

COMMITMENT STATEMENTS

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

Alliance members

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

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

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

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

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

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Care for people in the last few days and hours of life

Joint statement and call to action by the Leadership Alliance for the Care of Dying People, i.e:

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 (also representing the Richmond Group of Charities); Marie Curie Cancer Care (also representing Help the Hospices and the National Council for Palliative Care); Monitor; National Institute for Health Research; NICE (National Institute for Health and Care Excellence); NHS England; NHS Trust Development Authority; NHS Improving Quality; Nursing and Midwifery Council; Public Health England; Royal College of GPs; Royal College of Nursing; Royal College of Physicians; and Sue Ryder (also representing the National Care Forum).

Collective commitment by national organisations

In response to the independent review of the Liverpool Care Pathway for the Care of the Dying Patient (LCP)¹, the twenty one organisations listed above came together to form the Leadership Alliance for the Care of Dying People (LACDP). The Alliance's objectives were to support those involved in the care of people who are dying to respond to the findings of the review; and be the focal point for the system's response to the findings and recommendations of the LCP review. It has now achieved its objectives and will no longer continue as such, but its member organisations, along with others, will continue to work together to secure improvements in the consistency of care given in England to everyone in the last few days and hours of life and their families.

Members of the Alliance fully acknowledge, and are deeply concerned by, the failings highlighted in the *More Care, Less Pathway* report. It is clear that unnecessary harm and suffering were experienced both by people who were in the last days and hours of life and their families; and that some dying people received care that was simply unacceptable. Moreover, some families suffered unnecessary and additional distress because health and care staff did not communicate effectively with them when their family member was close to death. There can be no excuse for not treating people with dignity, compassion and respect when they are dying, which is the very time they most need this, nor for poor communication with their families. These failings should never have happened, and must never again be allowed to happen.

¹ www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients

Alliance members were reassured to hear that this was not everyone's experience. Whilst this does not, in any way, excuse or undermine the seriousness of the poor experiences, the Alliance would also like to commend those who have provided sensitive, skilled and compassionate care to dying people and their families.

Alliance members agree with the words in the End of Life Care Strategy 2008 that "the way in which we care for dying people is a measure of society as a whole and a litmus test for health and social care services". They are therefore determined to ensure that the failures of care that people have experienced are not repeated. Each of them commits to doing all they can to achieve and support others to achieve care for people in the last few days and hours of life which:

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

As part of achieving this, the Alliance has developed Priorities for Care of the Dying Person, which individual Alliance members are committed to taking forward in their work and which represent their collective vision of what care for dying people should be like. The Priorities for Care are that when it is thought that a person may die within the next few days or hours:

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

This statement of the Priorities for Care is accompanied by separate documents setting out, what health and care staff should do to deliver the Priorities for Care, and actions for commissioners and organisations providing health and care services. These documents are available as part of *One Chance to Get it Right*, the system-wide response to the Independent Review of the LCP, which accompanies this statement.

Annex A below lists key actions that Alliance members themselves have taken and plan to take to implement the Priorities for Care and further details are also available in *One Chance to Get it Right*.

The independent review found that where there were issues about the LCP, they were issues about how it was used – particularly that it came to be seen as a generic protocol - rather than about the LCP itself. Although there is no conclusive evidence about what distinguishes use of the LCP to support high-quality and effective, as opposed to poor, care for people in the last few days and hours of life, Alliance members believe that cultural factors were a key determinant. Poor care and treatment for people in the last few days and hours of life is not restricted to those for whom the LCP is used. The Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry² (the “Francis Inquiry”) highlighted an organisational culture that tolerated poor standards and a disengagement from managerial and leadership responsibilities. The Chair of the Inquiry, Sir Robert Francis, said: “The extent of the failure of the system...suggests that a fundamental culture change is needed.”³

The Leadership Alliance for the Care of Dying People is in no doubt that failings similar to those that occurred at Mid Staffordshire NHS Foundation Trust have contributed to poor care and treatment for people in the last few days and hours of life. The response to the Inquiry’s findings sets out system-wide action to address the Inquiry’s findings and its 290 recommendations. The programme of action described in that response is aimed at securing the culture change the Inquiry called for and achieving compassionate care throughout the NHS. It includes specific measures to: prevent problems; detect problems quickly; take action promptly; ensure robust accountability; and ensure staff are trained and motivated. These actions will impact on all care, including care for dying people and complement the actions taken in response to the findings of the LCP review panel.

Call to action to clinical commissioning groups (CCGs)

CCGs, working with NHS England Area Teams, should seek to ensure that continued improvements in end of life care are a priority in the new clinically-led commissioning system. Wherever possible, they should commission services that are co-ordinated and integrated across health and care, to improve quality and choice, as well as reduce emergency admissions. They should ensure adequate provision of specialist palliative care services. CCGs should also commission services in ways that support the development of a well-educated, skilled workforce that engages well with the population they serve.

