012 Foundation Programme Curriculum and the related outcomes for F1 and F2 doctors currently state that trainees will:

'Take part in a multidisciplinary approach to end of life care utilising tools such as the Liverpool Care Pathway'

The Foundation Programme Curriculum and the outcomes for F1 and F2 - drawn up by the Academy Foundation Committee under the Academy of Medical Royal Colleges – are approved by the GMC. The UK Foundation Programme Office operationalise the curriculum and outcomes, for example, ensuring that it is embedded in the e-portfolio.

Attached at Section B(i) are extracts from the outcomes for the Foundation Programme covering end of life care and some of the professional elements which underpin and are generic to good clinical care.

Please note that arrangements have been made to remove references to the Liverpool Care Pathway from the Foundation Programme Curriculum and specialty curricula and assessment systems.

Postgraduate specialty education and training

The standards governing postgraduate specialty medical and education, including GP, training are set out in the *Trainee Doctor*.

These standards are high level and do not specify what the content or outcomes of specialty training should be. The content and outcome requirements are specified in each of the 65 specialty curricula produced by the medical Royal Colleges and faculties

and approved by the GMC against the separate Standards for Curricula and Assessment Systems.

The GMC and the Academy of Medical Royal Colleges are currently developing a framework for generic professional capabilities that will be embedded in all 65 specialty curricula. These will include a theme around end of life care.

2. Postgraduate - Foundation and Specialty curricula and guidance

The curricula and outcomes for the Foundation Programme are approved by the GMC.

The curricula for specialty training are also approved by the GMC.

Section B(i) provides a summary of end of life care and some underpinning professional and clinical skills in Foundation training. Section B(ii) provides a summary of end of life care coverage in specialty curricula.

3. GMC ethical guidance - *Treatment and care towards the end of life: good practice in decision making*

The guidance provides a framework for good practice when providing treatment and care for patients who are reaching the end of their lives. It is aimed at doctors primarily but may be helpful to patients.

It is based on long-established ethical principles, which include doctors' obligations to show respect for human life; to protect the health of patients; to treat patients with respect and dignity; and to make the care of their patients their first concern. It expands on the principles of good practice in the GMC's *Good medical practice* (2013) and *Consent: patients and doctors making decisions together* (2008), and replaces the booklet *Withholding and Withdrawing Life-Prolonging Treatments* (2002).

4. *Consensus syllabus for undergraduate palliative medicine for Great Britain and Ireland, 2006*

In 1992, the Association of Palliative Medicine of Great Britain and Ireland developed a palliative medicine curriculum for doctors and students. This was updated for undergraduate medical education in 2006 in view of the fact that new medical schools had been established and more medical schools include palliative medicine as a regular question in the final examination.

This revised syllabus was endorsed by the Association for Palliative Medicine. It has developed from a research study by Paul Paes and Bee Wee to gain a consensus among experts in palliative medicine across Great Britain and Ireland as to what should be included. The document recognises the diversity of undergraduate medical programmes in different medical schools as well as the amount of time allocated to palliative medicine. It has been designed as a reference document to help individuals develop and enhance palliative medicine teaching within the undergraduate medical education programmes in their own institutions.

5. NMC

The NMC's standards for pre-registration nursing education state that all nurses '*... must support and promote the health, wellbeing, rights and dignity of people, groups, communities and populations. These include people whose lives are affected by ill health, disability, ageing, death and dying*'.

In addition, for those nurses who specialise in adult nursing, nursing those with learning disabilities and mental health nursing, the standards for pre-registration nursing education also state that they: '*Must understand and apply current legislation to all service users, paying special attention to the protection of vulnerable people, including those with complex needs arising from ageing, cognitive impairment, long term conditions and those approaching the end of life.*'

The NMC has three documents which are relevant to end of life care and which contain some generic themes:

- *The Code: Standards of conduct, performance and ethics for nurses and midwives;*
- *Guidance for the Care of Older People; and*
- *Essential skills clusters* – these form part of the pre-registration nursing education standards and contain elements that speak more directly to end of life care such as:
 - care, compassion and communication;
 - organisational aspects of care;
 - infection prevention and control;
 - nutrition and fluid management; and
 - medicines management.

These essential skills clusters (ESCs) are meant as guidance. How they are incorporated into education programmes is left to local determination by the approved education institution (AEI) delivering the training concerned. The programme providers can use the ESCs to develop learning outcomes at different levels or to map them against existing programme learning outcomes.

6. National end of life qualifications

Skills for Care has developed a range of qualifications for those working in social care which can equip them not only to recognise end of life situations but to manage them more effectively, working in partnership with the individuals, their families and carers and other organisations to deliver the best quality of care.

The new end of life care qualifications have been developed in conjunction with a wide range of employers including Marie Curie Cancer Care, the UK Home Care Association and Barchester Care in addition to a number of hospices as a direct response to this framework.

Supporting people to live and die well (2010): Units EOL 306 and EOL 307 – 'Support individuals during last days of life' are core for this area of work but many other units are also appropriate as indicated in the matrix. The units are already mapped to the 'Six Steps to Success' programme.

The range of qualifications at level 2, 3 and 5 enable social care staff to develop their knowledge and skills in communication, advance care planning, managing symptoms and pain, supporting spirituality, supporting individuals with loss and grief before death, and also in leading and managing effective end of life care.

www.skillsforcare.org.uk

7. National Common Core Competences and Principles for End of Life Care

Skills for Care and Skills for Health working in partnership with the Department of Health and the NHS End of Life Care Programme, developed workforce competences and core principles as they relate to end of life care.

They were produced following consultation with a wide range of expert groups and organisations.

The primary purpose of this development is to support workforce development, training and education, and to support the development of new and enhanced posts and roles across health **and** social care based on one common foundation.

Common competences underpin all levels of practice and are defined by:

- Linkages to levels defined by nationally recognised frameworks - e.g. National Occupational Standards (NOS), Knowledge and Skills Framework (KSF), National Workforce Competences (NWC), Qualifications and Credit Framework (QCF), continual professional development (CPD)
- Basic, Intermediate and Specialist Groupings – to enable further flexibility for local developments
- The Common Core Competences are:
 - Communication skills
 - Assessment and care planning
 - Symptom management, comfort and well being
 - Advance care planning

Underpinned by values and knowledge

Seven principles underpin all workforce and service development, activity and delivery irrespective of level and organisation. All of these link with the areas identified in the matrix. They are:

1. Choices and priorities of the individual are at the centre of planning and delivery.
2. Effective, straightforward, sensitive and open communication between individuals, families, friends and workers underpins all planning and activity.
3. Communication reflects an understanding of the significance of each individual's beliefs and needs delivery through close multidisciplinary and interagency working.
4. Individuals, families and friends are well informed about the range of options and resources available to them to be involved with care planning.

5. Care is delivered in a sensitive, person-centred way, taking account of circumstances, wishes and priorities of the individual, family and friends.
6. Care and support are available to anyone affected by the end of life and death of an individual.
7. Workers are supported to develop knowledge, skills and attitudes. Workers take responsibility for, and recognise the importance of, their continuing professional development.

Section B(i)

Summary of coverage of end of life care – including the underpinning competencies and outcomes - in the curriculum for doctors training in the Foundation Programme

Coverage includes references to:

- palliative care;
- nutrition/hydration;
- practical issues re clinical skills;
- consent;
- breaking bad news;
- relationship with patients;
- effective team working – referring up to seniors;
- audit – multi-disciplinary team meetings; and
- probity.

Foundation year 1 and 2 outcomes

Section		F1 and F2 outcomes	Relevant competences
1. Professionalism	1.1 Behaviour in the workplace	<ul style="list-style-type: none"> Acts with professionalism in the workplace and in interactions with patients and colleagues 	<ul style="list-style-type: none"> In all interactions with both patients and colleagues takes account of factors, where relevant, pertaining to patients' age, colour, culture, disability, ethnic or national origin, gender, lifestyle, marital or parental status, race, religion or beliefs, sex, sexual orientation, or social or economic status Respects and supports the privacy and dignity of patients.
1. Professionalism	1.4 Team-working	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> Displays understanding of personal role within their team including supporting the team leader and listening to the views of other healthcare professionals <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> Organises and allocates work within their clinical team to optimise effectiveness 	<ul style="list-style-type: none"> Integrates and interacts appropriately with their clinical team Contributes to multidisciplinary team (MDT) meetings Encourages open and appropriately directed communication within teams Demonstrates clear and effective communication within the healthcare team Cross-checks instructions and actions with colleagues e.g. medicines to be injected

2. Relationship and communication with patients	2.1 Treats the patient as the centre of care within a consultation	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Prioritises the needs of patients above personal convenience without compromising personal safety or safety of others • Works in partnership with patients in an open and transparent manner, treats patients as individuals and respects their perspective/views on their own treatment <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Works with patients and colleagues to develop sustainable individual care plans to manage patients' acute and long-term conditions 	<ul style="list-style-type: none"> • Considers the patient as a whole, respecting their individual needs, dignity and right to privacy, autonomy and confidentiality • Discusses management options with patients • Recognises patients' expertise about their care • Respects patients' views and encourages patients with knowledge of their condition to make appropriately informed decisions about their care • Demonstrates understanding to the whole clinical team that respect of patients views and wishes is central to the provision of high quality care • Considers care pathways and the process of care from patients' perspectives • Respects patients' right to refuse treatment or take part in research • Recognises and responds to patients' ideas, concerns and expectations • Deals appropriately with angry or dissatisfied patients.
2. Relationship and communication with patients	2.2 Communication with patients	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Communicates effectively and with understanding and empathy in 	<ul style="list-style-type: none"> • Ensures sufficient time and appropriate environment for communication • Listens actively and enables patients to express

		<p>straightforward consultations</p> <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Demonstrates increasing ability and effectiveness in communicating more complicated information in increasingly challenging circumstances • Deals increasingly independently with queries from patients and relatives 	<p>concerns and preferences, ask questions and make personal choices</p> <ul style="list-style-type: none"> • Recognises that patients may have unspoken concerns and communicates in an empathic manner to elicit and address these • Responds to patients' queries or concerns • Seeks advice promptly when unable to answer patients' queries or concerns • Explains options clearly and checks patients' understanding
2. Relationship and communication with patients	2.3 Communication in difficult circumstances	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Breaks bad news to patients or carer/relative effectively and compassionately, and provides support, where appropriate <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Recognises where patient's capacity is impaired and takes appropriate action 	<ul style="list-style-type: none"> • Demonstrates involvement with others in the team when breaking bad news • Considers any acute or chronic mental or physical condition that may have an impact on communication understanding • Considers patients' personal factors including relevant home and work circumstances • Ensures sufficient time and a suitable environment for discussions • Deals appropriately with distressed patients/carers and seeks assistance as appropriate

