

# SUMMARY OF ENGAGEMENT ON PROPOSED OUTCOMES AND GUIDING PRINCIPLES FOR CARE IN THE LAST DAYS OF LIFE

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Leadership Alliance for the Care of Dying People

# Alliance members

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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.

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# Background

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1. The Leadership Alliance for the Care of Dying People was formed in July 2013. It comprised 21 national organisations, which came together following publication of a report by an independent review panel that considered the Liverpool Care Pathway (LCP) to provide the focus for a system-wide response to the report.<sup>1</sup>
2. The LCP was an approach to the care of dying people developed during the 1990s, based on practice in hospices. Its aim was to transfer best practice to other settings, including hospitals and social care. 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 a patient's best interests; psychological and spiritual care; and care of the family.
3. Following concerns about the use of the LCP, particularly from families, the Minister for Care and Support commissioned an independent review, which was established in January 2013, under the chairmanship of Baroness Julia Neuberger. The panel published its report in July 2013, making 44 recommendations. Most of these were for national organisations.
4. All the national organisations to which the panel made recommendations were members of the Leadership Alliance. The Alliance's purposes included developing and publishing a system-wide response to the review panel's recommendations.
5. One of the key recommendations from the panel was that the LCP should be phased out over the next 6-12 months. This recommendation was accepted by the Minister for Care and Support.<sup>2</sup>
6. Use of the LCP was not mandatory and not all organisations that cared for dying people used it. However its use was widespread and there was considerable concern that it needed to be replaced by something else. The range of guidance and materials supporting the LCP included: training for health and care staff; template documents; and arrangements for audit and evaluation about how the LCP had been used and its outcomes.
7. In developing its programme of action in response to the review panel's recommendations, the Leadership Alliance spent considerable time debating the pros and cons of developing either a single, recommended set of materials for supporting care for dying people, or a process for endorsing such products. However, one of the key issues with the LCP was the way in which some organisations came to regard it as an end in itself, rather than using it pro-actively to engage with the needs of individual patients and their families. The review panel found that in some cases the LCP had come to be regarded as a generic protocol for the care of dying people, which is not the right approach. In such cases, the LCP had engendered a "tick box approach".

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<sup>1</sup> See <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

<sup>2</sup> See <http://www.publications.parliament.uk/pa/cm201314/cmhansrd/cm130715/wmstext/130715m0001.htm#1307156000015>

8. In considering what, if anything, should replace the LCP, the Leadership Alliance was very concerned not to introduce anything that could be used in the way that, in some places, the LCP had been used. Hence it concluded that in future, care for dying people should always focus on achieving high-level outcomes for dying people and the people who were important to them. There should be a personalised approach, delivering these outcomes for each dying person and their family, in ways that met their individual needs and preferences.
9. In October 2013, the Alliance began a public engagement on its proposals for the outcomes that care for dying people should deliver, wherever that care took place. It also engaged on “guiding principles for professionals”, to support the delivery of those outcomes.<sup>3</sup>
10. The engagement was done:
  - on-line;
  - through 12 workshops for patients, families, carers and professionals, held during October and November 2013;
  - via two workshops for organisations concerned with the care of dying people, held on 14 November 2013;
  - through two workshops for families who had given evidence to the independent review panel, held (in London and Leeds respectively) on 28 and 29 January 2014; and
  - through 20 one-to-one interviews with people who had direct experience of care for dying people and who were from population groups sharing the “protected characteristics” defined in the Equalities Act, or groups affected by health inequalities.
11. 592 responses were received on-line and a further 49 people commented via e-mail. Of this total of 641:
  - 23 were identified as coming from people who were health and care professionals, but who were also responding in the light of their experience as patients, carers or members of the public;
  - 328 were from other health and care staff;
  - 160 were from patients, carers and members of the public who were not also health and care staff;
  - 110 came from organisations or groups; and
  - it was unclear in what capacity the other 20 respondents were replying.
12. 601 attendances were recorded at the workshops for patients, families, carers and professionals held during October and November 2013. Initially, half the places on each workshop were reserved for patients, families and carers and half for professionals. However, patients, families and carers did not come forward in sufficient numbers for any of these workshops to fill the places allocated to this

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<sup>3</sup> The main engagement document is at: <http://www.england.nhs.uk/wp-content/uploads/2013/12/lacd-p-engage.pdf>

group. Hence, close to each event, extra places were released to professionals who had been turned away initially, because all the places for this group had been allocated. The final numbers attending the 12 workshops were:

- 282 professionals;
- 169 people recorded as families or others (the "others" were a very small category including eg a chaplain, a retired chair of social services, Department of Health (DH) officials with "observer" status);
- 150 attendees at three workshops where details of participants' backgrounds were not recorded.

13. The workshops for families who had given evidence to the review panel were attended by 70 such people.

14. 25 organisations (other than members of the Leadership Alliance) were represented at the two workshops for organisations, including some providers of NHS services. These included national charities, representing the views of significant numbers of people with particular interests, such as dementia and bereavement.

15. In total, the engagement got views from:

- 633 professionals, of whom at least 23 were also responding as patients, carers or members of the public;
- 391 people recorded as families or others (virtually all of these attended as family members);
- 178 attendees at workshops in October and November 2013 whose background was not recorded (the majority) or who did not fall easily into the category of either "professional" or "family member"; and
- 135 organisations.

In total, the Alliance got responses or views from almost 1,340 individuals and organisations.

16. This document summarises the results of the engagement and sets out how the Alliance has responded to it. Following the engagement, **the ten proposed outcomes have been replaced by Five Priorities for Care of the Dying Person and the "guiding principle for professionals" by a document setting out the *Duties and Responsibilities of health and care staff* in relation to the Priorities.** The Alliance has also published a handy reference to the *Duties and responsibilities and Implementation guidance* for service providers and commissioners, to support clinical practice.

17. The results of the engagement are summarised in relation to each of the proposed outcomes on which the Alliance consulted. Within each section, this document describes the overall conclusions from the engagement, also referring to the conclusions from the different engagement activities that the Alliance undertook.

18. Those families who had given evidence to the independent review panel and who attended the specific workshops for this group held in January 2014, asked that the summary of the engagement draw out specifically the conclusions from those



workshops about the proposed outcomes and guiding principles. This is done at **Annex A**.

19. There were some attendees at those two workshops who did not take part in the engagement on the proposed outcomes and guiding principles. Instead, they wanted to raise wider issues about care given to dying people, particularly on the LCP, and how failings in that care could be addressed. The Alliance provided facilities for them to do so, in parallel with the two workshops on the outcomes and guiding principles. Those who took part in the parallel discussions asked that their points be separately recorded and published. This is done at **Annex B**.

## Overall findings from the engagement

### What people said

20. Generally, the outcomes and supporting guiding principles were welcomed, as well conceived, and covering the most important components for effective care for people in the last days and hours of life. There was particular acknowledgement of the emphasis on communicating effectively with someone who was dying and their family and on holistic care – both of which were widely supported. It was welcomed that the Leadership Alliance had tried to set out what should happen not just from professionals' point of view (in the guiding principles) but also from the point of view of the dying person and their family (in "What this means for people approaching the last days of life and their family" under each outcome).
21. Whilst the outcomes and guiding principles were generally welcomed, some people questioned if they could be achieved for all dying people and their families, particularly against the current background of resource constraints in the NHS. A significant number of respondents asked what would be done to enforce the outcomes. There were also calls, including significant support amongst palliative care professionals, for systems of audit and measurement, to assess the effectiveness of the outcomes and guiding principles once they were introduced.
22. Linked to questions about how the outcomes would be enforced, there was consistent feedback from the engagement that the outcomes and guiding principles ought to be about what "must" or "will" be done, not what "should" be done.
23. Generally, it was considered that ten outcomes were too many and that they needed to be simplified. There was a concern amongst members of the public that the outcomes and guiding principles were too "medicalised". At the same time, some health and care staff were concerned that the outcomes and guiding principles did not, as the LCP had done, give specific guidance on eg what drugs could be administered and in what dosages.
24. There was also concern that the outcomes and guiding principles were too vague – it needed to be clearer exactly what had to be done. A particular point was that it needed to be clearer what timeframe the outcomes applied to: the "last days and hours" of life was not specific enough.
25. A recurring theme from all the engagement activity was dissatisfaction on the part of some members of the public that the relatives of dying people did not have the right to take decisions about the treatment and care to be given to the person who

was dying. There was considerable dissatisfaction amongst this group about the operation of the Mental Capacity Act 2005, in particular, the provision for taking a decision in someone's best interests, if it is established that a person lacks capacity at the relevant time to make the relevant decision.