² www.midstaffspublicinquiry.com/report

³ www.midstaffspublicinquiry.com/sites/default/files/report/Executive%20summary.pdf

Call to action to individual organisations providing services for people in the last few days and hours of life

Whilst action by national organisations will create the framework for effective local practice, that action will be most effective where it is complemented by positive leadership and commitment at a local level, ideally with groups of service providers in a particular area coming together with a common goal of providing excellent, seamless services for people approaching the end of their lives. On 15 July 2013, the Minister for Care and Support wrote to all Chairs and Chief Executives of NHS Trusts and NHS Foundation Trusts about the LCP review, including asking them to appoint a Board member with responsibility for reviewing how end of life care is provided in their particular trust.

The members of the Alliance hope that these Board members will commit to basing their services for people in the last few days and hours of life on the Priorities for Care and Implementation Guidance for Service Providers.⁴

The Alliance calls on service providers to:

- deliver positive leadership and commitment to our shared purpose of providing excellent person centred end of life care in line with Priorities for Care for dying people and their families;
- 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.

Call to action to health and care staff delivering care to people in the last few days and hours of life

The Alliance also calls on individuals who deliver services for people in the last few days and hours of life and their families to make the Priorities for Care of the Dying Person and the accompanying *Duties and Responsibilities of Health and Care Staff* part of their practice; and to support colleagues in doing the same.⁵

Call to action to specialist palliative care staff

The Alliance calls on specialists in palliative care to provide leadership, education and training in palliative and end of life care, and to help drive clinical provision that is safe, effective and evidence based. This will involve work with local stakeholders to support strategy development, and with commissioners and service providers to ensure there is adequate provision of specialist palliative care services at all times, including 24/7 access to specialist palliative care advice.

⁴ These documents form part of *One Chance to Get it Right*, the system-wide response to the Review of the LCP.

⁵ The *Duties and Responsibilities of Health and Care Staff* forms part of *One Chance to Get it Right*, the system-wide response to the Review of the LCP

Call to action to the public

The Alliance calls on members of the public to participate in a National Conversation about dying to raise awareness and understanding of this important part of life that we will all experience, and help ensure that we make people's care and experience of dying as good as it can be.

Individual organisations' commitments

The organisations below each commit to working collaboratively with each other and other national stakeholders to help raise the overall standard of care given to people in the last few days and hours of life in England. This includes taking part in any relevant work initiated by NHS England, which arranges the provision of NHS services in England and has statutory responsibilities in relation to the continuous improvement of services.

Care Quality Commission (CQC)

As the regulator of health and social care in England, CQC plays a key role in ensuring that people approaching the end of life receive safe, effective, compassionate, high quality care.

We are committed to the five Priorities for Care for Dying People and will ensure they, along with the implementation guidance for commissioners and service providers, are reflected in our work on care in the last few days and hours of life.

We will:

- reflect NICE guidance and other national guidance on good end of life care, as well as the Priorities for Care in our approach to inspections;
- continue to inspect registered services which deliver care in the last days and hours of life - hospices and hospice at home services, acute hospitals, care homes, nursing homes, community health services, and care provided by GPs. In our inspections we will assess and report on the quality of end of life care;
- in all acute hospital inspections, include inspection of end of life care as a core service wherever it is delivered within the hospital;
- include consideration of end of life care in our new inspection approach in the other sectors we regulate;
- undertake an additional bespoke programme of work in 2014/15 to learn from people's experience of end of life care across sectors and to develop our understanding of why some groups of people experience poor care – this is likely to include asking local commissioners about what they are doing to ensure good end of life care for all groups of people; and
- publish our findings to inform people about the quality and safety of end of life care, and to encourage improvement.

CQC as a Non Departmental Public Body is accountable to Parliament via the Secretary of State for Health. CQC is operationally independent of Government. An annual accountability meeting takes place with the Health Select Committee.

College of Health Care Chaplains (CHCC)

The College of Health Care Chaplains is a professional organisation of chaplains from all faith/belief groups. We promote best practice in pastoral, spiritual and religious care, for staff, patients and those important to them, of all faiths and none.

The CHCC is committed to taking forward the five Priorities for Care of the Dying Person in its on-going work. Members will work closely with staff in helping them fulfil their responsibilities and duties as outlined in the supporting document *Duties and Responsibilities of Health and Care Staff*, and in supporting those who are dying, and the people who are important to them.

We are committed to supporting the best quality of care for dying patients and will actively:

- work within the multidisciplinary team to ensure that the most appropriate spiritual, religious and cultural care is given to the dying person and their family/carers;
- work in our local situations to ensure such high quality care is embedded in our organisation's culture and the way we work;
- deliver, and help others to deliver, education and training to ensure continuously improving quality of care;
- work with key partners in the health and care system to proactively engage faith and belief bodies in a dialogue on the best quality of care for dying people; and
- share good practice to enable continuing development of both chaplains and the staff with whom we work, whether it be in a hospital, a hospice or in the community.