			<ul style="list-style-type: none"> • Manages three-way consultations e.g. with an interpreter or with a child patient and their family/carers • Understands how the communication might vary when the patient or carer has learning or communication difficulties themselves e.g. deafness • Deals appropriately with angry or dissatisfied patients, trying to calm the situation and seeking assistance as appropriate.
<p>2. Relationship and communication with patients</p>	<p>2.5 Consent</p>	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Obtains consent as appropriate in accordance with Consent: patients and doctors making decisions together (2008) including for core procedures <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Increases the breadth of procedures for which consent is taken in accordance with GMC guidance 	<ul style="list-style-type: none"> • Practises in accordance with Consent: patients and doctors making decisions together (GMC, 2008) and does not take consent when contrary to GMC guidance • Describes the principles of valid consent and obtains valid consent after appropriate training • Gives each patient the information they ‘want’ or ‘need’ in a way they can understand in order to obtain valid consent • In patients who lack capacity understands and applies the principle of ‘best interests’ • Ensures that the patient with capacity understands and retains information long enough to make a decision

4. Ethical and legal issues	4.1 Medical ethical principles and confidentiality	<p><i>F1 and F2 outcomes</i></p> <ul style="list-style-type: none"> Practises in accordance with the principles of Good Medical Practice, The Trainee Doctor and Confidentiality 	<ul style="list-style-type: none"> Provides care and treatment in accordance with the principles of patients' best interests, autonomy and rights
4. Ethical and legal issues	4.2 Legal framework of medical practice	<p><i>F1 and F2 outcomes</i></p> <ul style="list-style-type: none"> Takes personal responsibility for and is able to justify decisions and actions 	<ul style="list-style-type: none"> Demonstrates the knowledge and skills to cope with ethical and legal issues that occur during the management of patients with medical problems or mental illness Discusses the implications of a living will or advance decision to refuse treatment.
7. Good clinical care	7.3 Diagnosis and clinical decision-making	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> Makes appropriate differential diagnosis and formulates a management plan <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> Reviews initial diagnosis (with F1), refines problem lists and plans appropriate strategies for investigation and management 	<ul style="list-style-type: none"> Works towards an appropriate differential diagnosis and establishes a problem list Constructs a management plan and communicates requests/instructions to other healthcare professionals Makes a judgement about prioritising actions on the basis of the differential diagnosis and clinical setting

7.6 Safe prescribing (including fluids)		<p><i>F1 outcomes</i></p> <p>..... Prescribes medicines, blood products and fluids accurately and unambiguously and regularly reviews drug chart</p>	<ul style="list-style-type: none"> • Chooses appropriate intravenous fluids as vehicles for intravenous drugs and calculates the correct volume and flow rate
8. Recognition and management of the acutely ill patient	8.4 Manages pain	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Safely prescribes and administers common analgesic drugs including patient controlled analgesia <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Anticipates and prevents pain whenever possible • Ensures safe prescribing tailoring to changing requirements throughout patients' care journey 	<ul style="list-style-type: none"> • Recognises importance of pain control • Evaluates the cause and severity of pain (ideally using a verified pain score) • Manages pain safely and effectively • Prescribes analgesic drugs in a safe and timely manner • Communicates changes to analgesic prescriptions with other health carers in the community and hospital including acute pain and palliative care teams.
9. Resuscitation and end of life care	9.2 End of life care and appropriate use of Do Not Attempt Resuscitation (DNAR) orders/ advance decisions	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Understands the principles of providing high quality end of life care including the use of DNAR orders as outlined in Treatment and care towards the end of life: good practice in decision making (GMC, 2010) 	<ul style="list-style-type: none"> • Understands the value of 'diagnosing dying' • Prioritises symptom control as part of end of life care • Understands where and how to access specialist palliative care services • Demonstrates an awareness of Advanced Care Planning in end

		<p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Takes part in discussions regarding end of life care and DNAR orders <p>Uses the local protocol for deciding when not to resuscitate patients</p>	<p>of life care and the times when it may be appropriate</p> <ul style="list-style-type: none"> • Discusses patients' needs and preferences regarding end of life care wherever possible • Understands the ethics of transplantation and identifies potential donors to senior medical staff • Discusses and plans for preferred place of death wherever possible • Takes part in a multidisciplinary approach to end of life of life care utilising tools such as the Liverpool Care Pathway • Understands the importance of adequate discussion and documentation of DNAR orders • Describes the criteria for issuing DNAR orders and the level of experience needed to issue them • Discusses DNARs with the multidisciplinary team, the patient, long-term carers (both medical and non-medical) and relatives • Understands the accountability of the responsible clinician when a DNAR decision is made • Understands the role of the individual and the family in the communication of DNAR orders
--	--	---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

			<ul style="list-style-type: none"> • Recognises actual and potential conflicts between patients and their relatives • Recognises and acts appropriately when DNAR decisions are challenged/conflicts arise between interested parties • Facilitates the regular review of DNAR decisions.
10.3 Nutrition		<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Takes a basic nutrition history and considers this in planning care <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Ensures adequate nutrition (including nutritional supplements) for patients with acute illness and long-term conditions 	<ul style="list-style-type: none"> • Recognises nutritional disorders are common in patients with long-term conditions • Performs basic nutritional screen and recognises patients with potential for nutritional deficiencies and considers this in planning care • Formulates a plan for investigation and management of weight loss or weight gain • Demonstrates the knowledge, skills, attitudes and behaviours to assess patients' basic nutritional requirements • Recognises major nutritional abnormalities and eating disorders and establishes a management plan, where relevant with other healthcare professional input

			<ul style="list-style-type: none"> • Works with other healthcare professionals in addressing nutritional needs and communicating these during care planning • Makes nutritional care part of daily practice • Considers the additional effects of long-term ill-health on nutritional status and the effect of poor nutrition on long-term health.
--	--	--	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Section B(ii)

Coverage of end of life care in the curricula for postgraduate medical specialty education and training. (Specialty training takes place after Foundation training.)

1. General practice⁶⁴

Statement 3.03: *Care of Acutely Ill People*, page 11 - under the heading: *The essential features of you as a doctor*

Also under sub-heading *EF2 Attitudinal features*, the focus is on a trainee's professional capabilities, values, feelings and ethics and the impact these may have on the patient care they provide when dealing with end of life patients.

Para: *EF2.5* notes how the trainee must learn to manage the difference between what they think is an appropriate medical course of action and the course of action desired by patients, their relatives and their carers. Para: *EF2.5.1* states that this is particularly important for patients receiving palliative or end-of -life care.

Statement 3.05: *Care of Older Adults*, page 7 under the sub-heading *2 Person-centred care* sets out that:

One of the areas of competence trainees are assessed for is about understanding and relating to the context of their patients as individuals, and developing the ability to work in partnership with them. This means that a trainee should know the special features of prognosis of disease in old age and be able to apply the knowledge to produce an appropriate plan for further investigation and management which includes end of life care.

Page 9 of the statement under the sub-heading *EF1 Contextual features* focuses on where the trainee must understand their own context as a doctor and how it may influence the quality of the care they provide. Important factors are the environment in which the

⁶⁴ All page and subheading references under this heading refer to General Practice Specialty Curricula statements which can be found online at: www.gmc-uk.org/education/gp.asp

trainee works, including working conditions, community, culture, financial and regulatory frameworks. An example of this is provided in para *EF1.1* where trainees are required to learn to understand moral, ethical and emotional issues relating to the end of life.

The trainee is also referred to see statement 3.09 of the General practice curriculum on *End of life Care* as well as after death e.g. living wills, palliative care.

Also within statement 3.05: page 10 under the heading *EF2 Attitudinal features* are references to the trainee's professional capabilities, values, feelings and ethics and the impact these may have on the patient care they provide when dealing with end of life patients. An example of this is provided in para *EF2.2* where trainees are required to learn to recognise personal attitudes to the elderly, to the processes of growing old, becoming frail and to dying.

Statement 3.09: *End of life-care*, page 6, lists all the learning outcomes or objectives which relate specifically to end of life care and which are an important part of the General Practitioner's wider palliative care role. These learning outcomes are in addition to those detailed in the core statement *Being a General Practitioner*. The core statement and this statement should be used in conjunction with the other curriculum statements.

Trainees are also asked to refer to statement 3.04: *Care of Children and Young People* for palliative care for children.

In order to demonstrate the core competences in the area of end of life care, trainees are required to gain knowledge, skills and attitudes in the following areas:

- 1 Primary care management
- 2 Person-centred care
- 3 Specific problem-solving skills
- 4 A comprehensive approach
- 5 Community orientation
- 6 A holistic approach

EF1 Contextual features

EF2 Attitudinal features

EF3 Scientific features

Trainees must also acquire outcomes via the work-based learning environment in primary and secondary care as well as non-work based learning in the form of e.g. local hospices, courses, e-learning courses to help consolidate and build on knowledge gained in the workplace. For General Practice trainees, their specialty training programme should also offer case-based discussions where end of life care can be shared.

Statement 3.11: *Care of people with intellectual disability*, page 9 under the sub-heading *A holistic approach*, explains that trainees are assessed on their ability to understand and respect the values, culture, family structure and beliefs of their patients, and understand the ways in which these will affect the experience and management of illness and health. This means as a General Practitioner, trainees should understand that by the time the patient with intellectual disability has reached adulthood, the parents have gone through a different series of transitions to other parents; and, subsequently if their child dies, they may go through a bereavement process that differs from those whose child without intellectual disability dies.

2. Palliative medicine⁶⁵

Page 26 under the sub-heading *2.15 Public Health Related to Palliative Care*, trainees are required to gain knowledge competence to recognise ways to influence and improve the general health of a community in relation to relevant preventive, supportive and end of life care. Trainees must learn to recognise the influence of culture and beliefs on perceptions of health, illness and end of life care, and they are assessed on this via case-based discussions (CbDs) and mini clinical evaluation exercises (mini-CEX).

