One Chance to Get it Right: One Year On Report

An overview of progress on commitments made in *One Chance to Get it Right*: the system-wide response to the Independent Review of the Liverpool Care Pathway

Title: One Chance to Get it Right: One Year On Report
Author: NHSCS/ NHS Group/ Finance and NHS/ 17189
Document Purpose: Corporate Report
Publication date: July 2015
Target audience:
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1. Introduction

1.1 Background

In July 2013, the Independent Review of the Liverpool Care Pathway (LCP) made a number of recommendations in its report *More Care, Less Pathway* about how end of life care should be improved in the wake of complaints about instances of poor care associated with the use of the LCP.

The recommendations were considered by the Leadership Alliance for the Care of Dying People, consisting of 21 organisations from across the health and care system, including the Department of Health, under the leadership of the National Clinical Director for End of Life Care, Professor Bee Wee.

In June 2014, the Leadership Alliance published a system-wide response to the Independent Review of the LCP, entitled *One Chance to Get It Right*. Leadership Alliance members committed to actions in response to the Independent Review's recommendations and the actions were set out in Annex B of the response. The full *One Chance to Get It Right* report, with annexes, is available online at: https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations.

Alongside the response, the Leadership Alliance organisations set out collective and individual commitments that they as organisations had made to supporting the response and in particular, the five Priorities for Care of the Dying Person.

1.2 One year on report

In addition, the Department of Health signalled its intention to monitor progress against the actions in *One Chance to Get It Right* and to record this progress in a one year on report to be published in summer 2015.

To fulfil that commitment, the Department of Health has sought updates from all the former Leadership Alliance organisations who committed to actions in the response.

This report describes the actions organisations have taken since June 2014 and is organised under broad topics that reflect the themes identified in the response, as follows:

- Quality regulation and inspection;

- Guidance and professional standards;

- Improving the commissioning of care;

- Education and training;

- Sharing knowledge and good practice;

- Research;

- Work to promote the new approach to care in the last days and hours of life, including the Priorities for Care; and

- Other work being undertaken by the Department of Health, NHS England and others.

To update on progress on the implementation of the five Priorities for Care, this report also includes a section on implementation, setting out:

- NHS Improving Quality's work to support implementation;

- A summary account of how the Priorities are being put into practice in local areas and how they are being evaluated for effectiveness. This is based on several implementation case studies submitted by regional Palliative Care Network leads.

- Examples of implementation case studies.

Whilst the updates on implementation provide insight into how different end of life care teams and care provider organisations are incorporating the Priorities into the care dying people receive, they constitute a snapshot of examples of practice and are not intended to represent a comprehensive picture of implementation across the country.

1.3   Priorities for Care of the Dying Person

The five Priorities for Care of the Dying Person form the core of the new approach to care in the last days and hours of life articulated by the *One Chance to Get it Right* response. As a result they are referenced throughout this report and have a bearing on many of the actions described. They are that:

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

- This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

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

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

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

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

Expanded explanations of the Priorities for Care and guidance documents for health and care staff, providers and commissioners are available as annexes to the *One Chance to Get it Right* report.

2. Executive Summary

1. The Care Quality Commission (CQC) has made good progress in meeting the commitments made in *One Chance to Get it Right*. It has finalised and implemented its new inspection approach which fully incorporates the Priorities for Care and addresses specific issues arising from the *One Chance* response, such as education and training and advance care planning, in all the main settings where end of life care is delivered. A number of inspections have taken place since October 2014. These have identified examples of where care is outstanding, as well as examples of poor care, and set out what action is being taken as a result. The NHS Trust Development Authority is committed to working with the CQC to support improvement in providers and Monitor has aligned its approach on the leadership of NHS Foundation Trusts to CQC's new inspection approach.

2. Professional regulators, including the General Medical Council and the Nursing and Midwifery Council have met or are in the process of meeting the commitments they set out in the response, with specific actions to update codes of conduct, improve education and training requirements and curricula and raise awareness of end of life care in general and the messages from *One Chance to Get it Right* in particular. In doing so, in line with commitments made in the response, regulators have also paid particular attention to issues around nutrition and hydration, decision-making, professional candour and recordkeeping.

3. The National Institute of Health and Care Excellence has made good progress in developing and consulting on new guidance on the management of care for dying adults. The guidance is currently out to consultation and is due to be completed by the end of 2015.

4. NHS England, working with Public Health England and others, has set out a number of substantive actions and improvements to service commissioning and taken a proactive lead both in progressing practical actions to improve end of life care services in the medium term and in working with key partners, including end of life care charities, to articulate ambitions for future improvement.

5. NHS Improving Quality has taken a leading role in supporting and advising end of life care providers to adopt the Priorities for Care and in sharing and disseminating good practice based on the principles set out in *One Chance to Get it Right*.

6. Health Education England has taken important steps towards developing end of life care education, training and workforce planning. In particular it has established meaningful links with local education and training boards on the improvement of end of life care education and training, and actions are being taken forward centrally to develop resources, online tools and influence curricula.

7. The National Institute for Health Research has made significant progress in completing key pieces of research on areas of concern such as the use of opioids and the use of medically assisted nutrition and hydration, whilst also issuing calls for new research, overseeing two key projects to identify priorities for end of life care research and establishing a high quality research database resource.

8. Palliative and End of Life Care Networks have played a central role in prompting, coordinating and supporting local efforts to implement and embed the Priorities for Care and the learning from *One Chance to Get it Right*.

9. There have been a number of individual and collaborative efforts by former members of the Leadership Alliance, including Royal Colleges, to disseminate and promote the response and the Priorities for Care, share knowledge and good practice, conduct meaningful research and organise and contribute to education and training incorporating these messages.