In order to evaluate the implementation of the above actions, the national CHCC Organizing Professional Committee will monitor the activities of its members at its quarterly meetings and discuss how to improve and develop the support they give to people coming to the end of their lives.

Department of Health (DH)

The Government is committed to ensuring high quality compassionate care for everyone, including those in the last few days and hours of life. Our response to the Francis inquiry set out a programme of action to secure culture change and ensure compassionate care throughout the NHS. We are also determined to ensure that the five Priorities for Care become a reality for everyone who is dying in England.

In our role overseeing the Health and Care systems, the Department of Health has set NHS England, through the Mandate, a key objective of improving the quality of care given to people at the end of their life.

We will continue to measure progress on improving end of life care, including through looking at the outcomes of annual surveys of bereaved carers' views on the quality of care given to their relatives in the last three months of life.

We will use our assessments to ensure that those bodies which are accountable and report to the Department (the Care Quality Commission, Health Education England, NHS England, Monitor, the NHS Trust Development Authority, NICE and Public Health England) continue to work towards improving care for people in the last few days and hours of life.

We will coordinate progress reports from all organisations who have made commitments to address the Review Panel's recommendations. We will publish a one year on report in July 2015, setting out this progress.

The Department of Health is accountable for its policies, decisions and actions to Parliament and the public via the Secretary of State for Health. This process is overseen by the Departmental Board, which is composed of executive and non-executive directors.

General Medical Council (GMC)

The GMC's role is to protect, promote and maintain the health and safety of the public by making sure that doctors meet our standards for good medical practice. We do that by controlling entry to the UK medical register and setting the standards for undergraduate medical education and postgraduate education and training. We publish guidance for all doctors on the ethical principles and values that underpin good medical practice and the professional standards which the public have a right to expect from doctors. If any doctor fails to meet our standards, we have strong legal powers that enable us to take firm and fair action to protect patients from harm by restricting, or removing, a doctor's right to practise medicine in the UK.

We commit to undertaking a programme of work throughout 2014, to contribute to improving standards of care for dying people. This work will include:

- delivering a programme of activities to raise awareness of our ethical guidance on end of life care. Our guidance is highly regarded, and plays an important role in establishing the principles of good practice in this challenging area. We will focus in particular on raising awareness of our guidance on oral nutrition and hydration, advance care planning and decision making around cardiopulmonary resuscitation (CPR), vigorously promoting use of the guidance by doctors in their day to day practice;
- further developing our related online resources and promoting them to doctors, alongside the guidance, through our Regional Liaison Service in England and teams in Northern Ireland, Scotland and Wales;
- promoting the 'Priorities for Care' statement with the statement on *The Duties and Responsibilities of Health and Care Staff*, alongside our guidance and resources. We will use a range of communications channels to do this including our website, publications, meetings with doctors and proactive media work;
- identifying and taking forward opportunities to work with others, including the Nursing and Midwifery Council, Royal College of Nursing, National Council for Palliative Care, Age UK, British Geriatric Society and other organisations involved in promoting high quality end of life care. We will do this by, for example, where possible aligning our planned work programme with initiatives they have committed to for 2014. Activity is likely to include developing new resources, creating opportunities to speak to groups of doctors about the principles of good end of life care, and using networks and communications channels to signpost useful sources of support in improving end of life care;
- supporting the introduction of the Responsible Consultant/Clinician and Named Nurse roles in England (work being led by the Academy of Medical Royal Colleges and DH). On publication of Academy guidance on this role (expected June 2014), we will consider whether it would be helpful to produce more GMC guidance or other

resources to support doctors acting in the role of Senior/Responsible Clinician for the care of a dying patient;

- continuing to promote the advice in *Good medical practice* around doctors' responsibilities to be open and honest when things go wrong with a patient's care; to keep clear, accurate records; and to comply with systems set up to promote patient safety and improvements to healthcare services. We are taking part in discussions with NHS England and the other health and care regulators with a view to setting out a consistent, common responsibility for health and care professionals to be candid with patients when mistakes occur. We expect to publish a joint statement on this issue for consultation in summer 2014. We will start early engagement with our stakeholders on additional GMC guidance, during the autumn;
- continuing to ensure the inclusion of end of life care as a defined theme in the standards and outcomes we set for undergraduate medical education and training;
- writing a joint letter with the Medical Schools Council, in June 2014, to all UK medical school Deans to emphasise the importance of ensuring the curricula they set properly prepare students to deliver care for people who are coming towards the end of their life;
- ensuring the curricula for postgraduate medical education, including the foundation programme and specialty training – which are developed by the medical royal colleges and faculties and approved by the GMC – continue to set out the education and training to be undertaken in relation to end of life care;
- working with the Academy of Medical Royal Colleges (AoMRC) to develop a framework, by the end of 2014, for 'generic' professional capabilities which doctors in all specialties should be able to demonstrate. The framework will highlight areas such as shared decision-making, effective communication and team working and show how these capabilities can be emphasised in curricula, to better prepare doctors to care for people who are approaching the end of their life. We will work with the AoMRC and the colleges throughout 2014/15 to ensure these areas are sufficiently reflected in specialty training curricula; and
- publishing advice, in the second half of 2014, to help doctors identify and access GMC guidance, materials and other learning opportunities on end of life care which can be used to support doctors' Continuing Professional Development (CPD). We are developing an 'app' to support doctors' CPD and plan to launch this towards the end of 2014.