26. Some health and care staff recorded their concerns that the LCP, which had supported good care for dying people in many instances, was being phased out. A repeated theme was that the problems of poor care that had occurred under the LCP were problems about the way the LCP had been interpreted and used, rather than with the LCP itself. Many respondents called for improved education and training for health and care staff, rather than the replacement of the LCP. There was a call for an increase in resources for education and training to support the care of dying people, to demonstrate commitment to achieving consistent and improved care. It was also said that if other initiatives that supported end of life and palliative care were fully resourced, this would help resolve problems about the quality of care given to dying people.
27. There was confusion amongst some respondents about how the outcomes and guiding principles differed from the LCP. There was no correlation between respondents who were unclear on this issue and whether they wanted retention of the LCP. Generally, professionals who did not acknowledge a difference did not see the care they would deliver in line with the outcomes as being significantly different to the care that they were currently delivering, supported by the LCP. (The review panel found that in some circumstances, the LCP "works well".) Members of the public who did not acknowledge a difference were generally concerned that there was nothing in the outcomes and guiding principles about monitoring and enforcement, to ensure implementation.

### **How the Leadership Alliance has responded**

28. The Priorities for Care represent a different focus to that of the LCP. The LCP relied on an assessment that someone was dying (sometimes referred to as a "diagnosis of dying"), after which care focussed on assessing whether particular goals of care (eg the patient is not agitated, the person is not vomiting) were being achieved. Where they were not, the LCP set out specific actions that could be taken to achieve each of the goals. The Priorities for Care apply where there is the **possibility** that someone **might** die within the next few days and hours. There are no protocols for care. Under the Priorities, the goals of care, and care itself, should be individualised for each person, so that, for example, a person may prefer to be more alert despite having less pain relief than they could have, or being more comfortable even if this means being a bit more sleepy.
29. Publication of the Priorities for Care sets, for the first time in England, a clear baseline for what care for people in the last few days and hours of life should be like, against which care can be assessed. It creates an explicit, universal expectation across health and care about what care for dying people should be like.
30. NHS Improving Quality, which is a member of the Leadership Alliance, is developing materials to help NHS trusts, NHS foundation trusts and care organisations assess the quality of the care they are providing for dying people, by reference to the Priorities for Care.

31. The Leadership Alliance has published commitment statements, which describe how each of the 21 Alliance members will implement and take forward the Priorities for Care of the Dying Person. This accompanies a system-wide response to the findings of the review panel that considered the LCP. The system-wide response details specific actions Alliance members will take to implement the Priorities and in response to the specific recommendations made by the review panel. CQC will reflect the Priorities in its work on care in the last few days and hours of life, including relevant inspection work.
32. The Priorities for Care are, as far as possible, expressed in terms of what "must" be done. The guiding principles have been replaced by *Duties and responsibilities of health and care staff* to deliver the Priorities.
33. There are five Priorities for Care, compared to ten outcomes on which the engagement took place. The content and language of the headline Priorities is much simpler and clearer than that of the outcomes. The Leadership Alliance has published a "handy reference guide" to the Priorities, primarily, but not exclusively, for health and care staff, which includes a one to three word reminder of what each Priority is about. The Priorities for Care apply to the "last few days and hours" of life, making the timeframe clearer.
34. Following the feedback from the engagement, the Alliance identified that family members would find it helpful to have a short, clear exposition of what to expect when someone was dying, the kind of care they could and should expect, and where they could turn if they were concerned. The National Council for Palliative Care is leading work to produce a short guide on this, structured around the Five Priorities for Care and drawing heavily on the experiences of bereaved families.
35. The Mental Capacity Act Code of Practice makes clear that anyone who takes action or makes a decision in the best interests of someone who lacks capacity to make that decision must do whatever is possible to permit and encourage the person to take part in making the decision, try to find out the views of the person and, if it is practical and appropriate to do so, consult other people for their views about the person's best interests and to see if they have any information about the person's wishes and feelings, beliefs and values. The Code specifically refers to anyone engaged in caring for the person and close relatives, friends or others who take an interest in the person's welfare. A House of Lords Select Committee concluded recently that the Act has suffered from a lack of awareness and a lack of understanding and that implementation is "patchy". The Committee recommended the setting up of an independent oversight body to tackle poor implementation of the Mental Capacity Act.<sup>4</sup> The Government is considering this recommendation.
36. The duties and responsibilities of health and care staff that support the Priorities for Care make clear that any actions taken or decisions made on behalf of someone who lacks capacity, in their best interests, must consider what is known about their preferences, and wherever possible should involve the person in making the decision. The Alliance's recommendations on desired characteristics of education and training programmes for care in the last days of life include that by the end of the training programme, learners should be able to demonstrate understanding of how the Mental Capacity Act should be applied when the dying person lacks capacity.

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<sup>4</sup> See <http://www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm>

**Proposed Outcome A: People who have a progressive, life-limiting illness have been offered the opportunity to develop, document, review and update a personalised palliative care plan at different stages in their illness or condition.**

**What people said**

37. There was substantial agreement to this proposed outcome. Over 80 per cent of the online responses agreed the proposed outcome and almost 80 per cent agreed the proposed supporting principles. There were similar levels of agreement at the workshops held in 2013 and a strong support for a personal care plan amongst those at the two 2014 workshops who chose to take part in detailed discussion about the proposed outcomes and guiding principles. Of the 20 one-to-one interviewees, 19 said they would like a personal care plan for themselves. A particular feature of the proposed outcome that respondents welcomed was that it would lead to greater emphasis on the wishes and preferences of patients. There were some calls for Personal Palliative Care Plans to have statutory force.
38. Where there was any disagreement with the proposed outcome, the most common reason was that it appeared to be too general or vague. There was also concern that the proposals for both the outcome and supporting guiding principles would be affected by potential resource constraints. There was confusion about the timescale for personal care plans – whether they related just to the last few days and hours of life; from the point at which someone was diagnosed with a terminal illness or condition; or whether plans should be made whilst someone had no reason to think that they would die within the next few years or months. There was considerable comment and, in the workshops, debate, about what personal care plans should be called. There was significant consensus that the word “palliative” should not be included, as the plans should cover all aspects of care for dying people, not just palliative care.
39. There were extensive comments on the detail of the proposed guiding principles. Many of these related to the practicality of particular aspects, sometimes linked to resource constraints and/ or the circumstances in which someone might be dying. A particular area of concern was proposed guiding principle A2 ie: “People should be encouraged to identify individuals whom they would like professionals to involve in decision-making about their care if they themselves are unable to fully participate in such decisions. However there are legal limits of decision-making by other people on behalf of the dying person.” A particular criticism, including from members of the public, was that this did not seem to be wholly consistent with the provision in the Mental Capacity Act 2005: a common comment was that a relative, friend or other nominee of a dying person could only make decisions on behalf of that person if they held a relevant Lasting Power of Attorney for health matters. People who gave evidence to the independent review panel, attended one of the 2014 workshops and took part in discussions about the proposed outcomes and guiding principles expressed general concerns about the current provision for Lasting Power

of Attorney, noting that it could take time to obtain and that its cost is beyond the reach of some people. Some participants in these workshops were distressed when it was explained that in the absence of a relevant Lasting Power of Attorney, the current legal framework provides that if it is established that someone lacks the capacity to make relevant decisions about their treatment and care for themselves, clinicians take a “best interests” decision on behalf of that person. (The Mental Capacity Act Code of Practice does make clear that anyone who takes action or makes a decision in the best interests of someone who lacks capacity to make that decision must do whatever is possible to permit and encourage the person to take part in making the decision, try to find out the views of the person and, if it is practical and appropriate to do so, consult other people for their views about the person’s best interests and to see if they have any information about the person’s wishes and feelings, beliefs and values. The Code specifically refers to anyone engaged in caring for the person and close relatives, friends or others who take an interest in the person’s welfare. However, the experience of some of those at the January workshops was that this did not always happen in practice.)

40. These groups of people were also concerned about the statement in the explanatory text supporting outcome A and the associated guiding principles that: “A specific treatment can be legally refused (at the time, or in advance by you) but specific treatments cannot be demanded”. Those at the 2014 workshops who took part in the discussions about the outcomes and guiding principles were concerned in particular that there appeared not to be provision for patients and their families to “demand” foods and fluids when someone was in the last few days and hours of life. This concern was shared by some of the interviewees.
41. The consultation invited respondents to comment on: who should have a personal care plan; barriers to creating a plan; when planning for the last days and hours of life should start; who should write or co-ordinate the plan; when and how the plan should be implemented; what should be included in the plan; and what name should be given to plans. There were extensive comments on all these issues.