Page 33, under the sub-heading *2.21 Delivering Shared Care*, trainees must learn to demonstrate a positive attitude towards shared medical care and be able to deliver palliative care whatever the environment (hospital, hospice, nursing homes, day-care and the patient's home). Trainees are expected to acquire skills competence in planning for end of life care and are assessed on this via case-based discussions and mini clinical evaluation exercises.

Page 50, under the sub-heading *7.2 Theoretical Ethics and Applied Ethics in Clinical Practice of Palliative Medicine*, trainees are expected to demonstrate skills in ethical reasoning and decision-making in end of life care, at consultant level, both for their own patients and for those that are referred to them in an advisory capacity. Trainees are required to gain knowledge competence in explaining the challenges of resource allocation and futility in respect of the end of life, and they are assessed on this via case-based discussions.

Page 85 under the heading *4.2 Teaching and learning methods*, sub-heading *Formal Study Courses*, a list of courses are recommended for trainees to attend. One of these is a course on *Ethical issues in end of life care*.

3. Core Medical Training (CMT)

Of particular relevance are the 2012 Core Medical Training curriculum competences around the management of patients requiring palliative and end of life care (which can be found on p113 of the Core Medical Training curriculum).⁶⁶ This is accompanied by a supplementary document containing additional palliative and of life care competences. This more detailed supplementary document contains competences for both CMT and General (internal) medicine (GIM) curricula, and should therefore be read in conjunction with these documents.⁶⁷ They also refer to Advance Care Planning.

4. General (internal) medicine

Page 85 contains reference to palliative and end of life care, although the competences appear to overlap completely with the Core Medical Training level competences. See curriculum statement on the GMC website at: www.gmc-uk.org/2009_GIM_curriculum_revised_Aug_2012pdf.pdf_51545072.pdf

⁶⁵ All page and subheading references under this heading refer to the Specialty Curriculum Statement for Palliative Medicine which can be found online at: www.gmc-uk.org/Palliative_Curriculum_220410_V0.13.pdf_32485351.pdf

⁶⁶ See Joint Royal Colleges of Physicians' Training Board (JRCPTB) website at: [www.jrcptb.org.uk/trainingandcert/Documents/2009%20CMT%20framework%20\(revised%20Aug%202012\).pdf](http://www.jrcptb.org.uk/trainingandcert/Documents/2009%20CMT%20framework%20(revised%20Aug%202012).pdf)

⁶⁷ This is available online at JRCPTB website: www.jrcptb.org.uk/SiteCollectionDocuments/Management%20of%20Patients%20Requiring%20Palliative%20and%20End%20of%20Life%20Care%20CMT.pdf

5. Acute internal medicine Curriculum (AIM)

Page 97 contains reference to palliative and end of life care, although these competences are again identical to the competences found on page 85 of the General (internal) medicine curriculum and page 113 of the Core Medical Training curriculum. There is also a link on the Acute internal medicine section of the website to the supplementary palliative and end of life care competences document mentioned above, although the supplementary document itself does not specifically refer to Acute internal medicine, only Core Medical Training and General (internal) medicine. See curriculum statement on the GMC website at: www.gmc-uk.org/2009_AIM_Curriculum__AMENDMENTS_2012_.pdf_51544444.pdf

6. Broad Based Training

The Broad Based Training (BBT)⁶⁸ curriculum (a core training equivalent) has managed to integrate the legacy and updated palliative and end of life care competences more successfully than the Acute internal medicine, Core Medical Training or General (internal) medicine (page 51 of the Broad Based Training curriculum refers).

All doctors who complete Core Medical Training should have addressed certain competences specifically related to palliative and end of life care, as will all acute and general physicians, and all physicians in medical specialties who have followed a dual specialty-specific-and-General (internal) medicine pathway through higher specialty training.

7. Geriatric medicine⁶⁹

On page 68, under the sub-heading *Community Practice Including Continuing, Respite and Intermediate Care*, trainees are expected to acquire knowledge on end of life care including advanced care planning, and they are assessed on this competence via case-based discussions, mini clinical evaluation exercises and specialty certificate examinations.

Also on page 82, under the sub-heading *Intermediate Care and Community Practice*, trainees are expected to acquire knowledge on current national publications regarding end of life care and are assessed on this via specialty certificate examinations and case-based discussions.

8. Intensive care medicine (ICM)⁷⁰

On pages 1 to 5, under the introduction sub-heading *1.2 Definition of ICM*, Intensive care medicine is also referred to as critical care medicine i.e. as the body of specialist knowledge and practice concerned with the treatment of patients, with, at risk of, or recovering from potentially life-threatening failure of one or more of the body's organ systems. It includes the provision of organ system support, the investigation, diagnosis, and treatment of acute illness, systems management and patient safety, ethics, end of life care, and the support of families.

⁶⁸ See JRCPTB website at: www.jrcptb.org.uk/trainingandcert/Documents/2012%20BBF%20curriculum%20with%20Assessment%20Grid.pdf

⁶⁹ All page and subheading references under this heading refer to the Specialty Curriculum Statement for Geriatric Medicine which can be found online at: www.gmc-uk.org/2010_Geriatric_Medicine_Curriculum__AMENDMENTS_2013_.pdf_53858086.pdf

⁷⁰ All page and subheading references under this heading refer to the Specialty Curriculum Statement for Intensive Care Medicine which can be found online at: http://www.gmc-uk.org/20111007_CCT_in_ICM__COMPLETE__Aug2011_v1.0_.pdf_44816170.pdf

Pages 1 to 6, sub-heading 1.4 *The scope of Intensive care medicine practice*, explains that Intensive Care Medicine specialists are expected to have medical expertise in end of life care.

Page 1 to 32, para 5.5.1 refers to the *Final FFICM MCQ (Fellowship of the Faculty of Intensive Care Medicine Multiple Choice Question examination)*. This examination consists of multiple choice questions which test factual knowledge in the areas of science applied to clinical practice which includes end of life care.

Pages 2 to 6, under the heading *Training progression grid*, trainees are expected to demonstrate their progression of competency in each curriculum domain throughout the stages of Intensive care medicine training. This includes Domain 8: *End of life Care*, where trainees are expected to demonstrate knowledge and skill competencies by:

- (8.1) managing the process of withholding or withdrawing treatment with the multi-disciplinary team;
- (8.2) Discussing end of life care with patients and their families/surrogates and members of the health care team;
- (8.3) Managing palliative care of the critically ill patient;
- (8.4) Performing brain-stem death testing;
- (8.5) Managing the physiological support of the organ donor; and
- (8.6) Managing donation following cardiac death.

Pages 4 to 43, under the heading *4.8 Management of respiratory and cardiac arrest in adult and children*, trainees must also be able to discuss the importance of respecting the wishes of patients regarding end of life decisions.

9. Paediatric palliative care medicine⁷¹

On page 53, trainees at Level 3 (specialty training years 6-8 or ST6-ST8) are expected where appropriate and at a negotiated time, to be able to raise and agree management of end of life issues with young people and their families and record conclusions in medical notes for them to gain effective skills in recognising and responding effectively.

On page 62, trainees at Level 3, are expected to acquire an awareness of religious and cultural diversity and beliefs in counselling children and families regarding end of life care as part of their responsibility to ensure an open minded approach to equality and diversity in the paediatric team.

On page 63, trainees at Level 3, must be able to demonstrate skills in ethical reasoning and decision-making in end of life care for their own patients and those referred in their advisory capacity, as part of their responsibility for ensuring an open minded approach to equality and diversity in the paediatric team.

On page 79, trainees at Level 3, must be able to convey and share effectively difficult or bad news, including end of life issues with children, young people, parents or carers and help them to understand any choices they have or decisions to be made about on-going management and this is part of trainees gaining effective skills in giving information and advice to young people and their families in common and complex cases.

⁷¹ See Paediatric Palliative Care Medicine curriculum statement online at: www.gmc-uk.org/Paediatric_Palliative_Medicine_NEW_curriculum_document_June_2010.pdf_55904192.pdf

On page 86, trainees must also be able to facilitate planning for end of life care as part of their gaining effective managerial skills in taking on a positive managerial role to support effective service provision.

On page 101, under the sub-heading *Emergencies*, trainees at Level 3 are expected to know the ethical considerations of managing palliative medicine emergencies at the end of life, particularly those relating to euthanasia, the principle of double effect and terminal sedation, and if necessary to contribute to clinical ethics committee debates on these subjects.

10. Medical oncology⁷²

On page 90, under the sub-heading *Psychosocial aspects of cancer related disease*, trainees are expected to acquire knowledge competence in issues relating to end of life care and death and trainees are assessed on this via specialty certificate examinations and case-based discussions.

On page 137, under the heading *Management of Teenagers and Young Adults (TYA) with Cancer* trainees are expected to be able to manage end of life issues with teenagers and young adults and their carers. Trainees are assessed on this competence via specialty certificate examinations and case-based discussions.

11. Respiratory medicine⁷³

On page 133, under the heading *Managing Long Term Conditions: Integrated Care and the Promotion of Self Care*, trainees are expected to gain knowledge competency in knowing and understanding the requirements for appropriate end of life care in chronic respiratory disease. Trainees are assessed on this via mini clinical evaluation exercises and case-based discussions.

12. Cardiology⁷⁴

On page 47, under the sub-heading *Infection Control* End of life care, Cardiology is listed as an element of training/learning.

On page 65, *End of life care in Cardiology*, Cardiology trainees are expected to attain and become competent in managing end of life care since many cardiac conditions e.g. heart failure, adult congenital heart disease and valvular heart disease enter an end of life phase. The focus on care should change from therapies designed to alter the natural history of the disease to those aimed at symptom control. Trainees are expected to demonstrate competence in the areas of knowledge, skills and behaviours and are assessed on these areas via an exam case-based discussions, and multi-source feedback.

On page 141, *Module 9: Training in Catheter Ablation for Ventricular Tachycardia (VT)*, trainees are expected to deal sensitively with end of life decisions in patients with Ventricular Tachycardia. Trainees are assessed on this via multi-source feedback and patient surveys.