10. As well as monitoring the progress of all organisations against commitments made in *One Chance to Get it Right*, the Department of Health has completed work on updating the Mandate to the NHS and on the role of named responsible clinicians.

11. The evidence of progress set out in this report suggests a genuine, sustained commitment across the health and care system to the principles set out in the Priorities for Care. It also bears witness to the practical work being done to deliver genuine improvements to the care dying people and those important to them receive. This includes a commitment to preventing and avoiding repetitions of the poor care identified by the Independent Review of the Liverpool Care Pathway.

12. However, we know, thanks to the CQC's new focus on end of life care, that pockets of poor care still exist. Vigilance and continued commitment across the system will be required to ensure incidents of poor care are minimised, and that every dying person gets the high-quality, genuinely compassionate care they should expect.

3. Quality regulation and inspection

One Chance to Get it Right set out the importance of CQC incorporating the Priorities for Care of the Dying Person, and a number of specific issues raised by the independent review of the LCP, such as education and training, decision-making and leadership, into the work it does to assess care quality in its inspections.

3.1 CQC's new inspection approach in acute hospitals

CQC has been following its new approach to inspections in all inspections of acute hospitals since October 2014. The provider handbook outlining the approach is available at www.cqc.org.uk/content/hospitals-0.

Under the new approach, end of life care is one of the eight core services which CQC will always inspect in acute hospitals, by asking five key questions, namely, whether the service is:

- safe;

- effective;

- caring;

- responsive to people's needs; and

- well-led.

CQC publishes a rating for the end of life care service for each key question in every acute hospital it inspects.

CQC has defined and published the Key Lines of Enquiry which inspection teams follow to answer the five questions for every service. Key Lines of Enquiry, which are of particular relevance in responding to the issues raised in the *More Care Less Pathway* report, include:

- Do staff have the skills, knowledge and experience to deliver effective care and treatment?

- Does the governance framework ensure that responsibilities are clear, quality, performance and risks are understood and managed?

- How are risks to people who use services assessed, and their safety monitored and maintained?

- Are people's needs assessed and care and treatment delivered in line with legislation, standards and evidence-based guidance?

In addition, CQC has developed inspection frameworks for each acute hospital core service. This includes specific guidance on how CQC inspects end of life care services, which is available at:
www.cqc.org.uk/sites/default/files/20141128_eolc_core_service_assessment_framework_v0006.pdf.

This guidance defines the end of life care service as encompassing all care given to patients who are approaching the end of their life and following death, and which may be delivered on any ward or within any service of a Trust.

There are a number of prompts for inspection teams which are of particular relevance, outlined below.

3. Quality regulation and inspection

"Effective" key question prompts:

- Does EOLC achieve the Priorities for Care of the Dying Person set out by the Leadership Alliance for the Care of Dying People?

- What action has the service taken in response to the 2013 review of the Liverpool Care Pathway?

- Are they aware of GMC guidance for doctors in supporting nutrition and hydration in EOLC?

- Are nutrition and hydration needs included in people's individual care pathways?

- Is there a personalised end of life care pathway in use which helps staff identify and care for people at the end of their life?

- Are all team members aware of who has overall responsibility for each individual's care?

"Caring" key question prompts:

- How are patients who are likely to be in the last 12 months of life identified and what action does the service take? For example are people who are approaching the end of life identified, and offered and given the opportunity to create an advanced care plan, including end of life care wishes and any advanced directives (including organ donation)?

- How do staff ensure that sensitive communication takes place between staff and the dying person, and those identified as important to them?

- When a person is in the last days and hours of life, are the dying person and those identified as important to them, involved in decisions about treatment and care to the extent that the dying person wants?

- How are people who are receiving end of life care supported emotionally, especially people who do not have family, friends or carers to support them?

- How do staff ensure that the needs of families and others important to a person who is dying are actively explored, respected and met as far as possible, including after the person has died?

"Well-led" key question prompts:

- Is there a clinical lead for end of life care?

- Is there a service improvement lead for end of life care?

- Is there a Board member with end of life care responsibilities? And are staff aware of who this is?

- Are local governance arrangements clear about the role of the 'senior responsible clinician' in end of life care, particularly their involvement in decision-making?

Between November 2013 and mid-May 2015, CQC published reports from 105 inspections of acute hospitals across England which included publishing a service rating for end of life care. These showed that there was variation in the quality of end of life care services provided, with 57 rated "Good" and 4 as "Outstanding"; 40 were rated as "Requiring Improvement" and 4 as "Inadequate". However, 93% of end of life care services were rated as "Good" or "Outstanding" for the key question "Are services caring?"

Table 1 below summarises published ratings for end of life care services in the locations CQC inspected and rated between November 2013 and mid-May 2015:

Table 1 – CQC Inspections – Acute Hospitals Summary

CQC Ratings: End of Life Care - Acute Hospitals				
Domain	Outstanding	Good	Requires improvement	Inadequate
Caring	3	95	7	0
Effective	1	66	32	6
Responsive	9	58	36	2
Safe	0	55	46	4
Well Led	5	64	32	4
Overall	4	57	40	4

3.2   CQC's new inspection approach in other settings and sectors

Since October 2014, end of life care has been included in CQC's inspection approach in all services where it is delivered. This inspection approach reflects NICE Quality Standard 13, and in its assessment of care for people who are dying, CQC looks at how the five Priorities for Care of the Dying Person are delivered.

3.2.1   Community health services

In community health services, end of life care is one of four core services which CQC will always inspect. CQC inspects end of life care in community hospitals, specialist palliative care community services, and community health teams. The handbook outlining this approach has been published and is available at www.cqc.org.uk/content/hospitals-0.