### **How the Leadership Alliance has responded**

42. The Priorities for Care include: “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”.
43. The context of the Priorities (which is when it is recognised that someone might die in the next few days or hours) makes the timescale for this plan of care clear. The duties and responsibilities of health and care staff, which support the Priorities for Care, include: “Ideally, this planning should have started earlier in the illness and the plan updated as the situation changes.”
44. The Priorities for Care have to operate within the legal framework of the day, which currently includes the Mental Capacity Act 2005 and associated Code, as well as the provision for Lasting Powers of Attorney. Where relevant, the Priorities for Care and the duties and responsibilities of health and care staff set out this provision and what it means in terms of how decisions about the care and treatment of someone in the last few days and hours of life are taken.

45. The duties and responsibilities of health and care staff clarifies the position on decisions about eating and drinking. It says:

“The dying person must be supported to eat and drink as long as they wish to do and there is no serious risk of harm (for example through choking). However if there is likely to be a delay in assessing their ability to swallow safely, alternative forms of hydration must be considered and discussed with the person. Nursing and medical records on the assessment of intake must be kept.

“If the dying person makes an informed choice to eat or drink, even if they are deemed to be at risk of aspiration, this must be respected.”

46. In the light of the engagement, the Leadership Alliance has concluded that it is not currently feasible to prescribe aspects of personal care plans for those in the last few days and hours of life, such as what should be included, other than at a very high level, or who should write it. The engagement was very helpful in reinforcing that the circumstances in which people die are very different and no one model is going to be appropriate in every case.

**Proposed outcome B: People, including those thought to be in their last days of life, whose condition changes, are identified in a timely way, receive good care that is re-assessed at least daily (or more frequently as their condition requires), receive timely, appropriate medication and have their emotional, psychological, social and spiritual needs addressed.**

### **What people said**

47. There was substantial agreement to this proposed outcome. Around 85 per cent of the online responses agreed the proposed outcome and over 70 per cent agreed the proposed supporting principles. There were similar levels of agreement at the workshops held in 2013. However whilst those at the 2014 workshops who chose to take part in detailed discussion about the proposed outcomes and guiding principles, supported the intention of the outcome, they were concerned that there was insufficient detail in the guiding principles to provide reassurance that care in the last few days and hours of life would be of the highest quality. This concern was shared by some on-line respondents, who commented that some of the wording was too vague.
48. Some of those who commented on-line were concerned that outcome B referred to “people... thought to be in their last days of life...” Clinicians were concerned about the difficulties of “diagnosing” someone as being likely to die and about the problems that had arisen in some places as a result of the Liverpool Care Pathway being based on a diagnosis that someone was dying. Patients and carers were concerned that an assessment that someone was “thought to be in their last days

of life” could result in life-saving or life-preserving treatment being withdrawn, noting that in some cases people who are expected to die recover.

49. There were also significant concerns amongst those at the 2014 workshops who chose to take part in discussion about the outcomes and guiding principles, and from some interviewees, about specific provision in the guiding principles supporting outcome B.
50. A major concern was guiding principle B2 ie: “In hospital, people who have been identified as likely to die within the next few days, must be assessed by appropriately trained doctors at least daily, monitored by appropriately trained registered nurses regularly (at least four hourly)...” Comments included that four hours was too long for someone to be in pain. On-line respondents, those at the 2013 workshops and interviewees expressed similar concerns. Some respondents queried why guiding principle B2 provided for four-hourly checks in hospitals, whilst guiding principle B3 said: “At home, people who have been identified as likely to die within the next few days, must be assessed by an appropriately trained doctor or nurse at least daily...”, with guiding principle B4 making similar provision for people thought to be dying in care homes and other institutions. There were questions from some staff with experience of caring for people in care homes about ensuring sufficient staffing for the delivery of the guiding principles supporting outcome B in those settings.
51. Another area of significant concern across all the workshops, the interviewees and the on-line responses, was that the guiding principles might allow clinicians to refuse to give food and water to dying people and to withdraw the provision of intravenous fluids. The text that led to these concerns was explanatory text for dying people and their families that included: “If you are able to swallow safely and wish to eat or drink, you should be encouraged and helped to do so. In the last few hours of days of life, dying people often do not have a desire to drink but just need to wet their mouths to prevent dryness. A decision to give fluids through drips and tubes needs to be weighed up at the time by the doctors and nurses looking after you. They will be informed by your own preferences in making decisions...”
52. There was significant support for guiding principle B7 on the anticipatory prescribing of medicines; and B8 on medications being targeted at specific symptoms, used in the smallest dose that works, for the shortest time necessary and their use regularly reviewed and adjusted as necessary. In commenting on principle B5, a number of respondents suggested that across the outcomes as a whole, spiritual care should receive greater attention and that spiritual care should not be conflated with religious care.
53. Some clinicians raised questions about the delivery of outcome B and the associated guiding principles in hospitals. A number of respondents suggested dedicated facilities for those thought to be in the last few days and hours of life.

## How the Leadership Alliance has responded

54. The first Priority for Care of the Dying Person reads: "The possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly". The Priorities for Care apply where there is the "possibility" that someone might die in the next few days and hours: the approach is not based on a "diagnosis" or assessment that someone will die or is "likely" to die. The supporting text for this Priority refers explicitly to the possibility of someone's condition being potentially reversible. The approach described in the Priorities and the duties and responsibilities of health and social care staff is such that it is appropriate even if in the event, someone does not die in the next few days and hours of life.
55. This Priority, the other Priorities and the duties and responsibilities of health and care staff describe explicitly the elements of good care for people in the last few days and hours of life.
56. Provision on the frequency of assessment of someone's symptoms and what should be done to ensure the comfort of someone who might be dying is included in the fifth Priority for Care. The duties of health and care staff provide: "The frequency of review and how the person's comfort is monitored...must be individualised and agreed with the person and, if it is established that the person lacks capacity to make decisions about these matters, the decisions made must be in the person's best interests. Health and care staff must ensure that important assessments of a patient's condition, capacity to decide, or treatment and care needs (eg swallowing) are conducted openly ...". The duties and responsibilities of health and care staff also provide that medications must be regularly reviewed and adjusted as needed for effect.
57. The duties and responsibilities of health and care staff clarify the position on decisions about eating and drinking. They include:
- "The dying person must be supported to eat and drink as long as they wish to do so and there is no serious risk of harm (for example through choking). However if there is likely to be a delay in assessing their ability to swallow safely, alternative forms of hydration must be considered and discussed with the person. Nursing and medical records on the assessment of intake must be kept.
- "If the dying person makes an informed choice to eat or drink, even if they are deemed to be at risk of aspiration, this must be respected.
- "If the dying person is unable to swallow, decisions about clinically assisted hydration and nutrition must be in line with the General Medical Council 2010 guidance *Treatment and Care towards the End of Life* and relevant clinical guidelines."
58. The Priorities for Care make provision for anticipatory prescribing for medicines and similar provision on the use of medications to that in the proposed guiding principle B8. The Priorities for Care as a whole include more references to spiritual care and the duties and responsibilities of health and care staff make clear that this is not the same as religious care.



**Proposed outcome C: Regular, pro-active and responsive communication takes place between professionals and the person who is approaching the last days of their life and their family and carer. The content and outcomes of these discussions are clearly documented and shared with others involved in this person's care.**

**What people said**

59. There was substantial agreement to this proposed outcome. Almost 90 per cent of the online responses agreed the proposed outcome and almost 80 per cent agreed the proposed supporting principles. There were similar levels of agreement at the workshops held in 2013 and amongst those at the two 2014 workshops who chose to take part in discussion about the proposed outcomes and guiding principles and the interviewees.
60. Many of the comments related to how decisions about the treatment and care of dying people are taken, referring to the operation of the Mental Capacity Act 2005 and arrangements for Lasting Powers of Attorney for health (see paragraph 39).
61. A recurring theme was that communication needed to be two-way, with health and care staff listening to the concerns and views of the dying person and their family.
62. Those at the 2014 workshops who chose to discuss the outcomes and guiding principles and interviewees raised:
- The need for dying people and their families to be aware how they could get a second opinion if they disagreed with a clinician's judgement about the treatment or care they should receive.
  - The need for advocacy for those dying people who were unable to take decisions for themselves or communicate them.
  - The need for some dying people to have particular support to communicate eg a British Sign Language interpreter; and the need for alternative provision to using family members as interpreters in situations where someone was dying.