The GMC is independent of the government and the NHS. However every year, we are held accountable for our work by the UK Parliament, through the accountability hearings we have with the House of Commons Health Select Committee. Our work is also reviewed every year by the Professional Standards Authority for Health and Social Care (PSA) who publish their findings and recommendations in an annual report.

General Pharmaceutical Council (GPhC)

The General Pharmaceutical Council (GPhC) is the independent regulator for pharmacists, pharmacy technicians and pharmacy premises in Great Britain. It is our job to protect, promote and maintain the health, safety and wellbeing of members of the public, in particular the users of pharmacy services, by upholding standards and public trust in pharmacy.

We are committed to:

- ensuring that the pharmacists and pharmacy technicians we regulate respect the needs and wishes of patients who are at the end of their life;
- promoting the Priorities for Care of the dying person and the duties and responsibilities of health and care staff to pharmacy registrants and owners of registered pharmacies;
- taking account of the Priorities for Care of the dying person and the duties and responsibilities of health and care staff when we review our standards of conduct, ethics and performance in 2014/15 and education standards in 2015/16; and
- working with the professional body for pharmacists, the Royal Pharmaceutical Society, to make sure that appropriate additional guidance is produced.

We are accountable to Parliament through the publication of annual reports and accounts and our strategic plan. We are also subject to an annual performance review by the Professional Standards Authority for Health and Social Care.

Health and Care Professions Council (HCPC)

The Health and Care Professions Council (HCPC) regulates 16 professions working across health and social care. We set standards on conduct, ethics and behaviour, as well as competence and continuing professional development for the 320,000 individuals on our register. Many of these individuals will provide care for people who are dying and their families.

Behaving with honesty and integrity, communicating clearly and with respect and working in partnership with service users and those important to them is at the heart of good professional practice and these principles are articulated in our expectations of registrants. We are committed to taking forward the Priorities for Care, which extend these principles to the care for dying people, in our ongoing work by:

- continuing to ensure that these expectations are explored and understood as part of our ongoing programme of engagement with those on our Register, as well as with employers and educators;
- continuing to reinforce a person centred approach to care by proactively encouraging personal reflection on practice and a focus on how services bring benefits to service users and their families;

- continuing to revise out standards of conduct, performance and ethics, due to be republished in 2016;
- forming a working group in 2014, as part of the review of these standards, to consider themes from feedback, research and policy developments, including the Priorities for Care;
- considering strengthening our requirements of registrants with reference to their responsibility to identify and be open about failures of care as part of this working group review;
- considering our dissemination strategy to promote the new standards outlining our expectations of registrants; and
- promoting and communicating the Priorities for Care and the *Duties and Responsibilities of Health and Care Staff* guidance and our related expectations to our registrants and stakeholders in a number of ways, including through information and alerts on our website, newsletters aimed at registrants and education providers and established links with professional bodies of the professions we regulate.

We are held to account for our work by the UK Parliament through an annual appearance before the House of Commons Health Select Committee; and by the Professional Standards Authority for Health and Social Care through an annual performance review.

Health Education England (HEE)

Health Education England provides national leadership and strategic direction for education, training and workforce development and ensures a nationally coherent system is in place to help improve the quality of care delivered to patients. Our remit is to ensure there are enough trained people with the right skills and behaviours to meet patient's needs.

We are committed to taking forward the five Priorities for Care of the Dying Person in our ongoing work. In particular, we are committed to:

- supporting the development of more evidence-based education in all settings for the workforce that cares for people who are dying;
- working with NHS England and other organisations to take forward the Review Panel's recommendation on developing the future workforce; and
- working with stakeholders to influence curricula as appropriate.

We are accountable to the Secretary of State via the Department of Health and this process is overseen by the HEE Board.

Help the Hospices

Help the Hospices is the national membership body for hospice care and as such provides support, advice and leadership for the UK's hospice movement.

We commit to supporting the five Priorities for Care for Dying People as part of our ongoing work.

Our Commission into the Future of Hospice Care⁶ sets out a series of recommendations for the future development of the hospice movement. In taking these forward, our ongoing work will include:

- helping hospices to develop and strengthen partnerships with other organisations supporting people at the end of life;
- disseminating knowledge, expertise and examples of best practice;
- supporting hospices in developing new models of integrated care; and
- promoting learning and leadership within the hospice movement, and sharing with others through our ehospice website⁷.