Table 2 below summarises published ratings for end of life care services in the community health service locations CQC inspected and rated between November 2013 and mid-May 2015:

Table 2: CQC Inspections – Community Health Services Summary

CQC Ratings: End of Life Care - Community Health Services				
Domain	Outstanding	Good	Requires improvement	Inadequate
Caring	2	15	2	0
Effective	1	14	2	2
Responsive	3	12	4	0
Safe	0	11	8	0
Well Led	1	11	7	0
Overall	1	12	6	0

3.2.2 Care Homes

The inspection approach in care homes focuses on person-centred, individualised care, see www.cqc.org.uk/content/adult-social-care-providers#handbooks. Though care homes do not receive a specific rating for the quality of end of life care, the approach does include a specific question about care in the last days of life, as follows:

"How are people supported at the end of their life to have a comfortable, dignified and pain free death?"

3.2.3 GP services

CQC published its new approach to GP inspection in October 2014; see www.cqc.org.uk/content/gp-practices-and-out-hours-service-providers.

This approach looks at a number of population groups where end of life care is of particular importance, including older people, and people with long term conditions.

Although GP services do not receive a specific rating for the quality of end of life care, inspections will ask about end of life care to inform judgement about quality of care for these groups. For instance, under the key question "Is care effective?" inspector prompts include whether assessment, planning and delivery of care in the last 12 months of life is in line with evidence-based guidance, standards and best practice.

Detailed information about what CQC's approach means for inspections of GP practices in terms of end of life care is available online at: www.cqc.org.uk/content/gp-mythbuster-38-end-life-care.

3.2.4 Hospices

CQC published its new approach to inspection of hospices in October 2014; see www.cqc.org.uk/content/adult-social-care-providers#handbooks.

Inpatient hospices, day hospices and community-based hospice services, for adults and children, have been inspected and rated under the new approach from January 2015. During inspections, CQC looks at how the five Priorities for Care of the Dying Person are being delivered. 23 out of 24 hospices inspected and rated so far were rated as delivering 'Good' or 'Outstanding' care overall.

Table 3 below summarises published ratings for end of life care services in the hospice locations CQC inspected and rated between January and mid-May 2015:

Table 3: CQC Inspections - Hospices Summary

CQC Ratings: End of Life Care - Hospices				
Domain	Outstanding	Good	Requires improvement	Inadequate
Caring	14	10	0	0
Effective	3	19	2	0
Responsive	9	15	0	0
Safe	0	20	4	0
Well Led	4	18	2	0
Overall	8	15	1	0

3.3   CQC's thematic review work

CQC continues to undertake a thematic review of inequalities and variation in end of life care. CQC has conducted a review of data available at CCG level, selecting a representative sample of 43 clinical commissioning groups (CCGs) and requesting information on each CCG's local end of life care services. This request covered commissioning for end of life care services (including care in the last days of life), end of life care as part of the commissioning of other services, such as services for older people or people with dementia, and a specific focus on meeting the needs of people who may experience inequalities.

Responses have now been received from 40 CCGs in total. Initial findings are that the majority of CCGs were making provision for end of life care, although only half had a strategy for end of life care. A much smaller number were making specific provision for the priority groups CQC asked about, and this was most frequently for older people and people with dementia. Almost all CCGs said they had provision in place to ensure that health and social care staff in their area had the appropriate skills and training in end of life care, and some provided specific training for staff in end of life care for people with dementia. CQC will look at the impact of commissioning approaches on people's experience of end of life care across services during the fieldwork phase of the review.

Between August and October 2015, CQC will undertake fieldwork in 20 of the local areas included in the CCG sample. During the fieldwork CQC will look specifically at the barriers to good care which people experience, how inequalities are being addressed, and examples of good practice. There are four Key Lines of Enquiry which inspection teams will follow:

- Identification and communication: Are people identified at the appropriate time by a health or care professional, and enabled to have open and honest discussions?

- Co-ordination: Is care co-ordinated effectively to ensure that the person is at the centre of their care, including when they have multiple or complex needs or vulnerabilities?

- Access to good care: Do people and those important to them have timely and equitable access to good quality care in their preferred place of care, from the services they need?

- Care in last days: Does care in the last days and hours of life deliver the five priorities for care of the dying person?

CQC is working with the National Council for Palliative Care, Race Equality Foundation, and National Voices, to develop its understanding of people's experience through a programme of engagement work in the 20 local areas, which it will undertake over summer 2015.

As part of this work, CQC has conducted a survey about the experience of people with dementia at the end of life. Initial findings are that 37% of respondents felt not at all confident that people with dementia approaching the end of their life had their holistic needs met. People with dementia are one of the groups which CQC has prioritised in local area fieldwork, and CQC will highlight good practice at local level where it is identified.

CQC will publish a national report based on the findings of the thematic review in early 2016.

CQC continues to engage with the End of Life Care Partnership Working Group in its development of ambitions for end of life care, to ensure regulation of services which deliver end of life care is aligned with the wider context of improving the quality and safety of care which people experience at the end of life.

3.4   NHS Trust Development Authority

The NHS Trust Development Authority (NHSTDA) incorporated *One Chance to Get it Right* into its 2014/15 planning guidance for NHS Trusts and included this focus in its 2015/16 planning guidance. The NHSTDA is reviewing the responses submitted by Trusts as part of this process and reports that, although there is variation between Trusts, substantial progress has been made in implementing the system-wide response and the Priorities for Care.

Through this process, and using intelligence on end of life care from CQC reports and other sources, the NHSTDA is considering where NHS Trusts may require support and what that support might include. As part of this project, the NHSTDA is planning to run an event in 2015, involving the National Council for Palliative Care, the National Clinical Director for End of Life Care and NHS Improving Quality to showcase examples of good practice within Trusts and target support to Trusts.

3.5   Board level responsibility for end of life care

CQC's inspection approach includes the key question "Is the service well led?" Inspection teams in all settings look at governance and leadership issues, and specifically at Board level responsibility in acute and community trusts, as outlined above. The CQC thematic review may comment on local leadership issues where these relate to findings about inequalities in end of life care.