**How the Leadership Alliance has responded**

63. The second Priority for Care is: "Sensitive communication takes place between staff and the dying person, and those identified as important to them." The expanded explanation of this Priority includes: "Staff must check the other person's understanding of the information that is being communicated, and document this." It also includes: "[Communication] must be two-way, ie staff must listen to the views of the person and those important to them, not simply provide information."
64. The Alliance also concluded, particularly in the light of responses on this proposed outcome and proposed outcome A, that there was a need for the "first line" elements of any description of what constitutes good care for dying people to refer explicitly to the need to involve dying people and those people who are important to them, in decisions about the person's treatment and care, where that is possible

and appropriate. Hence, the third Priority for Care is: “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”.

65. The issue of second opinions is picked up under the third Priority. The duties and responsibilities of health and care staff that support this priority include: “If there is a continuing difference of opinion about the treatment or care of a dying person, or if additional reassurance about a decision would be helpful, health and care staff must consider obtaining a second opinion and getting support to facilitate communication to reach a consensus, for example from a social worker, advocacy worker or a chaplain or faith community leader...If significant disagreement remains, staff must seek advice on applying to the court for an independent ruling and inform the dying person (and those important to them) as early as possible.”
66. The Code of Practice on the Mental Capacity Act<sup>5</sup> makes clear that all practical and appropriate efforts to help someone communicate must be made as part of any assessment of someone’s capacity to make a relevant decision.
67. The arrangements for advocacy for people who are unable to make (including communicating) their own decisions about their treatment and care are governed by the provision in the Mental Health Act 2005 and for Lasting Powers of Attorney for health. The Priorities for Care set out what can be done within these arrangements, but it would be inappropriate for them to make provision for the use of advocates other than in the circumstances where this is currently provided for in law.

**Proposed outcome D: There are arrangements in place, with which the individual is in agreement, to share key information about his/her care, treatment and preferences between professionals, service providers and others relevant to the person’s care.**

### **What people said**

68. This outcome was generally welcomed by all groups of respondents. Ninety per cent of online respondents agreed with it and almost 80 per cent agreed with the guiding principles supporting it. There was similar support at the 2013 workshops. The outcome was also supported by those who attended the 2014 workshops and chose to take part in the discussions about the outcomes and guiding principles and by the interviewees, all of whom were happy that information could be shared with other professionals, but on the basis that the dying person would be aware that this was happening.
69. Generally, respondents thought collaboration between services, as well as personal knowledge of the dying person and their wishes, were crucial to delivering good care within and across care settings. Information-sharing was seen as key to informed decision-making. A significant number of respondents were of the view that existing practice on sharing information between professionals and services was not good enough. Particular issues included sharing information about care preferences, not just treatment. The use of shared folders/ diaries was widely supported respondents, especially in hospitals.

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<sup>5</sup> See [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/224660/Mental\\_Capacity\\_Act\\_code\\_of\\_practice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/224660/Mental_Capacity_Act_code_of_practice.pdf)

## How the Leadership Alliance has responded

70. As part of simplifying what were the outcomes and are now the Priorities for Care, the Leadership Alliance has incorporated the issue of information sharing between professionals and services into the second Priority for Care (“Sensitive communication takes place between staff and the dying person, and those identified as important to them”) and the fifth Priority (“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 duties and responsibilities of health and care staff include: “The way in which information about the person’s needs, wishes and views can be shared between the dying person, those identified as important to them and staff, must be discussed with the person, so that the method used is in accordance with individual preferences. For example, shared information folders or diaries may be a helpful way of enhancing communication for some. Those who have visual impairment may prefer to use other means for conveying their wishes eg using a CD or DVD.” They also include: “Adequate care planning information about the dying person must be available to ensure safe and appropriate clinical decisions are made about care and treatment, taking into account the individual’s prior wishes, in the event that the dying person is unable to participate in the decision at the time. If a dying person has to move between care settings, a clear emergency plan must be made and communicated so that action appropriate to the person’s needs and preferences can be taken if their condition changes unexpectedly.” The duties and responsibilities also set out what should happen if there is inadequate time to determine the person’s wishes about or suitability for attempts at cardiopulmonary resuscitation.

**Proposed outcome E: Local governance arrangements are explicit about the role of ‘senior responsible clinicians’, delegation arrangements when the person’s usual GP or consultant is not on duty, information sharing arrangements to enable timely decision-making, and how people who are approaching their last days of life, and their families, know who are their ‘senior responsible clinician’ and nurse responsible for leading their nursing care.**

### What people said

71. Generally, there was support for this outcome. Eighty five per cent of online respondents agreed with it; 75 per cent agreed with the supporting guiding principles. There was similar support at the 2013 workshops and amongst those who attended the 2014 workshops and chose to discuss the outcomes and guiding principles. However, there was significant disagreement with the detail of the proposed arrangements for ‘senior responsible clinician’, confusion about the role of the lead nurse and disquiet about guiding principle E4. This provided: “The person’s ‘senior responsible clinician’ and any doctor who deputises for him/her... has a duty to consult specialists in palliative care when the patient’s complex needs

warrant it.” Members of the public were concerned that this implied that not all health and care staff caring for people in the last days and hours of life had had appropriate training; professionals were concerned that not all specialist palliative care services were currently organised or resourced to provide this level of support.

72. On the detail of the proposed arrangements, proposed guiding principle B2 was: “In hospitals and hospices, the senior responsible clinician is the person’s named medical consultant during their rostered hours. Outside of that period, this responsibility is taken on by the senior responsible clinician for that clinical area/ward, as designated by local clinical governance and rostering arrangements... At home or in care homes, the person’s registered GP is the senior responsible clinician during surgery hours. Outside of that period, this is delegated to the GP’s deputising service...” Some on-line respondents raised potential concerns about access to senior clinicians or medical consultants in some hospices at some times, suggesting that the most senior member of staff on duty should be responsible for the care of dying patients at these times. Many on-line respondents raised concerns about the need for education and training to equip GPs to act as ‘senior responsible clinicians’. There was concern, shared by some of those who attended the 2013 and 2014 workshops and from interviewees, about GPs from deputising services acting as ‘senior responsible clinicians’. Concerns included access to such services and that they would not know the patient well. It was suggested that when a person’s registered GP was not available, it might be more effective for an appropriately trained senior nurse to act as the ‘senior responsible clinician’.
73. Proposed guiding principle E5 was: “The dying person and his/ her family and carers should know who is the registered nurse responsible for leading the care of that individual at any one time. This nurse is responsible for communicating effectively with the family, checking their understanding and ensuring that any emerging concerns are addressed.” Some respondents commented that communication was not only the responsibility of a named nurse: all professionals who were involved in the care of a dying person were responsible for communicating effectively with the family. Respondents also commented that the guiding principles themselves (as opposed to explanatory text) should set out how families’ concerns were being addressed should be documented. Some of those at the 2014 workshops who chose to discuss the outcomes and guiding principles noted that the lead nurse would not always be available and that in some instances, families might prefer to talk to someone other than the lead nurse, for example if they were more familiar with another nurse.
74. There were concerns, particularly by interviewees and those at the 2014 workshops who chose to discuss the outcomes and guiding principles, about explanatory text for outcome E which said: “If you are concerned that the decision being made is not right, you may request a second opinion from another senior or more specialist doctor”. Concerns were about the speed with which a second opinion could be obtained. It was suggested that a timeframe for this should be set out.

## How the Leadership Alliance has responded

75. The Leadership Alliance concluded that the complexities around setting out who was a dying person's 'senior responsible clinician' and work being done elsewhere on 'named clinician'<sup>6</sup> and 'named GP'<sup>7</sup> meant that it should not seek to introduce and define a new term of 'senior responsible clinician'. Instead, the duties and responsibilities of health and care staff provide: "Clinical teams must give the dying person, their families and those important to them the name of the Senior Doctor in the team who has overall responsibility for providing appropriate treatment and care for the dying person, and explain how that responsibility is handed over in times of absence or change in care arrangements or settings. This must be clearly documented and accessible to all those involved in the person's care."
76. The duties and responsibilities of health and care staff also include: "The name of the nurse responsible for leading the care of the dying person must also be given to the person and those important to them with an explanation of how this responsibility is handed over. This must be clearly documented and accessible to all those involved in the person's care." The Priorities for Care and the duties and responsibilities of health and care staff make clear that all those caring for a dying person have responsibilities to communicate effectively with the person and those who are important to them and that the content and outcomes of all discussions must be documented and accessible to all those involved in the person's care. This must include recording any particular concerns that the person and/or family carers have expressed.
77. On access to specialist care services, the implementation guidance for commissioners and service providers that supports the Priorities for Care includes that service providers and commissioners should: "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.
78. The Alliance has considered setting timeframes for obtaining second opinions, but concluded that the variation around the length of time which would be reasonable is so varied that any guidance on this would either be over complex (because it set out all possible circumstances and a range of timescales) or meaningless (because in order to cover all circumstances, it would have to set a long timescale, whereas shorter ones would be appropriate in most cases).