As a charity, we report to key stakeholders every year in our annual report and accounts giving details of what we have achieved and how we have performed against our objectives.

Macmillan Cancer Support

Macmillan Cancer Support is a charity that provides practical, medical and financial support for people with cancer and their families and advocates for better cancer care. We are committed to taking forward the five Priorities of Care for Dying People in our ongoing work.

We are also committed to:

- continuing to provide and improve services to ensure that people approaching the end of their lives and their carers receive high quality care and support. These services include the Macmillan Support Line, information publications, web and mobile information services⁸, volunteering schemes and self-help and support groups;
- continuing to work in partnership with other organisations, especially in the NHS, to develop new posts and services or to enhance existing services;
- reviewing our support, including educational support, for Macmillan end of life care professionals in the light of the Priorities for Care, and implementing the outcomes of this review over the next year;
- providing a range of innovative solutions such as the 'Values-Based Standard'⁹ to ensure staff and patient experience remains an interlinked priority; and
- advocating and influencing nationally and locally on achieving real improvements in services and greater choice for people approaching the end of life.

⁶ Available on the Help the Hospices website at: www.helpthehospices.org.uk/our-services/commission .

⁷ www.ehospice.com/uk

⁸ Available on the Macmillan website at: www.macmillan.org.uk/Cancerinformation/Endoflife/Endoflife.aspx

⁹ The Macmillan Values Based Standard identifies specific behaviours and practical things staff and patients can do on a day to day basis, to ensure people's rights are protected across the care pathway. More information is available on Macmillan's website at: www.macmillan.org.uk/Documents/AboutUs/Commissioners/Macmillan-Values-Based-Standard-Overview.pdf

We publish annual reports, which give details of what we have done to support people with cancer and their families and to improve cancer services.

Marie Curie Cancer Care

Marie Curie Cancer Care is a UK charity dedicated to the care of people with terminal illnesses. Marie Curie nurses work in the homes of terminally ill people and nine Marie Curie hospices across the UK. We provide expert care and the best quality of life for people with terminal illnesses. We have our own research teams and fund external research programmes. We also campaign on behalf of people with a terminal illness and their families across the UK.

We are committed to providing the best possible care for people with terminal illnesses and their families by providing high quality nursing and hospice care. We are committed to the five Priorities for Care of the Dying Person and the new approach to care in the last few days and hours of life in taking forward this ongoing work.

Specifically we are committed to:

- sharing ways to improve the experiences of patients and their families, including support for families after the death, whether in the community, hospice or hospital;
- doubling, over the next five years, our funding of research, including into better symptom management and into improving the experience for black and minority ethnic groups and other groups who are less likely to be able to access specialist palliative care;
- improving how care is delivered in ways that best meet needs of people and their families e.g. by supporting integration and increased provision of community-based services; and
- sharing learning from evaluations of interventions into new approaches to end of life care which may better meet the needs of people and their families and carers.

We publish annual Impact Reports showing the progress we have made in achieving our targets.

Monitor

Monitor is the sector regulator for health services in England. Our job is to protect and promote the interests of patients by ensuring that the whole sector works for their benefit.

We are committed to the five Priorities for Care of the Dying Person and will ensure they, along with the implementation guidance for commissioners and service providers, are reflected in our ongoing work in our capacity as sector regulator.

Good governance arrangements are required to ensure that the Priorities for Care result in quality care for dying people. It is part of our role to make sure public providers are well led and to make sure rules operate in the best interests of patients. In doing so, we work with the Care Quality Commission, whose role it is to monitor, inspect and regulate services to make sure they meet fundamental standards of quality and safety.

Hence, where failings in end of life care have been identified in NHS foundation trusts, including in governance arrangements, we are committed to:

- working closely with CQC, to identify where improvement is needed and to ensure appropriate and joined-up regulatory action is taken; and
- intervening, where necessary, to ensure such failings are corrected.

We are accountable to Parliament through the Health Select Committee and also through our annual report and accounts, which are laid before Parliament. Governance and accountability are overseen by our Board.

National Council for Palliative Care (NCPC)

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We work with government, health and social care staff and people with personal experience to improve end of life care for all. We campaign to make sure that every person approaching the end of life can access the care and support they need; and run a wide range of events across the year. These include national conferences and workshops on all aspects of palliative care, looking at specific conditions or diseases, care in different settings and national policy and guidance. NCPC leads the Dying Matters coalition which aims to change public attitudes and behaviours around dying, death and bereavement.

The NCPC endorses and supports the five Priorities for Care of the Dying Person. We also support the view of the Panel and the Alliance that there should be a “proper National Conversation about dying” as proposed by the independent review panel in the foreword to its report. By this we mean that everyone, members of the public, health and social care staff and the media are given opportunities meaningfully to take part in discussions about dying to raise awareness and understanding of this important part of life that we will all experience, and help ensure that we make people’s care and experience as good as it can be.