The NHS Trust Development Authority has gained explicit assurance from NHS Trusts that executive directors at the Trust are leading the end of life care agenda. Monitor and the NHSTDA also have a role to play in working with CQC to ensure that providers are well-led. Monitor, CQC and the NHSTDA published a statement of intent in May 2014 on how they would work together to support improvement in providers and in particular to develop a single overarching framework for judging whether or not an NHS service is well-led. Monitor is also working on updates to its framework for "well led" providers, aligned to CQC's inspection approach.

4. Guidance and professional standards

4.1 NICE Guidance

NICE is in the process of developing new guidance on the management of care for dying adults. Consultation on the draft scope of the clinical guideline was completed in August 2014. The results of the consultation have been analysed and the scope of the guideline finalised. Consultation on the guidance proper began on 29 July 2015 with publication planned for 16 December 2015.

4.2 Professional Standards and Guidance

4.2.1 Nursing and Midwifery Council - Revision of NMC Code

The NMC's revised Code was approved by the NMC Council in December 2014 and published in January 2015. It came into effect on 31 March 2015. The revised Code was supported by extensive liaison with key stakeholder groups and public consultation. It reflects and places greater emphasis on many of the issues highlighted in the Priorities for Care, including communication, involving patients, families and carers in decision making, providing support for families, carers and others identified as close to the dying patient, providing hydration and nutrition, delivering care with compassion, confidentiality, accurate record keeping, respecting the dignity of the patient, advocacy, delegation, evidence based decision-making and raising concerns.

In particular, the revised Code makes specific reference (at Section 1.2) to the need to make sure the 'fundamentals of care' (which include nutrition, hydration, bladder and bowel care, physical handling and ensuring that those receiving care are kept in clean and hygienic condition) are delivered effectively. The Code also states (at Section 3.2) that nurses must recognise and respond compassionately to the needs of those in the last days and hours of life.

4.2.2 General Pharmaceutical Council Review of Core Standards

The General Pharmaceutical Council (GPhC) has begun a number of initiatives to review its core regulatory standards. The GPhC launched a national conversation about patient centred professionalism in pharmacy which ended in June 2015. The information gathered will be used to inform the development of the new standards of conduct, ethics and performance. Alongside this, the GPhC is also reviewing education standards for pharmacists and pharmacy technicians. Each of these reviews will involve formal consultations with patients and the users of pharmacy services, registrants and stakeholders. Both reviews will conclude in 2016.

In addition to regulating pharmacy professionals, the GPhC also regulates registered pharmacies. Through the work to regulate pharmacies, the GPhC has set standards for registered pharmacies, and inspects them to make sure the standards are being met.

The GPhC has recently published guidance for its fitness to practise committees, entitled *Good decision making: fitness to practise hearings and sanctions guidance* which includes specific guidance about dishonesty, candour and raising concerns.

The GPhC have also published a joint statement with the Royal Pharmaceutical Society aimed at highlighting the importance of regulatory and professional standards and guidance as a way to protect patient safety and to promote responsibility and professionalism.

4.2.3   Health Care Professions Council Review of Core Standards

The Health Care Professions Council's (HCPC's) standards of conduct, performance and ethics are currently under review and a Professional Liaison Group was established to consider revisions to the standards drawing on the research and feedback gathering activities HCPC had undertaken to support the review. The draft revised standards of conduct, performance and ethics were considered by the Council in March 2015 and were subject to a public consultation between April and June 2015. HCPC is developing a communications plan to be implemented once the standards are agreed and will consider ways of engaging with registrants and other stakeholders on specific topics, such as recordkeeping. The revised standards are due to be published in January 2016.

The proposed revised standards currently include:

- a revised standard on recordkeeping. This would retain the principles of the current standard (10) but also aims to simplify and clarify expectations.

- a standard requiring registrants to justify the trust other people place in them by acting with professionalism, honesty and integrity at all times. These principles come into play in a registrant's duty to keep full and accurate records.

- a standard on treating service users and carers with respect. Under this standard professionals would be required to:

  - treat service users and carers as individuals, respecting their privacy and dignity;
  - work in partnership with service users and carers where appropriate; and
  - empower and support service users and carers to make informed decisions about the care, treatment or services provided.

- a standard on communicating appropriately with service users and carers, including listening to and taking account of their needs and wishes.

A detailed communication and dissemination plan for the revised standards will be developed in time for planned publication in January 2016.

4.2.4   General Medical Council

The General Medical Council (GMC) is continuing with its ongoing programme of work to give practical advice and support to help doctors deliver high quality end of life care. To this end, the GMC has continued to raise awareness of the advice contained in its guidance document, *Good Medical Practice (2013),* around professional conduct. The GMC has also continued to promote its end of life guidance and the Priorities for Care, at the local and national level, focusing on the key themes it has identified that doctors find challenging and which were highlighted in the review of the Liverpool Care Pathway.

As well as improvements to its own online content, the GMC has made end of life care a priority theme for the work of its liaison teams across the UK who regularly meet doctors, medical students and patients, clinical commissioning groups and other organisations involved in local healthcare services. The GMC has also moved forward with initiatives within undergraduate and postgraduate medical education and training to raise the profile of end of life care and ensure greater emphasis on the communication and decision-making skills essential to delivering a high standard of care to people at the end of life.

4.2.5 Falsification of records

The professional regulators in the Leadership Alliance pledged in the system-wide response to consider this issue and its implications for their own professional standards.

The NMC's revised code of practice makes it clear that falsification of records for any reason – not just in order to deflect future criticism of a failure of care – is unacceptable. Doing so would be a breach of the Code and could lead to fitness to practice proceedings being taken against the registrant concerned. This could lead ultimately to the registrant concerned being struck off the NMC's register.