⁷² See Medical Oncology curriculum statement online at: www.gmc-uk.org/education/medical_oncology.asp

⁷³ See Respiratory Medicine curriculum statement online at: www.gmc-uk.org/education/respiratory_medicine.asp

⁷⁴ See Cardiology curriculum statement online at: www.gmc-uk.org/education/cardiology.asp

13. Guidance – Prolonged disorders of consciousness – national clinical guidelines

Guidelines were also produced by the Royal College of Physicians in December 2013 and contain guidance (i.e. not just a simple checklist) around end of life care decisions for people who have a prolonged disorder of consciousness. It has the endorsement of the Association of Palliative Medicine.⁷⁵

Glossary of terms for Section B

ACCS – Acute Care Common Stem (core training option)

ACP – Advanced care planning

AIM – Acute internal medicine

BBT – Broad based training (core training option)

CbDs – Case-based discussions

CCT – Certificate of completion of training

CMT – Core Medical Training (core training option)

Final FFICM MCQ – Final Fellow of the Faculty of Intensive Care Medicine Multiple Choice Question examination

GIM – General (internal) medicine

GP – General practice/General practitioner

ICM – Intensive care medicine

Mini-CEX – Mini clinical evaluation exercise

MSF – Multi-source feedback

PS – Patient surveys

RCP – Royal College of Physicians

SCE – Specialty certificate examination

⁷⁵ See Royal College of Physicians website at:
www.rcplondon.ac.uk/sites/default/files/prolonged_disorders_of_consciousness_national_clinical_guidelines_0.pdf

Section C

Some additional training programmes and resources for end of life care

(Note: this is provided as examples only. It is not an exhaustive list. Much more education and training takes place locally and regionally.)

e-ELCA – e-learning for end of life care

e-ELCA is a library of e-learning sessions designed to enhance the training and education of all those involved in delivering end of life care to individuals who have been diagnosed with life limiting illnesses and are usually within the last 12 months of their life. It was developed to support the implementation of the 2008 End of Life Care Strategy.

It has a number of sessions that are on the Public Access website www.endoflifecareforall.com which are suitable for social care workers, administrative and clerical staff as well as volunteers and members of the public who may have an interest.

RCN resources

The RCN published, jointly with the RCGP, an End of Life Care Patient Charter.

The RCN also has a suite of documents entitled *Routes to Success*; a general overarching document, one aimed at acute hospitals and another aimed at care homes. These highlight the importance of decision-making, teamwork, communication, care planning and more.

Gold Standards Framework

The Gold Standards Framework (GSF) run quality improvement training programmes and validate accreditation in many settings, leading to the GSF Quality Hallmark Award. Training is delivered through workshops, distance learning, the GSF Virtual Learning Zone or from the GSF Regional Centres, with intrinsic evaluations assessing progress against national standards. GSF meets all national standards including, but not exclusively set by, the National Institute for Clinical Excellence, the Departments of Health, the Royal College of General Practitioners. The GSF has undertaken work on the commissioning of end of life care.

The GSF adopt a modular approach aimed at identifying the right patients, assessing their clinical and personal needs and planning coordinated care in line with their preferences. There are four modules: 1. Identify, 2. Assess, 3. Plan living Well, 4 Plan dying well. Each of the four modules has 3 outcomes which then turn into action plans. These also lead to accreditation in the case of care homes, primary care, community hospitals and in future acute hospitals, measured against key standards. The GSF summarise the standards as the five rights – right person, right care, right place, right time, every time.

Macmillan Cancer Support

Key resources developed by Macmillan include:

Foundations in Palliative Care: This is a facilitated learning programme, mainly designed for care-home staff, but applicable for other settings too. The main areas are:

- First Principles
- Communication
- Pain and Symptom Management
- Bereavement Care

Each module can be delivered separately if necessary, or as a complete programme. The programme supports participants to develop their skills in the workplace as they progress through each module.

Out of hours palliative care: <http://learnzone.org.uk/courses/course.php?id=35>:

For professionals involved in the delivery and coordination of out-of-hours (OOH) care. This modular course is based on the education section of a wider Macmillan Out-of-Hours Toolkit, which is currently under review. Users can dip in and out of the course topics according to relevance and personal preference. With particular relevance to End of Life Care, there are modules in the course including "Diagnosing dying", "End of life care", "The Liverpool Care Pathway" (written with the LCP in mind at that time, but still outlining important basic principles of End of Life Care), "Commonly used drugs in the Syringe Driver", "Palliative Care Emergencies", "Drug access in palliative care", and "Death verification".

Out of hours toolkit: <http://learnzone.org.uk/courses/course.php?id=64>:

Guidance and tools for sharing good practice in out-of-hours (OOH) care for cancer and palliative care patients. Within each chapter are sessions. Chapter 3 Session 1 covers "Symptom control and the end of life". Chapter 3 Session 2 covers "Session 2: Practical aspects of care at the end of life".

BMJ e-learning modules: Macmillan GPs have supported the development of e-learning modules for palliative care in the community and also palliative care during the out of hours period. The modules are targeted at GPs, GP trainees and hospital doctors. Links can be found here: http://learning.bmj.com/learning/module-intro/palliative-care-out-of-hours.html?moduleId=10025220&locale=en_GB (Palliative care during the out of hours period). http://learning.bmj.com/learning/module-intro/palliative-care-community.html?moduleId=5004331&searchTerm=%E2%80%9Cpalliative%20care%20in%20the%20community%E2%80%9D&page=1&locale=en_GB (Palliative care in the community).

Dying Matters: Macmillan is working in partnership with the National Council for Palliative Care to develop and deliver 'Dying Matters' communication skills training for GPs, as well as to train a number of GPs as facilitators so that they can deliver the course locally to other GPs. The training will increase the confidence and skills of GPs to initiate end of life conversations.

NHS Improving Quality

NHS IQ now holds a range of resources that were housed on the former National End of Life Care Programme website or that were links to other resources. Currently these are located under Domain 2 Long Term Conditions on the NHS IQ website. NHSIQ are particularly interested in identifying the practise of supported supervision and action learning models.

Resources:

1. EOLC core competences and updated docs:
www.endoflifecare.nhs.uk/education-training/core-competences.aspx
www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/developing-end-of-life-care-practice.aspx
2. Skills for care EoLC knowledge sets: www.skillsforcare.org.uk/endoflifecare/
3. Communications Skills training pages/reports: www.endoflifecare.nhs.uk/education-training/communication-skills.aspx
4. Training needs analysis tool programme website:
 - www.endoflifecare.nhs.uk/education-training/finding-the-right-direction-training.aspx
 - www.endoflifecare.nhs.uk/search-resources/resources-search/publications/end-of-life-care-facilitator-competency-framework-form.aspx
 - www.endoflifecare.nhs.uk/education-training/learning-resources-on-this-website.aspx
 - www.mylearningspace.me.uk/moodle/
 - www.endoflifecare.nhs.uk/education-and-training/learningresources2www.endoflifecare.nhs.uk/education-training/communication-skills/tnaquestionnaires.aspx
 - www.endoflifecare.nhs.uk/education-training/advance-care-planning.aspx
5. E-ELCA: www.endoflifecare.nhs.uk/education-training/e-elca.aspx
6. Skills for care care homes projects and training as shared by Anne Bagshaw www.skillsforcare.org.uk/areas/endoflifeinyh/eolyh_introduction.aspx
7. SaGE and Thyme training programme: www.endoflifecare.nhs.uk/search-resources/resources-search/case-studies/sage-thyme-foundation-level-workshop-communication-training-scheme.aspx
8. Finding the words: www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/finding-the-words.aspx
9. Routes to Success six steps care homes: www.endoflifecare.nhs.uk/assets/downloads/RtS_Care_Homes___Final__20100804.pdf
10. GSF framework training programmes: www.goldstandardsframework.org.uk/introduction-to-gsf-training-programmes
11. Connected communication skills training: www.royalmarsden.nhs.uk/education/school/courses/pages/connected.aspx

12. NCPC GP training Finding the 1 % resources:
 - www.ncpc.org.uk/event/gp-training-workshop-initiating-conversations-end-life-care-issues-0
 - <http://dyingmatters.org/gp>
 - http://dyingmatters.org/gp_page/dvd
 - http://dyingmatters.org/gp_page/signup
13. Macmillan Learn Zone <http://learnzone.org.uk/>
14. Macmillan Foundations in Palliative Care <http://be.macmillan.org.uk/be/s-206-learning-resources-and-courses.aspx>
15. NEoLCP Routes to success series:
www.endoflifecare.nhs.uk/search-resources/route-to-success-resources.aspx
16. Advance care planning it all adds up:
www.endoflifecare.nhs.uk/search-resources/resources-search/publications/acp-guide.aspx
17. Transform How to Guide:
www.nhs.uk/8203.aspx:- www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/transforming-end-of-life-care-in-acute-hospitals.aspx
18. QELCA training programme: www.stchristophers.org.uk/research/quality-end-of-life-care-for-all-qelca
19. www.endoflifecare.nhs.uk/education-training/learning-resources-other-websites.aspx
20. <http://dyingmatters.org/news/97>
 - Oxford learning Pathways-www.endoflifecare.nhs.uk/education-training/e-elca/oxford-learning-pathways.aspx
 - CLIP: www.endoflifecare.nhs.uk/education-training/learning-resources-other-websites.aspx
 - www.helpthehospices.org.uk/clip/intro.htm
 - www.skillsforhealth.org.uk/component/docman/doc_view/1273-end-of-life-pathways-final.html
 - www.helpthehospices.org.uk/our-services/international/resources/developing-services/education-and-training/
 - www.scie.org.uk/adults/endoflifecare/ideasforpractice/trainingforcaeworkers.asp

The following may also be a useful reference for GP end of life care training resources and is about to be circulated via the Dying Matters Finding the 1% campaign site which aims to support GPs in delivering high quality end of life care: <http://dyingmatters.org/gp>

Annex I:

Spiritual Care Assessment Tool Based on FICA approach

Spiritual Care Assessment Tool

The following assessment tool is included as an example of one approach to assessment of spiritual care needs.

FICA – originally devised by Dr. Christina Pulchalski MD

Suggested Questions.

These should be adapted to suit each person and revisited as patient circumstances change.

- | | |
|-----------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Faith | What things do you believe in that give meaning /value to your life?
and/or: Do you consider yourself spiritual or religious?
and/or: What is your faith or belief? |
| Importance
& | In what ways are they important to your life?
and/or: What influence do they have on how you take care of yourself? |
| Influence | and/or: How are your beliefs/values influencing your behaviour during your illness?
and/or: In what ways do your beliefs/values help you in regaining your health/wellbeing? |
| Community | Is there a person or group of people who you love or who are very important to you?
and/or: How is this supportive to you?
and/or: Do you belong to a religious/cultural community? |
| Address | Is there anything we can do to help you while you are with us?
and/or: Would it help to talk to someone about these issues? |

An example of a Spiritual Assessment in a non-religious person

- F** Naturalist.
- I** Feels at one with nature. Each morning she sits on her patio looking out over the trees in the woods and feels 'centred and with purpose'.
- C** Close friends who share her values.
- A** After the discussion about belief, she will try to meditate, focusing on nature, on a daily basis to increase her peacefulness.