<sup>6</sup> See <http://www.aomrc.org.uk/general-news/responsible-doctor-and-nurse-name-over-the-bed-seminar.html>

<sup>7</sup> See <https://www.gov.uk/government/publications/plans-to-improve-primary-care>

## **Proposed outcome F: People who are approaching their last days of life, and their families and carers, receive the benefit of specialist palliative care advice and support in a timely manner.**

### **What people said**

79. This outcome received general support, with over 80 per cent of online respondents agreeing with it and over 70 per cent agreeing with the guiding principles supporting it. However whilst supporting the idea that specialist palliative care services should be available, many respondents (both clinicians and members of the public) suggested that it may not always be possible or necessary to seek advice from specialist palliative care services. It might, for example, not be possible in emergency situations; and it might not be necessary because those caring for the dying person had all the skills and knowledge needed to provide good care. It was suggested that if all those who were dying needed the support of specialist palliative care services, there was a general need to improve the skills and knowledge of those providing care for people in the last days and hours of life. However, some interviewees and some of those at the 2014 workshops who chose to discuss the outcomes and guiding principles raised concerns around specialist palliative care services not being available and that they might be available only on the phone. Explanatory text supporting outcome F which caused particular concern read: "At the very least, those professionals who are looking after you, who might not be specialists in palliative care themselves, should be able to seek telephone advice from specialists on your behalf." Other respondents commented that there was a general lack of understanding about the role of specialist palliative care teams and in particular, of the fact that their role was more about pain management and comfort than healing.
80. There were concerns about whether specialist palliative care services were sufficiently well resourced to provide the level of cover needed to ensure that advice was available in all those cases where it would be helpful.

### **How the Leadership Alliance has responded**

81. On further consideration, the Leadership Alliance has concluded that proposed outcome F was misplaced. In many cases when someone is dying, there will be no need for support from specialist palliative care services. Those caring for dying people need to have relevant skills and knowledge and Alliance members are taking action to address specific issues that have been identified on this. Staff caring for dying people also need access to relevant information and advice, including from specialist palliative care services where that is needed. For the most part, the latter can be given over the telephone, but there may be occasions where someone from the specialist palliative care team needs to carry out a face to face assessment. Typically, this will need to happen soon, but not urgently. The Alliance is also very conscious of current resource constraints, which mean that it may take time in some areas to move to face to face assessment being available 24/7.

82. Hence, the Alliance has not included access to specialist palliative care as a Priority for the Care of the Dying Person. However:

- the explanatory text for the fifth Care Priority includes: “there must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this”;
- the duties and responsibilities of health and care staff include: “clinical teams must refer to specialist palliative care for advice or assessment when the person’s needs (or the needs of those important to them) are beyond their competency to provide for, or when initial measures have failed to provide adequate relief within at most 24 hours;” and
- the implementation guidance for commissioners and service providers that supports the Priorities for Care includes that service providers and commissioners should: “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.”

**Proposed outcome G: Families and carers feel supported, including knowing how to seek urgent help when this is needed for the dying person, whatever the time of day or night and having their own needs addressed or signposted to sources of help and support.**

#### **What people said**

83. This outcome received widespread support. Ninety per cent of online respondents agreed with it and 80 per cent agreed with the supporting guiding principles. These levels of support were reflected in the 2013 workshops and amongst those who attended the 2014 workshops and opted to discuss the outcomes and guiding principles, and the interviewees. Respondents stressed how important it was for good care for someone who was dying, that the needs of family members, friends and others were met. There were many practical suggestions about what this might mean eg where/ how telephone numbers should be stored; which professionals might need to be available to meet the needs of the family and friends of the dying person. There was strong support for particular guiding principles eg G4: “Family and carers should be welcomed and enabled to spend with the dying person, whatever time they and the dying person wishes”.

### **How the Leadership Alliance has responded**

84. The fourth Priority for Care is: “The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible”. The duties and responsibilities of health and care staff reflect detailed points made by respondents. For example, guiding principle G4 is carried forward, reference is made to the need, where someone is being cared for in a hospital or other institution, to show families and those important to the dying person where the toilets are located, how they make drinks and facilities for them to take a rest.

**Proposed outcome H: People who are approaching the last days of life, and their families and carers, experience ambulance transfer that is timely and takes place in a way that prioritises the person’s comfort and preferences and that staff conducting transfer know what to do if the situation changes unexpectedly.**

### **What people said**

85. There was support for this outcome, with almost 90 per cent of online respondents agreeing with it and almost 80 per cent agreeing with the guiding principles to support it. This support was reflected in the 2013 workshops and amongst interviewees and those who attended the 2014 workshops and chose to discuss the outcomes and guiding principles. The main concerns were about how this outcome would be achieved, with considerable discussion around “Do Not Attempt Cardio-Pulmonary Resuscitation” (DNACPR) orders. Some respondents stressed the needs for patients’ wishes about the place in which they died to be respected and hence for ambulance staff to have clear, up-to-date information about those wishes. Guiding principle H1 supporting included: “...there must be a clear and effective emergency plan in place so that ambulance staff know what action needs to be taken, that is appropriate to the person’s needs and preferences, if that person’s condition changes unexpectedly.” There was considerable discussion about what should be included in such plans.

### **How the Leadership Alliance has responded**

86. In the light of the overwhelming response that there needed to be fewer outcomes, the Leadership Alliance has incorporated requirements about ambulance transfers into the duties and responsibilities of health and care staff, under various Priorities for Care. References include: that it may not be necessary to transfer a dying person from their home or care home; the need for emergency plans where a dying person has to move between care settings; and what should happen where there is inadequate time to determine the person’s wishes about and suitability for cardio-pulmonary resuscitation and there is DNACPR documentation from another setting. The outcomes from engagement on this outcome have fed into collective work by ambulance services to support improvements in the consistency of service given to dying people.



## **Proposed outcome I: People approaching the last days of life and their families and carers experience care after death that is respectful to the deceased person, supportive of the family and carers and considerate of others who knew the person well.**

### **What people said**

87. There was strong support for this outcome, with almost 90 per cent of online respondents agreeing with it and almost 80 per cent agreeing with the supporting guiding principles. This support was reflected in the 2013 workshops and amongst interviewees and those who attended the 2014 workshops and chose to discuss the outcomes and guiding principles. However, there was concern about the way in which this outcome was worded and presented, in that people approaching the end of their lives do not experience "care after death". There were detailed suggestions about what needed to happen to make this outcome a reality, including: rapid verification that someone had died; better management by some professionals where someone who was expected to die dies at home, without a medical person present; and resources being available so health and care staff could attend to the immediate needs of families and carers and for bereavement counselling.

### **How the Leadership Alliance has responded**

88. In the light of the overwhelming response that there needed to be fewer outcomes and concerns that the wording of this outcome was insensitive, the Leadership Alliance has incorporated requirements about care after death into the duties and responsibilities of health and care staff, under various Priorities for Care. References include: that as soon as possible after someone's death and depending on the family's wishes, a health care professional should offer to attend the person to ensure their body is appropriately cared for and the immediate practical and emotional needs of those present and those important to the person who has died are attended to; and that when someone has died, the wellbeing of the bereaved family and carers must be considered and their immediate needs supported.

## **Proposed outcome J: Professionals are competent in the specific requirements for excellent care in the last days of life, and these skills are embedded within a high standard of professionalism.**

### **What people said**

89. There was strong support for this outcome, with 90 per cent of online respondents agreeing with it. However, significantly fewer people - just over 70 per cent - agreed with the supporting guiding principles. Widespread support for the outcome was reflected in the 2013 workshops and amongst interviewees and those who attended the 2014 workshops and chose to discuss the outcomes and guiding principles. It was suggested by a significant number of respondents that the issues of professionalism and competence were necessary underpinning to the delivery of good care for dying people and hence that this outcome should be listed first.