The GMC guidance on falsification of records in *Good Medical Practice (2013)* states that:

19. Documents you make (including clinical records) to formally record your work must be clear, accurate and legible. You should make records at the same time as the events you are recording or as soon as possible afterwards.

71. You must be honest and trustworthy when writing reports, and when completing or signing forms, reports and other documents. You must make sure that any documents you write or sign are not false or misleading.

> *a. You must take reasonable steps to check the information is correct.*
> *b. You must not deliberately leave out relevant information.*

The GPhC current standards of conduct ethics and performance include a standard that states "Keep full and accurate records of the professional services you provide in a clear and legible form". The standards also include reference to the importance of being honest and trustworthy, and acting with integrity.

The HCPC included in its consultation on its revised standards of conduct, performance and ethics, a new standard on record keeping as follows:

10. Keep records of your work

Keep accurate records

10.1 - You must keep full, clear, accurate and legible records for everyone you care for, treat, or provide other services to.

10.2 - You must complete all records promptly and as soon as possible after providing care, treatment or other services.

Keep records secure

10.3 - You must keep information in records secure by protecting them from loss, damage or inappropriate access.

The proposed standards also include statements about respecting confidentiality and being honest and trustworthy. These principles come into play in a registrant's duty to keep full and accurate records. The HCPC continues to engage with registrants to ensure their understanding of the standards of conduct, including the expectation on them to keep accurate records and to behave with honesty and integrity at all times. This engagement takes place through a number of channels, including direct advice to registrants in response to queries, tailored presentations, employer events, seminars for educational providers, the HCPC newsletter and website.

4.2.6 Duty of Candour

The GMC, NMC, HCPC and GPhC (and other regulators) have undertaken a joint piece of work to consult on and develop a joint statement on the duty of candour. The consultation took place in June 2014 and the joint statement was published in October 2014.

The GMC and NMC published joint explanatory guidance, in June 2015, on what a professional duty of candour means in practice for doctors, nurses and midwives. This covers the duty to be open and honest with patients, or those close to them, if something goes wrong (including advice on apologising), together with the duty to be open and honest with their organisation, and to encourage a learning culture by reporting adverse incidents that lead to harm, as well as near misses. The joint guidance was published in June 2015. In order to take this work forward and to implement the guidance, the GMC and the NMC both plan to develop a series of case studies that will demonstrate how the guidance applies in practice. Some of the case studies will be produced jointly to reflect scenarios where doctors, nurses and midwives are working together in teams to reflect how the duty of candour applies in those situations.

In addition, the NMC's revised code of practice has made explicit the existence of and the need to abide by a professional duty of candour, requiring registrants to volunteer information to persons harmed when things go wrong or when there has been a near miss; to act without delay if they believe there is a risk to patient safety or public protection; and to escalate all such concerns where appropriate.

The HCPC's proposed revised standards include a new core standard requiring registrants to be open and honest when things go wrong, dealing with mistakes and handling complaints, which will require specified actions from registrants, as follows:

8. Be open when things go wrong

Openness with service users and carers

8.1 - You must tell service users and carers when you become aware that something has gone wrong with the care, treatment or other services that you provide and take action to put matters right.

8.2 - You should apologise to service users and carers when something has gone wrong.

8.3 - You must make sure that those affected receive a full and prompt explanation about what has happened and any likely effects.

Deal with concerns and complaints

8.4 - You must support service users and carers if they want to raise concerns about the care, treatment or other services they have received.

8.5 - You must give a constructive and honest response to anyone who complains about the care, treatment or other services they have received.

4.2.7 Decision-making

The revised NMC Code contains strengthened generic requirements on decision-making, delegation, leadership and addressing concerns in general. Publicity accompanying the launch of the new Code has highlighted specific issues, such as decision-making. This builds upon previous work in this area, such as the publication in a more accessible form of the NMC's existing generic competency standards on decision-making on its website.

4.2.8 Nutrition and Hydration

The revised NMC Code contains new requirements on nurses supporting the nutritional and hydration needs of people in their care, as well as providing other fundamental elements of care, to all patients, including those in the final days and hours of life. The consultation on the draft revised Code has in itself raised the profile and awareness of nurses' responsibilities regarding nutrition and hydration. Publicity accompanying the launch of the new Code has also drawn attention to the new requirements around nutrition and hydration. This builds upon previous work such as the publication in a more accessible form of the NMC's existing generic competency standards on supporting patient nutrition and hydration on its website.

The HCPC considers that the duty of professionals to support patients to eat and drink where this is desired and not harmful is included in the requirement to promote, protect and act in the best interests of service users, which is contained in the standards of conduct, performance and ethics. Failure to do so could endanger a professional's registration. The HCPC highlights these expectations on a case-by-case basis where such issues are raised with regard to a registrant's practice. Additionally, the HCPC continually communicates and engages with its registrants to ensure they have a clear understanding of its standards, through queries and correspondence; newsletters, social media and the HCPC website; and through speaking engagements and events.

The Royal College of Nursing (RCN) has developed a new resource to support nurses to understand the nutrition and hydration needs of people at the end of their lives. To underpin this work, the RCN commissioned a review of the evidence relating to nursing care in the support of nutrition and hydration at the end of life. The RCN also undertook a survey of its members about their experience of end of life care in their care settings and what support and training they received. The new multi-platform online learning resource (accessible on a tablet, smartphone or PC) was made available online in June 2015 at www.rcneolnutritionhydration.org.uk.

To support this, the RCN also developed a 'Fundamentals of End of Life Care' resource, covering basic care, communication, symptom management, dignity, spirituality, bereavement and staff resilience. Both resources were made available in July 2015 and were developed to be accessible to nursing staff in all settings.