You can refer to the Chaplaincy Department at any time, but some specific situations may include:

- When one's own belief system prohibits involvement in the spiritual/religious/cultural care of the patient.
- When spiritual or religious/cultural issues seem particularly significant in the patient's suffering.
- When spiritual or religious/cultural beliefs or values seem to be particularly helpful or supportive for the patient.
- When spiritual or religious/cultural beliefs or values seem to be particularly unhelpful for the patient.
- When addressing the spiritual or religious/cultural needs of a patient exceeds your comfort level.
- When specific community spiritual or religious/cultural resources are needed.
- When you suspect spiritual or religious/cultural issues which the patient denies.
- When the patient or family have specific religious needs e.g. Confession, Holy Communion, Sacrament of the Sick, needs a prayer mat or private space to pray, sacred texts etc.
- When the patient's family seem to be experiencing spiritual/emotional pain or trauma.
- When members of staff seem to be in need of support.

Reference: Pulchalski C (1999) *Innovations in End-of-Life Care* November-December, Vol 1, No. 6. www2.edc.org/lastsacts/archives/archivesNov99/assesstool.asp

Annex J:

Report of rapid review on guidance on end of life care commissioned by the Leadership Alliance for the Care of Dying People

Report for Leadership Alliance for the Care of Dying People

Rapid Review

Vicki Morrey, October 2013

Contents

1. Introduction
2. Methods
3. Results
 - 3.1 Professional guidance and clinical practice
 - 3.2 Training and development resources
4. Discussion
5. Summary

1. Introduction

The recent independent review into the Liverpool Care Pathway (LCP) made a number of recommendations relating to key areas, including guidance, decision-making and training. A key recommendation was that the LCP should be phased out and that there should be a move away from the use of a 'pathway' of care in favour of developing individual 'care plans'.

The Leadership Alliance for the Care of Dying People, established in response to the findings of the Independent Review of the Liverpool Care pathway (LCP), commissioned a Rapid Review to provide an indication of the landscape of existing guidance and tools relating to the provision of end of life care. This Review focused on material relating to Professional Guidance and Clinical Practice. In particular, the Independent Review of the LCP identified the following key areas as requiring specific guidance and evidence based tools:

- care;
- prognosis and communicating prognosis;
- decision-making; and
- hydration and nutrition.

The Rapid Review focused on these aspects.

2. Method

Scope and Process

This exercise was restricted to material published from 2008 to date and primarily relating to the care of adults. There is some reference to children and young people where it was considered to be useful learning. The selection of 2008 as a cut-off date was guided by the publication date for England's first end of life care strategy. It also focused on guidance published within the UK. In addition, the websites of the World Health Organisation and the International Association of Hospice and Palliative Care were included. As a snapshot exercise, collating guidance from individual countries around the world was out of scope. This Review was carried out in October 2013.

Resources used and Search Strategies

This Review has been supported by the Help the Hospices Information Manager who undertook an extensive literature and database search. This was organised to include the scrutiny of eight literature databases, seven websites and all Royal Colleges. Key words included: "end of life", "terminal", "guidelines or guidance", "last days or last hours", "pathway or care pathway" Restrictions and filters applied. Where given, links were followed to articles citing original work. A significant amount of relevant material resulted from the Search Strategy and is reviewed under the agreed specified topic headings.

Literature databases

1. NHS Evidence. Search: ("end of life" OR terminal* OR "last hours" OR "last days") [Filters applied - Guideline = n752, Care pathways = n26, before date restrictions applied]
2. PubMed. Search: ("Guideline" [Publication Type] OR "Critical Pathway" [Mesh] OR guidance[tw] OR guide*[tw]) AND ("Terminal Care"[Mesh] OR "end of life"[tw] OR "last days"[tw] OR "last hours"[tw]) English language only.
3. CINAHL. Search: See appendix A
4. Embase. Search: See appendix A
5. The Knowledge Network. Search: ("last days" OR "last hours" OR "end of life" OR terminal*) Filter: Evidence & guidance = n279
6. WHOLIS (World Health Organization library catalogue)
7. RCGP Library. Search: care pathways[su] OR "end of life"
8. RCPL Library. Search: "end of life" OR pathway

Websites

1. National End of Life Care Programme website; publications search [Filter applied - care pathway: last days of life]
2. ehospice. Search: guidance OR guidelines
3. Healthcare Improvement Scotland. Publications search – Filter on "clinical topic" : palliative care
4. International Journal of Care Pathways. Search: "end of life" OR "last days of life" OR "last hours of life"
5. National Clinical Guidelines Centre
6. National Council for Palliative Care – online library. "Hand search".
7. Scottish Intercollegiate Guidelines Network

Royal Colleges websites

1. College of Emergency Medicine. (Sections checked: College guidelines; Clinical guidelines; Clinical Standards)
2. Royal College of Anaesthetists (Sections checked: Publications; Clinical standards, safety & quality)
3. Royal College of General Practitioners. (Sections checked: Clinical resources)
4. Royal College of Nursing See Page 46 of LCP Review
5. Royal College of Obstetrics & Gynaecology (Section checked: Guidance/ Search: end of life)
6. Royal College of Paediatrics and Child Health
7. Royal College of Pathologists (Search: end of life)

8. Royal College of Physicians of Edinburgh (Sections checked: Publications; Policy; Standards)
9. Royal College of Physicians of London. (Section checked: Resources – clinical guidelines)
10. Royal College of Physicians and Surgeons of Glasgow. Search: end of life
11. Royal College of Psychiatrists. Search: “end of life”
12. Royal College of Radiologists. (Section searched: Clinical oncology: publications & guidance; Clinical radiology: Standards)
13. Royal College of Surgeons of England. (Sections searched: Clinical standards & policies)

Colleges not checked: Royal College of Ophthalmologists

Where given, links were followed to articles citing the original work. All links checked October 2013.

3. Results

3.1 Professional guidance and clinical practice

The results of the search are organised into the categories of Professional Guidance and Clinical Practice. The agreed themes of care, communicating prognosis, decision-making and hydration and nutrition are used to organise the findings and are collated together in Tables 1 & 2, which align the themes with the relevant publications.

Professional Guidance

The specification indicated that professional guidance should include reference to:

- communication and shared decision-making between professionals and patients/families and between different professional;
- communication of information to support coordination of care, including facilitating accurate handover;
- Mental Capacity Act with respect to care in the last days of life; and
- guides and alerts that reflect common principles of good palliative care.

It is assumed that professional guidance may be acquired via two principle routes:

That which is produced by specific professional bodies

That which is produced generically and applied to professional practice

The findings refer to both sources and are grouped under each of the above categories.

Guidance produced by professional bodies:

- The General Medical Council *Treatment and care towards the end of life: good practice in decision making 2010*
- The Royal College of General Practitioners and Royal College of Nursing *Matters of life and death: helping people to live well until they die: general practice guidance for implementing the RCGP/RCN End of Life Care Patient Charter 2012*
- College of Emergency Medicine *End of life care for adults in the emergency department 2012*

Guidance to support professional practice:

- Gold Standards Framework (GSF)
- AMBER care bundle
- NCPC Publications on Mental Capacity Act
- National End of Life Care Programme publication, *Capacity, care planning and advance care planning in life limiting illness*
- National End of Life Care Programme Co-ordination and Implementation Guidance

Table 1 Guidance on professional practice

Topic	Guidance
<ul style="list-style-type: none"> Communication and shared decision-making between professionals and patients/families and between different professionals. 	<p>The General Medical Council's <i>Treatment and care towards the end of life: good practice in decision making 2010</i></p> <p>The Royal College of General Practitioners and Royal College of Nursing's <i>Matters of life and death: helping people to live well until they die: general practice guidance for implementing the RCGPIRCN End of Life Care Patient Charter 2012</i></p> <p>College of Emergency Medicine End of life care for adults in the emergency department 2012</p>
<ul style="list-style-type: none"> Communication of information to support coordination of care, including facilitating accurate handover. 	<p>AMBER care bundle</p> <p>Gold Standards Framework (GSF)</p> <p>College of Emergency Medicine <i>End of life care for adults in the emergency department 2012</i></p>
<ul style="list-style-type: none"> Mental Capacity Act with respect to care in the last days of life. 	<p>National End of Life Care Programme publication Capacity, care planning and advance care planning in life limiting illness</p> <p>National End of Life Care Programme Co-ordination and Implementation Guidance</p> <p>NCPC Publications on Mental Capacity Act</p>
<ul style="list-style-type: none"> Guides and alerts that reflect common principles of good palliative care 	<p>The General Medical Council <i>Treatment and care towards the end of life: good practice in decision making, 2010</i></p> <p>Gold Standards Framework (GSF)</p>

Clinical Practice

The specification indicated that guidance for clinical practice should include reference to:

- diagnosing dying, including prognostication for last days of life, managing uncertain recovery, withdrawal of active treatment, etc;
- managing issues relating to hydration and nutrition;
- technical guidance specific to disease groups can be
- personalised care in last days of life.

Existing guidance relating to these topics are set out in Table 2. In addition, there are NICE Pathways (e.g. dementia) and a NICE Quality Standard for End of Life Care.