We will work with national health and care organisations and members of the public, as well as health and care staff and the media, to contribute to that National Conversation, including through our leadership of the Dying Matters coalition.

We account to our subscribers and more widely for our activities by posting details on our website and through reviews of our activities included in the Report and Financial Statement which we publish every year.

National Institute for Health Research (NIHR)

The National Institute for Health Research (NIHR) provides the framework through which the Department of Health can position, maintain and manage the research, research staff and research infrastructure of the NHS in England as a national research facility.

Our aim is to improve care for people in the last few days and hours of life by strengthening the evidence base for specific treatments and care.

We are committed to the following actions:

- we have issued a call for research proposals on prognostic models, including prognostic tools, for people with advanced cancer;
- we have commissioned updates of Cochrane Reviews of evidence on medically assisted nutrition and on medically assisted hydration for palliative care patients;
- we have begun work on a Cochrane Review of evidence on the impact of opioids for cancer pain on patient consciousness, appetite and thirst;
- we are working with the James Lind Alliance and others to find out what research is important to people who are likely to be within the last years of life, their families, and the professionals who work with them;
- we are commissioning a mapping of evidence requirements from the Priorities for Care of the Dying Person; and
- we will consider what further research is needed, in light of these actions.

The NIHR is managed and funded by the Department of Health, and we are accountable to the Secretary of State.

NICE (National Institute for Health and Care Excellence)

NICE provides guidance to support healthcare professionals and others to make sure that the care they provide is of the best possible quality and offers the best value for money.

We provide independent, authoritative and evidence-based guidance on the most effective ways to prevent, diagnose and treat disease and ill health, reducing inequalities and variation. Our guidance is for the NHS, local authorities, charities, and anyone with a responsibility for commissioning or providing healthcare, public health or social care services. We also support these groups in putting our guidance into practice.

We are committed to the five Priorities for Care as a basis for delivering good care in the last few days and hours of life. In addition:

- we are currently developing new Guidance on the management of care for dying adults which we hope to publish in 2015;
- we will revise our recently redrafted Quality Standard on End of Life Care following the publication of this new Guidance;
- subsequently, we will also update our existing guidance on palliative care and end of life service guidance as part of our ongoing surveillance and updating programme; and
- we are also aiming, shortly, to develop separate guidance for End of Life Care in children.

NICE is a Non Departmental Public Body, accountable to the Department of Health, and via the Secretary of State, to Parliament. However, operationally we are independent of Government and our guidance and other recommendations are made by independent committees. The NICE Board sets our strategic priorities and policies, but the day to day decision-making is the responsibility of our Senior Management Team.

NHS England

NHS England is trustee of the NHS budget and has a legal duty to promote a comprehensive health service, and to oversee the delivery of NHS services, including the continuous improvement of the quality of treatment and care. We are committed to the implementation of the five Priorities for Care of the Dying Person.

In our role as commissioner of health services, and through our clinical leadership of the system, we will:

- use the NHS Outcomes Framework to drive measurable improvements in the quality of care, in particular improving the experience of care for people at the end of their lives, improving hospitals' responsiveness to personal needs, and enhancing the quality of life for carers;
- ensure that high quality person centred end of life care is supported by the transformation agenda for a modern model of integrated care;
- ensure that the requirements for the implementation of the Priorities for Care are in place across the services for which NHS England has direct commissioning responsibility;
- work with and provide support to clinical commissioning groups as they commission high quality services for people at the end of their lives, including the commissioning of specialist palliative care;
- take the Priorities for Care forward through Compassion in Practice 6Cs to support health and care staff deliver compassionate care for the dying person;
- ensure equity of access to high quality care and services for the most vulnerable and excluded in society through our commitment to deliver high quality care for all; and
- continue to work with national organisations to implement the commitments we have collectively made.

NHS England is accountable to the Secretary of State through the Mandate, delivery of which is overseen by the NHS England Board. Through the CCG and Direct Commissioning Framework, NHS England ensures ongoing assessment of the delivery of improved quality and outcomes.

NHS Trust Development Authority (NHS TDA)

The NHS Trust Development Authority (NHS TDA) is responsible for providing leadership and support to the non-Foundation Trust sector of NHS providers. As part of its role, the NHS TDA monitors the performance of NHS Trusts and provides support to help them improve the quality and sustainability of their services.

The NHS Trust Development Authority is committed to the Priorities for Care for Dying People and will:

- support NHS Trusts to implement the five Priorities for Care and the Implementation Guidance for Service Providers the expectation for which is included in the NHS TDA's planning guidance 2014-15; and
- seek assurance that trusts have processes in place to ensure they are delivering care in line with the Priorities for Care and the Implementation Guidance.

Governance arrangements for the NHS TDA are overseen by its board of directors. As an Arms-Length Body of the Department of Health, the NHS TDA is accountable to Parliament and the public via the Department and the Secretary of State.