90. Many of the comments received on this outcome were to the effect that the training given to some health and care staff who are involved in caring for people in the last days and hours of life was insufficient; and that there was a real need to remedy this. There were repeated calls for training to support care for dying people being made mandatory for all those who provide such care.
91. It was acknowledged that providing care for dying people and their families was difficult for health and care staff and some calls for additional psychological support for staff involved in this. Some respondents noted that in many cases, training and development was needed both to build both staff's skills and their confidence in caring for dying people.
92. Another key theme was the need to define the competences required by different groups of staff involved in providing care for dying people, particularly those who are not palliative care specialists. There was universal agreement that "compassion" should be a requirement from any person (including eg porters, cleaners) who had contact with a dying person and their family. In discussions about competences needed for good care for dying people, good communications skills, including listening skills, were cited repeatedly.

### **How the Leadership Alliance has responded**

93. In response to wider comments, the Leadership Alliance has described the Priorities for Care of the Dying Person in terms of what should happen for the dying person and their family, rather than on what needs to happen to achieve this. The latter is set out in the *Duties and Responsibilities of health and care staff* and in *Implementation guidance for service providers and commissioners*. The *Duties and responsibilities of health and care staff* set out, in the introduction, that staff need appropriate education and guidance to enable them to deliver their duties and responsibilities and that employers and the health and care system must support such education and training. The *Implementation guidance* sets out what service providers and commissioners - who are responsible for ensuring staff have the skills needed for their roles and receive appropriate ongoing training and development - should do to ensure education, training and support for staff delivering care to dying people. The *Implementation guidance* also recommends learning objectives, content and educational approaches for education and training programmes for care in the last days of life. The Alliance's "call to action" to service providers to improve the overall quality of care for dying people includes that service providers should: create, promote and support a culture of care and compassion where the individual and their family remain central to decision making and care delivery; and create a learning environment where staff can feel supported and developed, ensuring that they have the confidence and competencies to care for dying people and their families.
94. The Alliance has produced advice to help individuals and organisations delivering care to people in the last days and hours of life identify what competences are relevant for particular roles in delivering that care.
95. CQC inspections will include checking whether care is delivered by qualified, competent staff, who are supported in their development and roles.

96. Individual members of the Leadership Alliance have specific responsibilities for ensuring initial training for particular groups of staff equips them to carry out their roles effectively. The Alliance initiated work to assess the coverage of end of life care in standard, guidance and curricula for health and care staff. For doctors, the GMC and the Medical Schools Council are writing to the Deans of Medical Schools reminding them of the need to ensure that curricula equip students effectively to support good care for dying people. The GMC is working with the Academy of Medical Royal Colleges to enhance the coverage of skills that are generic to all specialty training, but also particularly relevant to the care of people in the last days and hours of life (such as decision-making, effective communication and team working). For nurses, Compassion in Practice is a programme of national and local initiatives with the aim of achieving a culture of compassionate care across health and care services. In response to the recommendations of the Francis Inquiry,<sup>8</sup> the Government announced the introduction of values-based recruitment for all students entering NHS-funded clinical education programmes. This will include testing candidates' attitudes towards caring, compassion and other necessary professional values. Starting with pilots, every student who seeks NHS funding for nursing degrees will first serve up to a year as a healthcare assistant, to promote frontline caring experience and values, as well as academic strength.

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<sup>8</sup> <http://www.midstaffspublicinquiry.com/report>

# Annex A:

## Key themes from the January 2014 workshops for families who gave evidence to the review panel

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1. Those families who had given evidence to the independent review panel and who attended the specific workshops for this group held in January 2014 asked that the summary of the engagement draw out specifically the conclusions from those workshops about the proposed outcomes and guiding principles. This annex sets out those conclusions.

### **Proposed outcome A: People who have a progressive, life-limiting illness have been offered the opportunity to develop, document, review and update a personalised palliative care plan at different stages in their illness or condition.**

2. There was very strong support for a Personal Care Plan but there was some confusion over whether this was intended just for the palliative stage of illness or whether it was for people with a life-limiting illness or, indeed, for people who are currently healthy. Participants varied over when they thought a plan should be completed. Most felt that the palliative care stage was too late to complete a plan because the person and their family and carers would be feeling too stressed and occupied with other things. Others felt that many people would not want to complete a plan earlier because they could be in denial about their illness or not wanting to consider death.
3. Despite confusion over when a plan should be completed, there was a strong feeling that everybody should be encouraged to complete one so that their wishes are known.
4. There were considerable concerns about Lasting Power of Attorney, which could take time to obtain and be costly. There was concern and distress that if a Lasting Power of Attorney for health welfare was not in place, doctors would act in what they considered to be a dying person's "best interest", even if the family and carers wanted different treatment or care for their relative.
5. Participants were concerned that it appeared that a patient could refuse food and fluid, but not demand them.
6. Dying people should have the right to require health and care staff **not** to consult a named person about their treatment and care. In indicating people they were happy for information about their care and treatment to be shared with, dying people might want to cite particular information for particular people.
7. More clarification was required on how a Personal Care Plan would be updated.

**Proposed outcome B: People, including those thought to be in their last days of life, whose condition changes, are identified in a timely way, receive good care that is re-assessed at least daily (or more frequently as their condition requires) and have their emotional, psychological, social and spiritual needs addressed.**

8. There was unanimous support for the intention behind the principle.
9. Participants said there was insufficient detail in the guiding principles under proposed outcome B to provide reassurance that care for dying people would be of the highest quality.
10. The time frames suggested for adjusting medicines and checking on comfort levels were considered inadequate. There was a strong feeling that these must be negotiated with each person or their family and carers. Comfort levels should be checked on a very regular basis, negotiated with the person, their family and carers.
11. 'Comfort levels' should include such things as the importance of being in a suitable place to die with peace and dignity; and the importance of eg being able to have hearing aids in.
12. In the case of a person dying at home, participants asked who was going to show family members and carers how to undertake the tasks to keep the person comfortable. There were concerns that health professionals should not make any assumptions about the capability of family members and carers to carry out these tasks.
13. Participants felt unanimously that a person at the end of life must be hydrated and offered food, which was a basic human right.
14. They queried the word 'promptly' with regard to giving medication for pain or nausea. It was not clear what 'promptly' meant or who would define it.
15. Participants considered that doctors should explain fully the effects of medication if a syringe driver was used, especially if that would mean the person would become drowsy or unconscious. The last moments before a dying person becomes unconscious are generally precious to relatives.
16. Those at the workshops were not fully confident that health professionals would try to contact a dying person's family before taking a decision in the person's 'best interests'. Participants said that attempts to contact the family before any decision was taken should be documented.

**Proposed outcome C: Regular, pro-active and responsive communication takes place between professionals and the person who is approaching the last days of their life and their family and carer. The content and outcomes of these discussions are clearly documented and shared with others involved in this person's care.**

17. Participants stressed the importance of communication between health and care staff and dying people and their families and carers. Communication should be two-way, with health professionals listening to what dying people and their families and carers have to tell them. For this to happen, dying people and their families need to feel that their opinion is respected and they should never feel intimidated.

18. The importance of communication in all circumstances was stressed – including with people who could not speak (eg because they had had a stroke); people assessed as lacking mental capacity to make relevant decisions; and people very close to death, who may still be hearing.
19. Reference was made to the need for professionals to communicate with each other effectively.
20. The need for professionals to make genuine attempts to contact a dying person's family if there were changes in the person's condition, and for those attempts to be documented, was stressed. Participants noted that if the family was not contacted, there was much more risk of decisions with which family members disagreed being made in the patient's best interests.
21. Participants wanted clear information about how, if they disagreed with a health professional's decisions about the treatment or care of a dying person, they could get a second opinion. One person suggested that if there was still disagreement after the second opinion, the dying person's GP should have the final say.
22. The role of advocate was considered very important. One person felt that every person who was dying should have an advocate. One option was for this role to be filled by trained volunteers.

**Proposed outcome D: There are arrangements in place, with which the individual is in agreement, to share key information about his/her care, treatment and preferences between professionals, service providers and others relevant to the person's care.**

23. There was strong support for sharing of information with other health professionals and many participants wanted this to include social care professionals. Participants said that in order to comment substantively on the proposed outcome and supporting guiding principles, they would need more details about what information could be shared, with whom and in what circumstances.
24. There was strong support for a shared information folder which one person suggested could be on an iPad/Tablet as well as in a paper version.