The RCN is planning a second phase of work in autumn 2015 to disseminate and promote the resources and evaluate their usefulness and impact on nursing knowledge and patient experience. This will include a series of workshops in partnership with the National Council of Palliative Care.

5. Improving the commissioning of end of life care

NHS England made a number of commitments in *One Chance to Get it Right* to improving the commissioning of end of life care services, including the services for which it has direct responsibility as commissioner. In November 2014, it published *Actions for End of Life Care: 2014-16*, which sets out its ongoing commitment to improving end of life care and incorporates the actions flowing from *One Chance to Get it Right* within a broader set of priorities for that period. In 2015, NHS England and its partners across the health and social care, and statutory and voluntary community, plan to publish an *Ambitions for End of Life Care* document, which will provide a system-wide vision for improving end of life care into the future.

5.1   Embedding the Priorities for Care in Commissioning

NHS England has committed (with the NHS Commissioning Assembly) to embedding the Priorities for Care in commissioning processes. The recently published NHS Standard Contract for 2015/16 includes a new requirement that providers of care under the contract "must have regard to Guidance on Care of Dying People", as a result of the publication of *One Chance to Get it Right*.

NHS England is working to improve equity of access to high quality care and services for the most vulnerable and excluded in society through the commitment to deliver high quality care for all, and will continue to work on this for people with learning disabilities and people with dementia as part of its work plan for 2015/16. NHS England's "New Models of Care" programme has approved six vanguard sites with a specific focus on the quality of care within care homes.

NHS England is also actively contributing to the CQC's thematic review of inequalities and variation in end of life care for those groups who appear to have a comparatively worse experience of care.

5.2   Progress on services NHS England is responsible for commissioning

In November 2014, NHS England began work with the health and justice clinical reference group to address the commissioning of prison and offender health care at the end of life. The objectives are:

- to benchmark best practice activity across the secure and detained estate;

- to identify and understand those elements of end of life care that are unique to secure and detained settings, including the implementation of the Priorities for Care for the dying person as set out in *One Chance to Get it Right*;

- to identify training needs for providers and commissioners; and

- to support and facilitate training for providers and commissioners.

Ongoing work includes:

- supporting Macmillan Cancer Support, which has pledged to support best practice training – a group is being established to support this work, led by Macmillan's Prison Project lead;

- the development by NHS England and the National Offender Management Service (NOMS) of a community charter to suit the secure and detained environment and to fulfil the community commitment to palliative and end of life care;

- developing links with the Patient Involvement Team to support those affected, either directly or indirectly, by the death of a loved one; and

- work being done as a separate expert panel to develop resuscitation guidelines. This work supports the agenda in respect of 'care after death ' guidelines.

5.3. Improving availability of specialist palliative care, including out of hours

NHS England has published a sample service specification for end of life care which can be used by CCGs – this includes specific attention to the *Priorities for Care: Implementation Guidance for Service Providers and Commissioners* document (published as Annex E of the *One Chance to Get it Right* response in June 2014), including its focus on access to specialist palliative care 24 hours a day, 7 days a week.

In addition, NHS England is:

- developing a full service specification for specialist palliative care which can be used as a basis for commissioning and for peer review or service accreditation – work on this is ongoing with expected completion in Autumn 2015.

- working with Public Health England, to develop and pilot a national clinical data set for adult specialist palliative care which will support clinical assessment and enable clinical outcomes and patient experience to be measured. Pilot sites have been selected and the 2015-16 technical feasibility pilot was launched in May 2015.

- testing, at 39 pilot sites during 2015/16, the development currencies (groups of healthcare provision with broadly similar resource usage) that will underpin any future payments system for specialist palliative care. The development currencies use a case-mix classification that takes into account complexity of patient needs. The currencies will be made available for widespread use in 2016-17, at the same time as the National Clinical Data Set. Together, the currencies and dataset will improve understanding of patient populations that largely non-NHS providers serve, and facilitate discussions between service providers and commissioners about greater accuracy in meeting the needs of those populations.

5.4. NHS England work on seven day services

NHS England has committed to identifying barriers and potential solutions to people having their end of life care needs met whenever necessary.

The NHS Services Seven Days a Week Forum has identified that the general reduction of services at weekends, across primary and community health settings and social care, combined with a reduced hospital offer, may put additional pressure on, and cause the failure of multi-setting and multi-agency arrangements set up to support people with complex needs, including vulnerable people and those in their last days and months of life. The Five Year Forward View commits NHS England to develop a framework for implementing seven day services affordably and sustainably, to meet patients' changing needs, prevent harm and remove unacceptable variations in outcomes.

5. Improving the commissioning of end of life care

Ten evidence-based clinical standards, to end the current variation in outcomes at the weekend, together describe the minimum standards of care that all in-patients admitted through urgent and emergency routes should expect to receive. Those standards have relevance to end of life care as well as other aspects of care and treatment.

NHS England has required commissioners and providers to agree Service Development and Improvement Plans for 2015/16, setting out plans to make significant progress towards implementation of at least five of the standards.

NHS England has also announced a new independent taskforce to develop a five-year action plan for cancer services that will improve survival rates and save thousands of lives. The taskforce has been asked to deliver the vision set out in the NHS Five Year Forward View, which calls for action on three fronts: better prevention; swifter diagnosis; and better treatment, care and aftercare for all those diagnosed with cancer. This includes end of life care for those who need it.

6. Education and training

Work to improve the education and training of health and care staff formed a major part of the *One Chance to Get it Right* response. This section sets out the work being done by the main bodies responsible for education and training, namely, Health Education England (HEE), the General Medical Council (GMC), the Nursing and Midwifery Council (NMC), and the Royal Colleges.