Table 2 Guidance relating to specific aspects of clinical practice

Topic	Guidance
<ul style="list-style-type: none"> • Diagnosing dying, including prognostication for last days of life, managing uncertain recovery, withdrawal of active treatment, etc. 	GSF – includes prognostic indicator College of Emergency Medicine. <i>End of life care for adults in the emergency department</i> (Best Practice Guidance 2012) EAPC recommended framework for sedation in palliative care
<ul style="list-style-type: none"> • Managing issues relating to hydration and nutrition 	Royal College of Physicians and British Society of Gastroenterology <i>Oral feeding difficulties and dilemmas: a guide to practical care, particularly towards the end of life</i> 2010 NCPC & APM <i>Artificial Nutrition and Hydration: Guidance in end of life care for adults</i> (pre 2008 but useful in context of Mental Capacity Act)
<ul style="list-style-type: none"> • Technical guidance specific to disease groups 	Diabetes UK <i>End of life diabetes care: clinical care recommendations</i> 2012 NHS Improvement <i>End of life care in heart failure: a framework for implementation</i> 2010 British Heart Foundation, Marie Curie Cancer Care, NHS Greater Glasgow and Clyde <i>Caring Together</i> NCPC <i>Improving end of life care in neurological conditions: a framework for implementation</i> 2010

	<p>NCPC <i>Parkinson's and the last days of life: consensus statement on the management of symptoms for people with Parkinson's and related conditions in the last days of life 2011</i></p> <p>NCPC, National End of Life Care Programme, Neurological Alliance: <i>End of life care in long term neurological conditions: A framework for implementation 2011</i></p> <p>National End of Life Care Programme <i>End of life care in advanced kidney disease: a framework for implementation 2009</i></p> <p>NCPC <i>Out of the shadows: End of life care for people with dementia 2009 (references the Pan Birmingham Palliative Care Network's Supportive Care Pathway)</i></p>
<ul style="list-style-type: none"> Personalised care in last days of life 	<p>GSF – includes prognostic indicator</p> <p>AMBER Care Bundle</p>

Additional UK Resources

It is recognised that a key concern reflected in the LCP Review is that of both quality and equity of care in all end of life care settings. The use of a single tool under a blanket approach to implementation has resulted in problems of misunderstanding and misapplication. A number of other resources to support the adoption of good practice across all settings have been produced and made available for health and social care professionals.

These are reflected in the work of the National End of Life Care programme, developments in other UK countries, children and young people's sector and Care Homes. These have all made a useful contribution to the development of helpful resources to improve end of life care in a given setting. Details of these resources and approaches are indicated below.

(i) Route to Success Series

The national End of Life Care Programme has been pro-active in both developing and promoting a variety of helpful guides and resources. Key among them is their Route to Success series detailed below.

The aim of The Route to Success series is to provide health and social care staff with simple guides to support the implementation of the End of Life Care Pathway. The series covers the topics detailed below:

By setting:

- Acute hospitals
- Acute hospitals 'how to' guide
- Care homes
- Prisons
- Ambulance
- Environment of care

By professional group:

- Occupational therapy
- Social workers
- Nursing Domiciliary care

By individual group:

- Homeless people
- Lesbian, gay bisexual and transgender people
- People with learning disabilities

Several publications in this series have been evaluated and a range of support sheets have also been produced to accompany the series

(ii) Resources in Scotland

The Dignity Care Pathway developed by the University of Dundee with Community nurses in Tayside. While recognising the difficulty with the term 'pathway' this tool appears to be significantly different in approach. It is based on the Chochinov theoretical model of dignity care. It has four sections: a manual, a Patient Dignity Inventory, reflective questions, and care actions. Used by community nurses it was reported to have helped them identify when patients were at the end of life, identified patients' key concerns, and aided nurses in providing holistic end-of-life care.

(iii) Resources in Wales

Wales did not adopt the LCP and introduced its own approach to end of life care. The latest version of this is *The All Wales Integrated Care Priorities*. The approach aims to improve care for dying patients in Wales by promoting the delivery of best practice care, facilitated by a care priorities approach.

Care is agreed and delivered using a three step approach as detailed below:

- *Step One:* Is it agreed by the family/carers and the professional team caring for the patient that the patient is dying, all reversible causes have been excluded and death is now imminent?

The professionals involved in this decision-making process should be a senior nurse and a General Practitioner or a Medical Consultant. Do not proceed to Step Two if there are any doubts expressed by the family/ carers or by the professionals giving care regarding the diagnoses of any reversible causes.

- *Step Two:* What are the priorities at this time for the patient and their family/carers?
- *Step Three:* What can the doctors and nurses caring for the patient do to make the patient comfortable, alleviate any pain or distress and allay any fears and concerns of the family/carers?

As ever, each professional has a personal responsibility to be vigilant to the patients changing condition, diligently review the situation and respond appropriately to address need. When caring for the dying, this extends to being particularly sensitive and accommodating to the needs of the close family and carers.

This model is well established in Wales and patients in Wales do not appear to have been affected by the issues relating to the LCP in England.

(iv) Babies, Children and Young Adults

Together for Short Lives has produced comprehensive guidance in the publication *A Guide to end of life care of children and young people before death, at the time of death and after death 2012*.

British Association of Perinatal Medicine *Palliative care (supportive and end of life care): a framework for clinical practice in perinatal medicine 2010*

ACT *A care pathway to support extubation within a children's palliative care framework 2011*

Together for Short Lives *A core care pathway for children with life limiting and life threatening illnesses 2013*

(v) Care Home Support

Some guidance and education tools have been developed specifically for use in care homes. The national End of Life Care Programme publication *Route To Success in End of Life Care* for the care home setting led to the successful development of the 6 Steps Programme. This was originally developed in the North West as a programme of learning for care homes. It has since been widely adopted and amended for use in other settings. It contains the core principles of approaches to end of life care and aims to build confidence and skills among health and social care professionals.

NCPC produced the *Care to Learn Pack* a similar structured approach to end of life care in Care Homes.

3.2 Training and Development Resources

Resources and Search Strategy

In order to ensure all relevant material was captured, the search scope was extended to include training and development resources. This search revealed that guidance on end of life care is produced in a variety of mediums and captured under various headings. Some useful products and programmes containing helpful approaches to end of life care practice emerged under the category of Education.

The National End of Life Care Programme's website provided the majority of information with further support of the Help the Hospices Information Manager. The search revealed an extensive amount of material from an impressive array of source providers and is detailed below.

Search Results

Advance Decisions to Refuse Treatment Training Programme - The ADRT Training Programme produces training and guidance for health and social care.

Lessons Learned - Lessons Learned is an interactive e-learning programme from Macmillan Cancer Support designed to address the experience of patients and their carers when facing end of life issues. You will need to register to use the site, but there is no charge.

'be.macmillan' learning resources and courses – These are a selection of learning programmes to improve knowledge of all aspects of palliative care. Including a CD explaining how to manage breathlessness in patients.

Current Learning in Palliative Care (CLIP) - A collection of 15 minute, online tutorials, developed by Help the Hospices from *Helping the Patient with Advanced Disease: a Workbook*, Regnard C, ed. Radcliffe Medical Press 2004.

With Respect training materials from the Dignity in Care Network website
Hosted by the Dignity in Care Network, two collections of dignity-specific training resources designed for health and social care staff providing care for a) residents of care homes, or b) for people living in their own homes.

Evaluation Toolkit - An evidence-based framework for assessing the outcomes of end of life care learning event and changes in confidence and competence.

Common Core Competences for End of Life Care (DH 2009) covers all four competence areas and the overarching values and knowledge. The toolkit is available on the East Midlands Cancer Network website.

NHS Local - end of life - A collection of resources related to end of life care, including videos submitted by members of the public listing 5 things they want to do before they die. www.nhslocal.nhs.uk/page/end-life

New end of life care education and training strategy - South East London Cancer Network and Marie Curie Cancer Care have developed a comprehensive end of life care education and training strategy.

Skills for Care - Working in consultation with carers', employers and service users, Skills for Care aims to modernise adult social care in England by ensuring qualifications and standards continually adapt to meet the changing needs of people who use care services.

Social Care Institute for Excellence (SCIE) - SCIE improves the lives of people who use care services by sharing knowledge about what works. Their website includes a growing number of end of life care learning resources.

Skills for Health - Skills for Health is the UK's health sector skills council. It helps the whole sector develop solutions to deliver a skilled and flexible workforce in order to improve health and health care.

The Center to Advance Palliative Care (CAPC) website - US resource offering palliative care tools, training and technical assistance.

Communication Skills Training Materials

Connected - Connected is the national communication skills programme for the NHS.

Living and Dying with COPD - An educational package including short film clips of professionals about Advance Decisions to Refuse Treatment.

Mental Capacity Act E-Learning Site - These short narrated presentations introduce practitioners to the Mental Capacity Act and explain its impact on palliative care.

Mental Capacity Act training materials - The Department of Health, in partnership with the Welsh Assembly Government and the Social Care Institute for Excellence, published five sets of training materials to support the implementation of the Mental Capacity Act 2005. These include the Mental Capacity Act Core Training Set, which provides in-depth information and guidance on what the MCA means to people working in health and social care. This was developed by the University of Central Lancashire and the Social Care Workforce Research Unit at King's College, London.

Other education and training resources

Self Care resources on www.selfmanagement.co.uk - A library of self-care resources, from Department of Health guidance papers to online toolkits to help patients directly or those caring for people living with long term health conditions.

Walk a mile in my shoes - scrutiny of dignity and respect for individuals in health and social care services: a guide - Designed to assist Overview and Scrutiny Committees to raise awareness and understanding of dignity and respect for individuals who are receiving health and social care services. It is evident that there is a significant amount of material available in the form of training resources to provide good quality guidance on end of life care practice. Significantly, Specialist Palliative Care staff usually provide most of this level of training, especially that relating to communication skills. Additional results and a brief commentary on the resources identified is detailed below:

e-ELCA (End of Life Care for All)

Commissioned by the Department of Health and delivered by e-Learning for Healthcare in partnership with the Association for Palliative Medicine of Great Britain and Ireland, e-ELCA supports the implementation of the Department of Health's national End of Life Care Strategy. e-ELCA aims to enhance the education and training of everyone involved in delivering end of life care, so people at the end of their lives can receive well-informed, high quality care delivered by confident and competent staff and volunteers, across health and social care, wherever they happen to be. Over 150 interactive sessions of e-learning are available covering: Advance care planning Assessment Communications skills Symptom management, comfort and wellbeing Social care Bereavement Spirituality Integrating learning.

Common Core Competencies and Principles for Health and Social Care Workers working with Adults at the end of life

Published jointly between National End of Life Care Programme, Skills for Health, Skills for Care and the Department of Health. The principles and competences outlined in this document form a common foundation for everyone whose work includes care and support for people nearing and reaching the end of their lives, whether their primary

involvement is health or social care and support-related. The core competences and principles cover:

- communication skills;
- assessment;
- advance care planning; and
- symptom management, comfort and well-being.

Thinking and Planning Ahead: learning from each other.

Available from the National End of Life Care Programme

A volunteer training programme about Advance Care Planning designed to help people:

- understand what advance care planning is and how to do it; and
- assist others with advance care planning.