**Proposed outcome E: Local governance arrangements are explicit about the role of 'senior responsible clinicians', delegation arrangements when the person's usual GP or consultant is not on duty, information sharing arrangements to enable timely decision-making, and how people who are approaching their last days of life, and their families, know who are their 'senior responsible clinician' and nurse responsible for leading their nursing care.**

25. Participants were generally in favour of having a 'senior responsible doctor'. However there was not agreement that the 'senior responsible doctor' should, if the dying person was being cared for in a hospital or hospice, be their named medical consultant. Some participants said a less senior doctor might be more appropriate, if they had palliative care skills.

26. Participants queried whether a dying person or their family could choose a different “senior responsible clinician” to one allocated to them.
27. Generally, there was agreement to the proposals that at times, the role of ‘senior responsible doctor’ would be delegated, but participants stressed the need for any doctor to whom the role was delegated to have specific, previous knowledge of the patient and how they were being treated and cared for.
28. Participants asked what dying people and their families should expect as a matter of course, in terms of the opportunities they would be given to speak to the senior doctor responsible for their care.
29. There was strong objection to the senior responsible doctor role being delegated to out of hours GP services, where a dying person was being cared for at home. Participants felt strongly that the role should be carried out by someone with more knowledge of the dying person and their treatment and care, such as a GP from the same practice or someone from the district nursing service known to the person and the family and carers.
30. Participants were concerned with the proposal that a dying person’s ‘senior responsible clinician’ (and any doctor deputising in this role) should be under a duty to consult specialists in palliative care, where a dying person’s complex needs warranted this. The concern was that this implied that people who were leading the care of a dying person might not have had the necessary training in end of life care.
31. It was noted that the outcome and supporting guiding principles did not contain much information on the lead nurse role: this should be expanded on. Participants agreed that people dying in care homes must also have a lead nurse.
32. Participants stressed that at those times when the lead nurse was not available, it would be important that they could contact someone else whom they knew and who was familiar with the dying person and their care and treatment.
33. Some participants wanted greater clarity about the proposed role for the lead nurse in making sure that any concerns about the care and treatment of the dying person were addressed. In particular, a significant number of participants wanted provision that all communications about concerns would be documented; and guarantees that the dying person and their family would receive information about how their concerns had been addressed.
34. Participants were concerned that provision for a second opinion (referred to in text under “What this [outcome] means for people approaching the last days of life and their families and carers”) might not be available immediately. As any need for a second opinion when someone was in the last days and hours of life would be urgent, participants wanted to see timeframes within which one would be forthcoming, if it was requested.

**Proposed outcome F: People who are approaching their last days of life, and their families and carers, receive the benefit of specialist palliative care advice and support in a timely manner.**

35. There was discussion about who decides that a person is approaching the last days and hours of life. Participants said that the decision should be made jointly, by more than one doctor, and that palliative care professionals should give an opinion before the decision was made. It was key for the dying person and their families

and carers that they were told clearly of any decision that a person was in the last days and hours of life.

36. Participants were concerned about the proposal that only telephone support from specialist palliative care services might be available to professionals caring for dying people. They wanted palliative care specialists to be available to attend, wherever the dying person was being cared for, acknowledging that this would have significant resource implications.

**Proposed outcome G: Families and carers feel supported, including knowing how to seek urgent help when this is needed for the dying person, whatever the time of day or night and having their own needs addressed or signposted to sources of help and support.**

37. There was unanimous support for this proposed outcome, but it was felt that the guiding principles needed to include a lot more detail on how families and would be supported.
38. One particular addition that many participants wanted to see was that the guiding principles should set out explicitly how health and care staff would explain, sensitively, to family members that a person was now in the last days and hours of life. Participants wanted to see the guiding principles setting out that such decision would not be made without discussion with the dying person and their family and that they should be able to seek a second opinion, if they did not agree that the person was in the last days and hours of life. Participants considered that health professionals should have training on how to have these conversations with families.
39. Participants were looking for a wide interpretation of: “families and carers should have their own needs regularly assessed”. They wanted it to include provision for support on all practical aspects of caring for someone at home. It should include that any discharge of a dying person from hospital to home would be well organised, with the family having an allocated key worker who could coordinate care, including the equipment and training needed to look after the dying person. Participants were concerned that in some cases, even with appropriate support, families would not be able to give good care to a dying relative: health professionals should consider the home situation carefully and not assume automatically that care at home was possible.
40. Participants wanted the guiding principles to provide for health and care staff to be pro-active in seeking and securing support for families and carers. The pressures on families and carers at this time generally cause emotional distress, which means that families are ill-equipped both to find out what support they need and how they can get it and to secure the necessary support.
41. It was suggested that the guiding principles should make clear that health and care staff had a responsibility to ensure families knew what to expect when someone was dying; and that where the dying person was being cared for at home, what sort of emergencies might arise.
42. Participants wanted the guiding principles to make clear that support for families would extend beyond the death of the family member.
43. Participants wanted the guiding principles to make clear that where someone



was dying in hospital, there should be open visiting times, with a culture which encouraged family members to visit. The guiding principles should set out that visiting families members should be shown where there was a nearby toilet they could use; and that they should be offered cups of tea or shown where they could make them. The guiding principles should also make provision for those people visiting a dying person who wanted a bed set up nearby to have one, wherever this was practicable, so they could stay near their relative. If the person who is in the last days of life has another relative in the hospital, there should be an opportunity for the two people to spend time together.

44. Participants said that the guiding principles should include that when someone died in hospital, health professionals must respond promptly.
45. Participants commented that the "Family and Friends" questionnaires might not be a true reflection of the standard of care given, because in some cases, the completed form had to be returned to the staff who had given that care.

**Proposed outcome H: People who are approaching the last days of life, and their families and carers, experience ambulance transfer that is timely and takes place in a way that prioritises the person's comfort and preferences and that staff conducting transfer know what to do if the situation changes unexpectedly.**

46. There was general support in principle for an emergency plan for ambulance transfers for the individual dying person. However, there was confusion about what this would contain, how it would be drawn up and where it would be kept. Participants commented on the standards of ambulance service they would like to see eg vehicles that would take a trolley so the dying person could lie down; space for the carer.
47. Participants said that a copy of the emergency plan should be kept as part of someone's Personal Palliative Care Plan. It would be important for NHS ambulance staff, including paramedics, to be clear how they would access the current version of the emergency plan for a particular dying person.

**Proposed outcome I: People approaching the last days of life and their families and carers experience care after death that is respectful to the deceased person, supportive of the family and carers and considerate of others who knew the person well.**

48. There was unanimous support for this outcome.
49. Participants were confused about the timescale covered by this outcome, because it referred to "care after death" delivered to "people approaching the last days and hours of life and their families and carers". Discussion included what should happen whilst someone was dying, including that no-one should be left alone during this time: if hospitals and other institutions where people died did not have health and care staff available to be with someone who was dying, they should consider establishing volunteer schemes. Participants also felt strongly felt that people should not have to die on an open ward: the outcomes and guiding principles should provide that someone who was dying could have a private room or other designated space, to ensure peace and dignity.

**Proposed outcome J: Professionals are competent in the specific requirements for excellent care in the last days of life, and these skills are embedded within a high standard of professionalism.**

50. It was suggested that this outcome should be the first, as high standards of competence in caring for dying people were a pre-requisite for delivering good quality care in the last days and hours of life. If professionals had the necessary skills and knowledge, the other outcomes should follow.
51. Participants emphasised the need for people and their families and carers to be able to feedback in “real time” to doctors and nurses about the care they received. The onus should be on health and care staff to proactively ask for comments. Dying people and their families should receive responses to any complaints or comments they make. Participants stressed the need for checks on the quality of care at the time it was given, not after someone had died. Generally, participants’ experience was that Patient Advice and Liaison Services (PALS) and formal complaints systems were not effective in responding quickly to concerns and complaints and securing resolution at the time it was needed.
52. Participants stressed the need for health and care staff to be trained to be respectful, kind and compassionate. They should also have good communications skills and understand the importance of, and practice, two-way communication. Listening skills were critical.
53. Participants acknowledged that more training for professionals would have resource implications.

# Annex B:

## Wider comments made by families who gave evidence to the review panel and attended one of the Alliance workshops held for this group in January 2014

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1. Some families who attended the January 2014 workshops did not want to take part in the process of giving detailed comments on the Outcomes and Guiding Principles on which the Alliance was engaging. They wanted to raise wider issues about care given to dying people, particularly on the LCP and how failings in that care could be addressed. The Alliance provided facilities for them to do so, in parallel with the two workshops on the outcomes and guiding principles. Those who took part in the parallel discussions asked that their points be separately recorded and published.