6.1 Health Education England work on education and training

HEE is taking a system-wide approach by promoting, supporting, embedding and implementing the Priorities for Care across its 13 Local Education and Training Boards (LETBs) and its stakeholder networks. It is also part of the NHS England partnership working group on end of life care and Public Health England's National End of Life Care Intelligence Network to ensure an integrated, consistent and coherent approach across the healthcare system in providing high quality end of life care.

During 2014/15, HEE identified a wealth of relevant education and training resources relating to end of life care that were available to the NHS workforce but found a lack of evidence on which types of education and training approaches delivered high quality care for the dying. As a result, HEE is currently reviewing the efficacy of existing education and training resources to determine the effectiveness of education and training resources in upskilling the NHS workforce to deliver high quality end of life care. The Review will report its findings to HEE during summer 2015.

HEE will work in partnership with NHS England and other key stakeholders to showcase the outcomes from the Review, with a focus on best practice and effective education and training resources which deliver excellence in end of life care across the NHS workforce.

6.1.1 Development of evidence-based education and training on care of the dying in all settings

HEE has engaged its 13 LETBs in developing and influencing education and training on care of the dying. A central HEE workforce development budget has been allocated to embed evidence-based education in all settings that care for the dying and to improve workforce planning to ensure sufficient staff are trained. The commission to each of the four geographical Directors for Education and Training requests evidence and best practice from LETBs in developing and influencing education and training on care of the dying.

In response, LETBs have undertaken a range of activities on end of life care education and training, ranging from piloting of effective approaches to end of life care to funding specific projects and training programmes to upskill the local NHS workforce. This work is ongoing.

HEE is awaiting the completion of its review into the efficacy of education and training resources, practice and programmes to inform its strategy to embed evidence-based education in all settings. It has allocated funding to promote those resources found to have a positive impact on the quality of care for the dying and will work with key strategic partners – NHS England, PHE, NHS Employers and the CQC – to map and identify the best methods of promotion so that frontline professionals and all healthcare providers can use these resources as part of continuing professional development and training.

The GMC has supported this work by sharing data from its Medical School Annual Returns about coverage of end of life care in undergraduate medical education. This supplements the information already published, in *One Chance to Get it Right*, about coverage in postgraduate

education. The GMC has also shared details of its plans for strengthening the professional elements of postgraduate curricula through a generic professional capabilities framework (described later in this report) and details of its wider programme of work aimed at promoting guidance and resources on end of life care.

HEE Yorkshire and Humber has taken a regional approach and piloted end of life care education and training with registered and unregistered providers of care. It has also conducted a literature review of end of life care training resources and worked with primary care providers. The learning from these three projects has shown that employer buy-in and investment in staff training was essential to improve the quality of care for the dying.

6.1.2 Development of appropriate workforce planning to support the commissioning and delivery of good quality end of life care provision.

HEE has published its workforce plan for 2014/15 which focuses on developing a professional healthcare workforce across primary, secondary and social care to improve the quality of patient care and patient experience.

HEE is working with NHS Employers to consider effective approaches in engaging Trusts to review resources and investment in education and training on end of life care. This will inform the development of a strategy to improve NHS Trust investment into end of life care workforce education and training.

HEE is engaging with the CQC to explore the potential to improve NHS Trust investment into end of life care workforce education and training.

The HEE national workforce plan reflects demand in both the acute and community sectors of nursing. However, information from community employers is indicating that rising demand for nurses in the acute hospitals may be reducing supply into community posts. HEE have established a Transforming Primary and Community Nursing programme with NHS England to identify what further actions can be taken as a system to ensure sufficient jobs are created in the community and that individuals are incentivised and supported to choose them. Specifically, the programme aims to ensure an adequate supply of highly skilled, competent nursing staff to improve individual outcomes and support the move to care closer or in the patients' home, including those in the last stages of their life.

Strategically, HEE is working with NHS England and the wider system through its Workforce Advisory Board to better understand the wider primary care workforce needs of the Five Year Forward View. This is to ensure the wider workforce – such as community and district based nursing – is growing sufficiently to keep pace with the growth of GPs and to deliver the new models of care. This will align and connect with HEE's Independent Commission on Primary Care.

6.1.3 Development of e-ELCAs (End of Life Care for All - online learning modules)

The review of e-ELCA to remove references to the Liverpool Care Pathway has been completed by the Association for Palliative Medicine (APM) in partnership with HEE. References found in e-GP (e-Learning for General Practice) have also been identified and removed. Planned work to ensure all e-ELCA content is up to date is being undertaken by the APM and will be completed by December 2015. To maximise the use of e-ELCA as a training resource, four workstreams have been put in place by HEE working with the APM, the National Clinical Director for End of Life Care and other Leadership Alliance members, as follows:

- a "Training Needs Analysis" session has been developed to identify the training needs of staff and how e-ELCA can be used to support education and training to enhance the quality of care for patients in the last days of life and support for their families;

- existing e-ELCA sessions specifically relating to care in the last days and hours of life have been identified as 'core' sessions and grouped by broad staff groups and care settings;

- a guide has been produced that maps e-ELCA sessions, including the 'core' sessions and other useful relevant sessions and case studies, against the nine high-level learning objectives in Annex E (iii) of *One Chance to Get it Right* to enable those commissioning and developing training programmes to identify sessions depending on the programme, level of practice of the intended learner, duration and format;

- a broader guide and other resources have been produced to help health and care staff and educators maximise the effectiveness of e-ELCA as an end of life care training resource and increase its usage. An online survey and a small number of focus groups were undertaken between January and March 2015 to identify examples of how individuals and organisations have successfully used e-ELCA and what factors need to be in place to increase uptake.

HEE delivered a progress report on the e-ELCA content review to the End of Life Care Partnership Working Group meeting in March 2015 and subsequently promoted e-ELCAs through refreshed communications across its network and partners.