Sage and Thyme

Communication training tool. This model was developed by clinical staff at the University Hospital of South Manchester NHS Foundation Trust (UHSM) and a patient in 2006. It was designed to train all grades of staff how to listen and respond to patients/clients or carers who are distressed or concerned. It places published research evidence about effective communication skills within a memorable structure for clinical practice.

Lessons Learned

Lessons Learned is an interactive e-learning programme from Macmillan Cancer Support designed to address the experience of patients and their carers when facing end of life issues. It was developed with St Margaret's Hospice, Somerset, NHS Somerset and Yeovil District Hospital NHS Trust. Topics covered include:

- anticipatory care;
- partnership resolution to complaints – to lead to improved practice which can be replicated in other settings;
- the challenges of different clinical care settings;
- the importance of philosophy, attitude and environment;
- identify issues important to carers;
- the challenges of integration of services; and
- provides examples of good practice.

Current Learning in Palliative Care (CLIP)

A collection of 15 minute, online tutorials, developed by Help the Hospices from *Helping the Patient with Advanced Disease: a Workbook*, Regnard C, ed. Radcliffe Medical Press 2004. CLIP consists of worksheets for self-learning which can be applied to:

- individual learning;
- group learning (small and large);
- with tutor support;
- lecture theatre settings; and
- online.

Has a focus on the last days/hours and covers adjustments, managing distress and the time around the death.

National Dignity Council 'With Respect'

Hosted by the Dignity in Care Network, two collections of dignity-specific training resources designed for health and social care staff providing care for a) residents of care homes, or b) for people living in their own homes. This is helpful with relevant generic references, but not specific to end of life care.

Evaluation Toolkit - An evidence-based framework for assessing:

- the outcomes of end of life care learning
- changes in confidence and competence: The tool is linked to the Common Core Competencies for end of life (DH 2009), covers all four competence areas and the overarching values and knowledge. The toolkit was developed by the East Midlands Cancer Network and is now available on the National End of Life Care Intelligence Network e-learning hub – my learning space.

NHS Local - end of life

A collection of resources related to end of life care, including videos submitted by members of the public listing 5 things they want to do before they die.

New end of life care education and training strategy

South East London Cancer Network and Marie Curie Cancer Care have developed a comprehensive end of life care education and training strategy.

NHS East of England.

ABC end of life care programme. An online programme.

North East of England Regional Skills Development Group & Skills for Health.

End of life care: learning and development pathway.

Living and Dying with COPD

An educational package including short film clips of patients' and carers' stories and views on diagnosis and end of life dialogue and an 'expert panel' discussion on ways to approach these issues with tips on how to improve the consultation. Recommended for use by a facilitator as part of an educational package on communication skills, or COPD care.

Royal College of Physicians, National End of Life Care Programme, Association for Palliative Medicine of Great Britain and Ireland.

Improving end-of-life care: professional development for physicians: report of a working party. London: RCP, 2012.

NHS Education for Scotland.

Palliative care in practice: end of life care. [online]

Princess Alice Hospice, Esher

European certificate in essential palliative care. [online]

British Lung Foundation

Coping with the final stages of chronic lung disease

Advance Decisions to Refuse Treatment Training Programme

The ADRT Training Programme produces training and guidance for health and social care professionals about Advance Decisions to Refuse Treatment.

Mental Capacity Act E-Learning Site

These short narrated presentations introduce practitioners to the Mental Capacity Act and explain its impact on palliative care.

Mental Capacity Act training materials

The Department of Health, in partnership with the Welsh Assembly Government and the Social Care Institute for Excellence, published five sets of training materials to support the implementation of the Mental Capacity Act 2005.

These include the Mental Capacity Act Core Training Set, which provides in-depth information and guidance on what the MCA means to people working in health and social care. This was developed by the University of Central Lancashire and the Social Care Workforce Research Unit at King's College, London

In discussing the scope of this paper it was noted that it would be useful to include examples of good practice and how the learning from these could be utilised going forward. These are detailed below:

Examples of Good Practice

There are numerous examples of good practice driven by the National End of Life Care Strategy and arising from work undertaken by a number of organisations, including:

- cancer networks;
- workforce deaneries;
- care home organisations;
- PCT/CCG's;
- local consortia – e.g. hospice, hospital, community collaborations;
- clinical networks; and
- National End of Life Care Intelligence Network.

It is notable that the defining characteristics of the above include:

- a structured approach by a designated organisation, e.g. a cancer network, working to a specific brief to bring about positive improvement;
- the engagement of expert practitioners, such as hospices and specialist palliative care teams, in the production of protocols, guidance and practice aids;
- joint collaboration between providers; and
- a systematic approach to deliver on a locally agreed strategy for end of life care.

These areas of good practice provide useful learning and serve to demonstrate that the application of available guidance under the support of expert practitioners can be effective in achieving positive outcomes. It is apparent that the implementation of the LCP was not necessarily supported by expert practitioners in all cases or was part of

a systematic approach to changes in practice. The joint development of a local plan for end of life care and the subsequent supported implementation appear to be key elements to improved practice and outcomes.

4. Discussion

The searches undertaken have revealed there to be an extensive amount of available material for both guidance and training and development. With only one or two exceptions (namely end of life care guidance available from the Social Care Institute for Excellence, and NCPC and APM Artificial Nutrition and Hydration guidance) all material is recent and clearly has the End of Life Care Strategy as the point of reference. For ease the review will be discussed under the headings of credibility, accessibility and ease of application.

A. Guidance for Professionals and to support Clinical Practice

Credibility

Please note that for the purposes of this report the credibility of material is determined by the source references, design and content. No attempt has been made to evaluate each piece of work, published guidance or tools.

Professional guidance and guidance related to clinical practice have been produced by various professional bodies and cite established experts and authentic research. Where non-palliative care organisations have produced guidance there is acknowledgement of support from specialist organisations, for example NCPC and the National End of Life Care Programme and references to accepted published material such as the GMC's *Treatment and Care towards the end of life (2010)*.

Guidance has been produced for a number of diverse settings and contexts, including emergency medicine, gastroenterology, people with learning disabilities, neurological conditions, heart failure, respiratory disease, dementia and diabetes. On examination there is a high level of consistency in the approaches adopted in the guidance in terms of the principles of good management in end of life care. Specific guidance relating to nursing is produced as a combined document between the Royal College of General Practitioners and the Royal College of Nursing. It would be beneficial to strengthen nursing specific guidance.

Communication between professionals and with the family, assessment, co-ordination of care and symptom management are all apparent in the published guidance contained in tables 1 and 2.

It can be concluded that there is a considerable quantity of professional and clinical end of life care guidance available. It may also be concluded that it is consistent in content, reliably informed with credible points of reference.

Accessibility

For guidance to be relevant it needs to be readily accessible. As the guidance available has been produced by a variety of sources there are several points by which relevant guidance can be accessed. These include; direct distribution from specific professional bodies, National End of Life Care Programme, National Council for Palliative Care and Help the Hospices. Accessibility is likely to be variable at local level and heavily dependent on the quality of local NHS organisation or network communications and websites.

Non-NHS organisations such as care homes, care agencies, private hospitals and charities providing care services are largely reliant on promotion and marketing to raise awareness and signpost to sources of guidance and support.

The National End of Life Care Programme has been an important development in relation to increasing the accessibility of resources as it appears to have provided a central point of comprehensive information, including details and links to a broad range of resource material. In the absence of the National End of Life Care Programme consideration needs to be given to ensuring awareness of and access to available guidance in the future.

It may be concluded that resources should be widely promoted, readily available and easily accessible. There may be merit in establishing an 'official' register of credible resources.

Ease of application

It may be argued that ease of application of guidance materials to practice may be enhanced by consistency in style, language and presentation. There are wide variations in the style and presentation of the various resources on guidance. They range from comprehensive, detailed reference documents to more practical implementation frameworks. This may present some barriers to use in certain settings or lead to variations in interpretation within a given area. Some aspects of care have the benefit of specific individual guidance, including:

- Withdrawal of hydration and nutrition
- Communication
- Advance care planning
- Neurological conditions
- Advanced kidney disease
- Advanced heart failure
- Advance respiratory disease
- Diabetes
- Sedation
- Symptom management

Guidance in the form of a tool is available via practical frameworks for practice such as the Gold Standards Framework and the AMBER care bundle. Each individual guidance publication is independent and, as such, there are no common approaches of style and format. While there is consistency of content there is diversity in ease of reading and ready application to patient situations. In the absence of the LCP it would be worth rationalising the source documents in presentation and adaptability. Reliable guidance is certainly available but the challenge could be ensuring its ready transfer to patient care planning.

It can be concluded that while there is widespread consistency in the content of the various guidance documents, there is wide variation in style, presentation and format. This could pose challenges when applying the guidance to patient care planning.

Training and Development

The search revealed there is a considerable amount of training materials in circulation. In addition the search highlighted several areas of local practice developments and training packages. Many of these have been driven by the Cancer Networks' response to the End of Life Care Strategy.

There are numerous examples of collaboration between hospices, hospitals, community, and academic centres working together to develop models of good end of life care alongside the production of training modules. It is strongly evident that specialist palliative care practitioners see the education and development of professional colleagues as integral to their role. It is understood that alongside the delivery of formal training and development sessions many palliative care clinicians provide free informal training for their non-specialist colleagues on a regular basis.

Learning materials have been produced by the major organisations which have end of life care as their main focus. These include; Macmillan Cancer Support, Marie Curie Cancer Care, Help the Hospices and the National Council for Palliative Care. This supports the understanding that as a specialism, palliative care takes seriously the responsibility to equip professional colleagues with the knowledge and skills to provide appropriate end of life care. The European Certificate in Essential Palliative Care, developed by Princess Alice Hospice is an excellent example of a local centre of excellence developing a learning tool as a means of sharing the knowledge, skills and expertise which underpin their practice with a wider audience.

Communication skills training has received a high priority and emphasis. This is evident both from a statutory perspective with the national Connections communication programme and by its inclusion in most locally developed training programmes. Commissioning priorities and Peer Review have also fostered a strategic approach to end of life care education and training. It is worth noting that as there is a commercial value attached to training it is entirely possible that there are more training materials being used by generic trainers in health and social care than have been identified. It is clear that end of life care education and training materials are plentiful and many originate from credible and reliable sources. As such they can command a reassuring level of confidence.

There remains the issue of workforce development and access to training. Anecdotally it appears that there are predictable constraints on funding and release of staff to attend further education and development. This may be a significant factor in the future if an adequate understanding of end of life care issues will be required by clinicians in order to develop appropriate individual care plans.