### Outcomes and guiding principles

2. A substantial number of participants were of the view that the Outcomes and Guiding Principles on which the Alliance was engaging were “another version of the Liverpool Care Pathway”. Participants at one workshop said they would not tolerate this. In one of the workshops, representatives from DH and NHS England were challenged to show what the differences were and how the proposed Outcomes and Guiding Principles would deliver the five domains in the NHS Outcomes Framework 2014/15 (ie Preventing people from dying prematurely; Enhancing quality of life for people with long term conditions; Helping people to recover from episodes of ill health or following injury; Ensuring that people have a positive experience of care; and Treating and caring for people in a safe environment and protecting them from avoidable harm).
3. The Outcomes and Guiding Principles should be mapped against the LCP, to demonstrate the differences.
4. There was some criticism of the focus in the workshops and the outcomes and guiding principles on the proposed Personal Palliative Care Plans. One particular criticism was that if the dying person had agreed, and in particular signed, such a plan, this could detract from the accountability of medical professionals to deliver appropriate treatment and care. One participant, said: “... [patients] don’t want to take ownership of this”.
5. Whatever replaced the LCP should include a right not to have food and water withheld. Some participants said they had been told that stopping hydrating people made for a quick and painless death. Those participants disputed that was the case.
6. Some participants at one workshop had worked with particular medical professionals to produce a “patient’s charter” for end of life care. Key elements were: hydration; nutrition; pain relief; non-sedation; second opinion on diagnosis/likely outcome; patient of choice; involvement in medical decisions; patient/ family agreement to any Do Not Resuscitate orders; care interventions not ended without consent; and consultation with relatives or a trusted advocate on any issues about a person’s mental capacity. Participants were looking for the final version of the

Outcomes and Guiding Principles to reflect the content of the charter. At the other workshop, it was said that what was needed was a written “duty of care”.

7. It would be helpful if the final version of the Outcomes and Guiding Principles could be based on the experiences of those families whose relatives had experience good care in the last days and hours of life, including where that care was given under the LCP.
8. One of the parallel workshops did comment in some detail on the Outcomes and Guiding Principles, including that:
  - all references to “should” needed to be replaced by “must” or “will”;
  - there should be a clearer link between the Outcomes and Guiding Principles and the findings of the independent review of the LCP;
  - there was no mention of life-limiting illnesses;
  - there should be provision for the involvement of a palliative care nurse in the care of everyone who was dying;
  - there should be provision for listening to and involving carers other than health and care professionals;
  - there needed to be effective provision for a genuinely independent second opinion to be sought and gained quickly, where families requested it;
  - the Outcomes and Guiding Principles should provide for shared decision-making; and
  - they should provide for proper support for relatives.

### **Monitoring, enforcement and redress**

9. One of the main themes in these discussions was the need for effective monitoring, policing and “statutory rule” of the care given to dying people. Participants were concerned about what would ensure that the Outcomes and Guiding Principles were adhered to and that the failings in care that had occurred for some people who had been placed on the LCP were not repeated. The Outcomes and Guiding Principles should have statutory force, with the possibility of redress under the judicial system where they were not implemented.
10. Participants said that in some cases where someone was placed on the LCP, the LCP had not been followed properly, particularly in relation to hydration and nutrition. One participant referred to a “policy/ practice gap”. Linked to this, participants were concerned to ensure effective sanctions against health and care staff who delivered poor care for dying people. Such people should not be allowed to deliver end of life care. A number of people called for criminal prosecutions, including for “wilful neglect”. There was agreement that there should be a statutory “duty of candour” on NHS staff.

11. There was a specific call for professional misconduct sanctions if hydration was denied when it was needed and requested by either the dying person or their family.
12. Participants were keen to establish what sanctions were going to be taken against health and care staff who had implemented the LCP inappropriately. There were calls for justice for the families of people whose relatives had died after receiving poor care on the LCP, as well as for help for family members to deal with the psychological problems they had experienced as a result of seeing their relatives undergoing unnecessary suffering and, in some cases, harm. There was support for a public inquiry about the use of the LCP.

### **Acknowledging the possibility of recovery**

13. Another theme was the need for the Outcomes and Guiding Principles to focus on the possibility that a patient might not be dying and could recover. It was difficult to decide accurately whether someone was in the last days and hours of life. It was critical that any approach for the care of dying people provided for treatment and care that was reversible, against the contingency that the original assessment that someone was dying had been wrong. This had not happened with the LCP. At least one person who had been placed on the LCP attended one of the workshops.

### **Mental Capacity Act**

14. The need for changes to the Mental Capacity Act 2005 was mentioned at both workshops and a dominant theme at one of them. A key concern was that a person's next-of-kin had no rights to make decisions for a dying person unless either they had been appointed as an Independent Medical Capacity Advocate under the Act; or they had relevant Lasting Power of Attorney for personal welfare. Those at the workshops felt that there should be more rights for a person's next-of-kin (or other family members) to make decisions about the treatment and care of someone who was dying. There was a strong view that there should be arrangements for advance care planning under which all preferences expressed would prevail, not just advance decisions about refusing specific treatments. There should be scope for such plans to cover dying "in our own time" ie without death being hastened by withdrawal of hydration, nutrition and medication or by the administration of particular drugs. At one workshop, there were calls for changes to the Mental Capacity Act: one participant argued that without these, there would be no choice or control for dying people or their families.

### **Records**

15. At one workshop, there was a call for a document setting out the plan for the dying person's treatment and care to be drawn up. A specific consultant would have responsibility for this document, which would be kept with the dying person. All those involved in the person's treatment and care would be required to abide by the document.
16. Participants noted that in some cases, proper records of changes in the condition of someone who was on the LCP had not been kept. Hence, there had been no review of whether it was appropriate for the person to continue to receive treatment and care on the LCP.

17. Many families of people who had died whilst on the LCP had encountered difficulties in trying to establish the details of decisions taken about the care and treatment of the person who was dying, including the basis for those decisions. Participants referred to missing records and records that had been completed later than they should have been or which had been altered. Some people called for prosecutions in such cases. Generally, many participants felt that there had been collusion in covering up instances of poor care for dying people and mistakes that had been made in such care, particularly between staff and health managers.
18. Participants referred to “retrospective medical records”. It was said that there was provision for compiling medical records retrospectively eg where the circumstances of a medical emergency made it inappropriate to compile records at the time. It was said that in such cases, no clinical details or “real time” assessment of a person’s condition was recorded. It was said that there was widespread, often inappropriate use of retrospective medical records and that this should be stopped.
19. Participants considered that death certificates should record whether someone had been on the Liverpool Care Pathway. Where someone had been on the LCP for more than a few days (15 days and 3 days were suggested) before they died, there should be an investigation. It was also felt that if health and care staff knew that the fact that someone had been on the LCP was going to be recorded on the death certificate and that there would be an investigation if they had been on it for more than a few days, this would help ensure the LCP was used in appropriate circumstances and carried out appropriately.

### **Other issues with the LCP**

20. Other issues that participants said they had encountered with care on the LCP included:
  - lack of evidence that someone was dying before they were placed on the LCP;
  - lack of informed choice about the treatment and care given to the dying person, particularly in relation to the administration of morphine by syringe driver;
  - lack of discussion with relatives about that treatment and care, including inappropriate use of euphemisms; and
  - the LCP was not properly monitored, nor evaluated;

### **Governance for end of life care**

21. Participants agreed there was a need to engage the Chief Executives of hospitals, ensuring they understood what constituted good care for dying people and took proper responsibility for making sure that such care and treatment was delivered.
22. Every Board should have a Director with responsibility for end of life care.

### **Reporting concerns about care given to dying people**

23. Participants at one workshop called for the creation of “issue logs” in which families could report their concerns and opinions about the treatment and care of a dying person, with health and care staff required to respond.

24. At the other workshop, there was a call for a clear process, to be followed when there was disagreement between health and care staff and families about the treatment and care of a dying person. There were also calls for an ombudsman to be based in each hospital and for "Patient Champions" with whom patients and their families could raise concerns. It was said that the NHS needed a more powerful complaints and advocacy service than that provided by Patient Advice and Liaison Services (PALS).
25. Reference was made to the "Ask SAL" helpline. (This a partnership project between the Southend, Essex and Thurrock Safeguarding Adults Boards and Essex County Council. Individuals can use this helpline to report if they see, hear or suspect that a vulnerable adult is being abused.) It was said that this helpline should be available nationally and extended so that it covered possible abuse to anyone receiving health or care services.