

ONE CHANCE TO GET IT RIGHT

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

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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.)