NHS Improving Quality (NHS IQ)

NHS Improving Quality provides improvement and change expertise that delivers real benefits for people using NHS services. It is committed to promoting and supporting delivery of high quality end of life care for all, and will help take forward the five Priorities for the Care of the Dying Person by actively:

- supporting continuous quality improvement working with a wide range of multi-professional teams, strategic clinical networks, service providers and commissioners across health and care sectors;
- building leadership capability and change expertise to support quality improvements in delivering end of life care; and
- promoting, supporting and championing the best quality of care for dying people and their families, so learning and best practice can be shared across England.

We are hosted and funded by NHS England and we have a whole system responsibility as described in the Memorandum of Understanding with the Department of Health. We will account for our progress against these commitments through regular communications with our stakeholders and the publication of case studies.

The Nursing and Midwifery Council

The NMC is the nursing and midwifery regulator for the whole of the UK and as such our key role is to protect the public. We do this by setting standards of education, training and conduct for all nurses and midwives; ensuring that nurses and midwives keep their skills and knowledge up to date; ensuring that nurses and midwives uphold the standards of their professional code; and having fair fitness to practise processes in place to investigate allegations against nurses and midwives.

We are committed to taking forward the five Priorities for Care of the Dying Person and the principles contained in the *Duties and Responsibilities of Health and Care Staff* document in our ongoing work, ensuring that they are embedded into the values and behaviours exhibited by all nurses and midwives who care for people in the last few days and hours of life.

We are committed to:

- disseminating as appropriate any further system-wide guidance on end of life care and associated topics such as hydration and nutrition;
- ensuring the five Priorities for Care of the Dying Person are reflected in:
 - the NMC Code: Standards of conduct, performance and ethics for nurses and midwives” and in any relevant underpinning standards and guidance published by us in support of the Code. We are reviewing the Code and will publish a revised version in December 2014. We will ensure the revised version of the Code will give enhanced priority to matters such as hydration, nutrition, communication and decision-making;
 - our requirements for revalidation, where this is appropriate;
 - our pre-registration education standards; and
 - our fitness to practise proceedings;
- carrying out an evaluation of our pre-registration education standards and reporting on this in 2015/16. This evaluation will focus on end of life care, hydration and nutrition and will assess whether the current standards are adequate or need strengthening; and
- carrying out a review of other current post-registration standards and guidance commencing in 2015/16 in light of the five Priorities for Care. In addition, we produced, in April 2014, a stand-alone document containing the competencies of our pre-registration education standards and the essential skills clusters that underpin them – this will make it easier for people to understand what standards of competency and behaviour they should expect from nurses;

We are accountable to Parliament for our progress against these and other commitments through our annual report and our annual appearance before the Health Select Committee. We are also subject to an annual performance review by the Professional Standards Authority for Health and Social Care.

Public Health England (PHE)

Public Health England’s role is to protect and improve the nation’s health and to address inequalities through working with national and local government, the NHS, industry and the voluntary and community sector. PHE is an operationally autonomous executive agency of the Department of Health.

We consider high quality care for dying people and their families to be an important public health issue. We are fully committed to the five Priorities for Care and to improving care in the last few days and hours of life, for people in England.

We are committed to:

- providing high quality information about end of life care to underpin the work of policy makers, commissioners, service providers and professionals, as well as to inform dying people and their families and contribute to a national conversation about dying. This includes the continuing work of the National End of Life Care Intelligence Network; and
- examining ways to develop community approaches to support dying people and their families.

We are accountable for our performance to the Department of Health and, via the Secretary of State, to Parliament and the public.

Royal College of General Practitioners (RCGP)

The RCGP is the professional membership body and guardian of standards for family doctors in the UK. We speak up for standards in primary care, we play a leading role in the formation of policy, we work to improve GP education and training and we provide continued support to GPs to help them keep their knowledge and skills up to date. We also provide research leadership in primary care, identifying priorities, securing funding, managing projects and sharing outcomes.

We believe that caring for people nearing the end of their lives is part of the core business of General Practice and we are committed to the five Priorities for Care of the Dying Person and to the principles contained in the *Duties and Responsibilities of Health and Care Staff* document.

We are committed to:

- promoting excellence in end of life care;
- supporting end of life care commissioning; and
- supporting primary care workforce development, education and training.

We are governed according to the requirements set out in our royal charter, ordinances, bye-laws and standing orders and this is overseen by the RCGP Council and Trustee Board.

Royal College of Nursing (RCN)

The RCN represents the interests of nurses and nursing, promotes excellence in practice and shapes health policies. The RCN also develops and educates nurses professionally and academically and develops the science and art of nursing and its professional practice.

We are fully committed to the five Priorities for Care of the Dying Person and to the principles contained in the *Duties and Responsibilities of Health and Care Staff* document.