The training and development of generalist practitioners is taken seriously by specialist palliative care professionals and considered an integral part of their role. There is a large amount of education and training material available. The major organisations with a focus on end of life care have all produced learning packages. Most end of life care education is delivered by SPC practitioners, often at no cost. Constraints on budgets appear to be affecting the ability for staff to access training and development activities.

5. Summary

The Leadership Alliance for the Care of Dying People is considering how to advise health and care staff about what needs to occur in place of the LCP. It is well documented that there remains high levels of dissatisfaction in many cases with people's experience of end of life care. This is not only related to experience of the LCP and it is important to gain a better understanding of the reasons for this before making further proposals and recommendations. The recommendations of the Independent Review include adopting an individual end of life care plan rather than following a set pathway. Such a move would rely on the existence of a sufficient standard of guidance and the availability of appropriate education and training. It is necessary to understand to what extent these already exist and whether they are adequate for the intended purpose. In relation to guidance the Rapid Review has:

- Provided evidence of the extent of provision of guidance for professionals and clinical practice
- Established the reliability of quality
- Established there are high levels of consistency among the guidance
- Established the credibility of the authors and points of reference

In relation to the availability of training and development the Rapid Review has:

- Provided evidence of the extent of provision
- Identified the major contribution by specialist palliative care practitioners in the development and delivery of education and training
- Identified the important contribution of charitable organisations in the provision of materials and training
- Confirmed the quality and reliability of training materials
- Raised an alert on the constraints impeding staff access to training and development

It is important to note that the scope of this paper does not allow for a detailed evaluation of the material identified. Reliance of quality and credibility is qualified by the reputation and credentials of the authors and publishers and the extent of its use and application.

It is important for the Leadership Alliance to better understand the balance between what already exists and how it is practically implemented. The important question to address is *"Is the gap a lack of available quality guidance or lack of application and poor practice?"*

The results of this snapshot review would suggest that there is good quality, accessible material readily available. Furthermore it is evident that there are expert practitioners supporting the education and learning of professional colleagues.

It was noted that, although consistent in content, the various guidance is presented in very different styles and format. This may prove to be problematic if the application

of guidance to individual care plans is to be recommended. It is suggested that there might be benefit, going forward in an agreed format making the content clearer and its application easier.

The previous National End of Life Care Programme was particularly valuable in providing a central contact point for all reliable, “accredited” information and resources.

This Review has established the existence of relevant guidance. It has also identified the varying forms and styles of presentation which may prove challenging if it is to have maximum impact on practice.

There is evidence of an extensive range of education and training materials. These are a combination of formal and informal modules and packages. Highly rated programmes of learning are attributed to leading charitable organisations with a focus on end of life care. Communication skills training features highly and several courses and modules of learning are available. It should be noted that formal academic programmes of learning such as undergraduate curricula, diplomas, degrees and postgraduate courses are not included but are addressed in a separate exercise.

The delivery of education on end of life care is heavily dependent on the contribution of specialist palliative care practitioners, often provided free of charge. There is a widespread shared understanding that formal and informal education of non-specialist colleagues is integral to the role of a specialist practitioner.

The challenge for the future lies in bringing together in an accessible format the wealth of high quality resources and tools, aligning them to any newly developed principles of practice and enabling their ease of application to individual care planning.

Appendix A: Additional Search Strategies

CINAHL

1. CINAHL; exp PRACTICE GUIDELINES/; 30703 results.
2. CINAHL; exp CRITICAL PATH/; 3079 results.
4. CINAHL; exp HOSPICES/ OR exp HOSPICE AND PALLIATIVE NURSING/ OR exp HOSPICE CARE/; 9781 results.
5. CINAHL; exp PALLIATIVE CARE/ OR exp TERMINAL CARE/; 33954 results.
6. CINAHL; exp TERMINALLY ILL PATIENTS/; 7049 results.
7. CINAHL; "last hours" .ti,ab; 44 results.
8. CINAHL; "last days" .ti,ab; 165 results.
9. CINAHL; "end of life" .ti,ab; 8308 results.
10. CINAHL; terminal* .ti,ab; 8221 results.
14. CINAHL; exp PROFESSIONAL PRACTICE, EVIDENCE-BASED/ [Limit to: Publication Year 2008-2013 and (Language English)]; 18405 results.
15. CINAHL; pathway.ti,ab [Limit to: Publication Year 2008-2013 and (Language English)]; 5592 results.
16. CINAHL; guidance.ti,ab [Limit to: Publication Year 2008-2013 and (Language English)]; 6041 results.
17. CINAHL; guideline* .ti,ab [Limit to: Publication Year 2008-2013 and (Language English)]; 18764 results.
18. CINAHL; palliative.ti,ab [Limit to: Publication Year 2008-2013 and (Language English)]; 6512 results.
19. CINAHL; 1 OR 2 OR 14 OR 15 OR 16 OR 17 [Limit to: Publication Year 2008-2013 and (Language English)]; 54575 results.
20. CINAHL; 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 18 [Limit to: Publication Year 2008-2013 and (Language English)]; 19015 results.
21. CINAHL; 19 AND 20 [Limit to: Publication Year 2008-2013 and (Language English)]; 1490 results.

Embase

1. EMBASE; exp TERMINAL CARE/; 45189 results.
10. EMBASE; exp CLINICAL PATHWAY/ [Limit to: Publication Year 2008-2013]; 2052 results.
12. EMBASE; exp PRACTICE GUIDELINE/ [Limit to: Publication Year 2008-2013]; 118753 results.
13. EMBASE; 10 OR 12 [Limit to: Publication Year 2008-2013]; 118753 results.
14. EMBASE; 1 AND 13 [Limit to: Publication Year 2008-2013]; 837 results.
15. EMBASE; 14 [Limit to: Human and (Languages English) and Publication Year 2008-2013]; 682 results.

Annex K:

Terms of Reference and Membership of the LACDP Clinical Advisory Group

Terms of Reference

1. To consider the Independent Review of the Liverpool Care Pathway recommendations within the theme of 'clinical practice' and how these should/ could influence practice; and advise the Leadership Alliance on taking these recommendations forward. In doing this, the Group will consider care in the last days of hours wherever that care takes place, including social care settings. As appropriate, the Group's advice will cover care for children in the last days and hours of life, as well as adults.
2. To oversee and facilitate a set of workshops to gather views and ideas from service users, clinicians and carers across the country about good practice in caring for somebody in the last days and hours of life, and how this can be achieved.
3. To draft appropriate advice on care in the last days and hours of life, for clinicians, managers and leaders, and information for the public if necessary. In the light of further consideration, the Group will advise the Leadership Alliance on the exact scope and nature of the advice it proposes to develop and secure the Alliance's agreement to the final specification for the work. In taking forward this work, the Group will consider care in the last days of hours wherever that care takes place, including social care settings. As appropriate, the Group's advice will cover care for children in the last days and hours of life, as well as adults.
4. To liaise closely with the Guidance, Education and Training Group (GETAG) on mutually relevant issues.

Membership List

Dr Bee Wee (Chair)	National Clinical Director, End of Life Care - NHS England
Candice Pellett	Senior Case Manager District Nurse; CPT, Queen's Nurse - Lincolnshire Community Health Services
Dr David Brooks	President - Association for Palliative Medicine of Great Britain and Ireland
Claire Henry (to March 2014)	NHSIQ
Carole Mula	Nurse Consultant - National Nurse Consultant Group (Palliative Care)
Irene Carey	Clinical Lead - AMBER care bundle work – decision-making in uncertain recovery

Sheilah Blackwell	Nurse Consultant - National Nurse Consultant Group (Palliative Care)
Ann Farenden	National Professional Advisor, Regulatory Development - CQC
Dr Matt Carey	Specialty trainee in general medicine - Health Education Thames Valley
Dr Martin Vernon	Clinical Director - University Hospital South Manchester NHS Foundation Trust, and British Geriatric Society
Jo Hockley	Nurse Consultant - St Christopher's Hospice
Susan Swientozielskyj	Head of Long Term Conditions Nursing Directorate – NHS England
Heather Richardson	Clinical Lead – Help the Hospices
Bill Noble	Medical Director – Marie Curie
Rosie Loftus	Joint Chief Medical Officer - Macmillan Cancer Support
Kevin Stewart	Head - National Care of the Dying in Hospitals Audit
Steve Barnard	Head of Clinical Governance - North West Ambulance Service NHS Trust
Sharon Blackburn	Sharon Blackburn RGN RMN, Policy & Communications Director - National Care Forum
Dr Leann Johnson	Clinical Fellow to Mike Durkin (Domain 5) in NHS England.
Tony Bonser	Lay representative
Anne McFarlane OBE	Lay representative
Natalie Laine	Lay representative
Helen Findlay	Lay representative
Elizabeth Lloyd-Dehler	Lay representative

Annex L:

Terms of Reference and Membership of the LACDP Guidance, Education and Training Advisory Group

Terms of Reference

The Guidance, Education and Training Advisory Group will provide advice to the Leadership Alliance for the Care of Dying People and its individual members particularly on actions that can be taken to improve education, training and advice in relation to the care of people in the last days and hours of life.

Membership List

Bee Wee (Chair)	NHS England
Sue Swientozielskyj	NHS England
Jacqueline Naylor	Department of Health
Sue Ambler	Health Education England
Peter Nightingale	RCGP/Marie Curie
Chris Bell	Nursing and Midwifery Council
Rob George	Association for Palliative Medicine
Katherine Hopkins	National Nurse Consultant Group (Palliative Care)
Mark Dexter	General Medical Council
Winnie Wade	Royal College of Physicians
Maaïke Vandeweghe	Care home sector
Anita Hayes	NHSIQ
Stephen Richards	Director of Professional Engagement, Macmillan Cancer Support

Vicki Morrey	Rapid review on existing guidance for end of life care commissioned by the Leadership Alliance
Penny McNamara	Sue Ryder
Kate Birrell	CQC
Damian Day	General Pharmaceutical Council
Gail Eva	University College Hospital
Keri Thomas	Coordinator for Primary Care & Acute Hospitals: Gold Standards Framework
Alistair Henderson CE	Academy of Royal Medical Colleges
Stephanie Aiken	Royal College of Nursing (RCN)
Chris Farnham	Chair of the APM Education Committee
Steve Barnard	North West Ambulance Service NHS Trust