We are also committed to implementing the following actions within a year of the response being published:

- communicating and disseminating a clear message of expectation about what dying people and their families should expect from nurses, as set out in the five Priorities for Care;
- ensuring that nurses in all settings are supported in understanding their role in delivering end of life care. We will achieve this by disseminating the Priorities for Care through articles, direct mail, our key principles, our website and our workshops. Regional education staff, linking with local trusts and other providers, will also help to communicate this message;
- developing, by autumn 2014, key principles for nurses delivering care for people in the last days and hours of life;
- creating, by autumn 2014, a central portal on our website to act as the gateway to RCN and others' resources on the care of dying people;
- updating, by spring 2015, our Nutrition Guidance with specific information on end of life care and developing key messages relating to hydration; and
- working with other national organisations, including Public Health England on wider end of life care commitments including updating and aligning, by spring 2015, a number of end of life charters.

The RCN's work priorities are determined by the Strategic plan and departmental operational plans and funding allocated to meet the organisations objectives. This is overseen by the RCN Council.

Royal College of Physicians (RCP)

The Royal College of Physicians supports and represents physicians, sets and monitors standards of medical training and develops evidence-based clinical guidelines and audits. The RCP also develops education programmes to provide physicians with the knowledge and skills they need for high performance.

We are committed to the five Priorities for Care of the Dying Person and to the principles contained in the *Duties and Responsibilities of Health and Care Staff* document.

We are committed to:

- continuing to improve the care of the dying people, ensuring patient and carer involvement;
- reviewing education and training programmes with our partners on the Joint Royal Colleges of Physicians Training Board¹⁰ to ensure that physicians have the knowledge and skills to deliver holistic compassionate care for dying people; and using our expertise in quality improvement, clinical audit, clinical standards, clinical leadership and palliative care in support of the Priorities for Care.

We are governed according to the requirements set out in our royal charter and bye-laws and this is overseen by the Board of Trustees and the RCP Council.

¹⁰ The Joint Royal Colleges of Physicians Training Board (JRCPTB) is a partnership between the RCP, the Royal College of Physicians of Edinburgh (RCPE) and the Royal College of Physicians and Surgeons of Glasgow (RCPSG). The RCPL, RCPE and RCPSG, through the JRCPTB, design and develop curricula and assessment methods for postgraduate core and specialty medical education, in agreement with the General Medical Council (GMC).

Sue Ryder

Sue Ryder is a national charity providing health and social care services in local communities. We provide free care to those affected by life-changing illnesses, delivered through our care centres, homecare services and healthcare clinics, both in the UK and internationally. We work with national and local government, NHS bodies and charity alliances to champion the issues that matter to the people Sue Ryder cares for.

We are committed to the Priorities for Care of the Dying Person and support the plans for a common description and understanding of what good care looks like in the last few days and hours of life. In our role as a specialist provider of palliative care we are committed to clear communication which is at the heart of compassionate care for end of life.

We are committed to:

- supporting personalised approaches to care of the individual and their families and we have invested in training in personalised care for all our staff;
- enabling all providers of end of life care to self-assess how personalised their care provision is, as set out in the document, *Progress for Providers – End of Life*¹¹; and
- continuing to work both within our care settings and across the care environments we touch to support, educate and develop excellent communication skills in order to facilitate meaningful conversations with patients and their families to achieve a peaceful, timely and dignified death.

We have clearly outlined the skills and competencies required for our staff via our Skills Framework work which we completed in January 2014 and which applies to all care and nursing staff.

Our annual report and accounts set out what we have achieved.

¹¹ <http://progressforproviders.org/checklists/progress-for-providers-end-of-life>, published in October 2013

Annex A

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

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

- Health Education England and the other Alliance members will initiate work that guides health and care staff and educators in the use of the e-learning programme, e-ELCA¹², as a resource to support education and training.
- The Alliance has initiated work that will make existing advice to health and care staff on care for dying people, including the advice that already exists in relation to specific diseases and conditions, more accessible, through the creation of a central repository.
- The National Institute for Health Research (NIHR) has commissioned updates of Cochrane Reviews of evidence on medically assisted nutrition and on medically assisted hydration for palliative care patients, and these were published by the Cochrane Collaboration in April 2014. The NIHR has also commissioned a mapping of evidence requirements from the Priorities for Care.
- The Alliance will use the outcomes from the results of the mapping and the recently established James Lind Alliance Priority Setting Partnership, which will work with families and others to find out what palliative and end of life care research is important to people who are likely to be within the last years of life, their families and those identified as important to the dying person, and the health and care staff who work with them, to inform the programme of future research around care for people in the last few days and hours of life.

Further details of this work are set out in the system-wide response to the recommendations of the review panel on the LCP. The system-wide response accompanies this document.

¹² e-ECLA is a series of over 150 highly interactive sessions of e-learning on end of life care, which aims to enhance the training and education of health and social care staff involved in delivering end of life care to people.