6.1.4 Shared decision-making

HEE has developed an e-learning module to support shared decision-making which can be accessed at www.e-lfh.org.uk/programmes/shared-decision-making. This is not specifically aimed at end of life care but the interdisciplinary nature of the module makes it relevant for all types of training curricula aimed at healthcare professionals. HEE is reviewing penetration rates to assess accessibility to e-learning materials and whether this resource is incorporated in NHS Trust workforce training plans.

6.1.5 Nutrition and Hydration

NICE Clinical Guideline 174 recommends that hospitals establish systems to ensure that all health care professionals involved in prescribing intravenous fluids are trained in the principles covered in the guideline. E-Learning for Health and NICE have created content in the form of an e-module for the Foundation e-Learning Project to help Foundation doctors meet the NICE standard. This aims to support all prescribers and trainee prescribers to safely and effectively assess, prescribe for and review adult patients requiring intravenous fluids.

6.2   General Medical Council work on education and training

6.2.1   Joint letter to medical schools from the GMC and the Medical Schools Council

The GMC and the Medical Schools Council wrote jointly on 1 July 2014 to all Deans of medical schools reminding them of the need to ensure that the curricula they set should equip students effectively to support the care of dying people. As a follow up, the GMC included a question in the annual return it requires medical schools to complete as part of its quality assurance processes. The purpose of this question is to check whether medical schools have reflected on *One Chance to Get it Right* and made any changes as a result of the report.

The responses show there is a mixed economy of end of life care teaching across the medical schools. A summary of the responses is set out in Box 1 below. More detailed information about how each school covers end of life care teaching has been published with the Medical School Annual Returns. These are available on the GMC website at: www.gmc-uk.org/education/26867.asp.

The GMC has fed its analysis of the responses into the work that HEE is doing to take a closer look at end of life care teaching methods, assessment tools and learning experience. The GMC intends to work with HEE to identify areas of practice to focus on in 2015, as part of the next Medical School Annual Return process or through its quality assurance processes.

As part of the GMC's ongoing quality assurance visits programme, it has established arrangements to identify examples of 'notable practice' in teaching and training in relation to end of life care.

Box 1: GMC analysis of responses received from Medical Schools

Question posed to Medical Schools:

How does your school teach students how to best handle the issue of the care of dying people? Paragraph 14J of Tomorrow's Doctors, 2009, which covers the doctor as a practitioner and includes outcome requirements on the diagnosis and management of clinical presentations, requires that students must contribute to the care of patients and their families at the end of life, including management of symptoms, practical issues of law and certification, and effective communication and team working. The care of dying people is an important issue, and it is key that students are prepared effectively. We would like to know how you have reflected on and made changes as a result of the Leadership alliance on the Care of Dying People report.

Analysis of responses

The returns from medical schools show that undergraduate medical education comprises a mixed economy of theoretical and practically-based learning on end of life care. The returns highlight the complexity and integral nature of the clinical and professional skills required of doctors dealing with vulnerable patients and those closest to them. Many schools refer to the changes made in the delivery of education in light of the review of the Liverpool Care Pathway (LCP) and the system-wide response. Across the board, schools appear to be factoring in the key elements specified in the GMC's outcome requirements, its ethical guidance and in the five Priorities for Care. Some schools report that they actively explore with students why the LCP was withdrawn and its limitations.

Are schools meeting GMC outcome requirements in paragraph 14 of Tomorrow's Doctors 2009; and have they responded to changes following the abolition of the Liverpool Care Pathway?

The returns indicate that schools are placing considerable emphasis with end of life education on the elderly and frail. Practical experiential opportunities, including working within hospices, prescribing and case based discussion feature as elements across schools. In addition to lectures and seminars, role play (on communication and breaking bad news) and e-learning form part of the blended learning provided by schools. There was also reference to education focussing on the complexities associated with patients who wish to die in their own homes and the importance of interaction between professional groups, particularly in the community setting.

Clinical: In terms of the clinical components, education focuses on care planning, symptom and pain management, medication and drug charts and 'do not resuscitate'. A number of schools referred to clinical placements. One school highlighted that in year 4, there is a focus on the care of patients with malignant and life-limiting disease. This pathway includes placements and learning in oncology, haematology, as well as palliative and hospice care.

Professional: In respect of the associated professional and human factors related skills, there is coverage of ethics, communication with patients and those closest to them, and multi-disciplinary team approaches to care. Some schools highlighted coverage of the components of breaking bad news, understanding and responding to patients and relatives' grief and respecting different cultural and religious beliefs about death and bereavement. Schools also cited the practical instruction which students receive about the death certification process.

6.2.2   Development of Framework of Generic Professional Capabilities

The GMC and the Academy of Medical Royal Colleges are jointly consulting on a draft framework for generic professional capabilities, which would apply to all specialty training. The framework will describe the human qualities required of doctors such as being able to communicate effectively, to work as part of or lead a team, to share decision-making with patients and to apply a range of other professional skills or judgements in complex or difficult circumstances. These themes are integral to all clinical care, but particularly important to end of life care, as was highlighted in the *One Chance to Get it Right* report. The consultation runs until 22 September 2015.

6.2.3   End of life care resources for doctors

Recognising the challenges of ensuring that helpful resources are accessible to and known about by busy working doctors, the GMC has continued with work to make its own resources as practically helpful and widely accessible as possible. It has been working to deliver in 2015:

- a continuing professional development (CPD) electronic application ('app') for all doctors to help them plan, carry out and evaluate their CPD. The aim is to enable doctors to access information about end of life care and encourage them to think how to use this information to develop their understanding of the issue more fully. The 'app', which will be launched during summer 2015, is based on GMC CPD guidance and emphasises the importance of relevant and reflective learning and development as part of appraisal processes. This product will give GMC greater reach into the medical profession to promote and provide support on professional, legal and ethical issues. It will also facilitate provision of GMC advice on good practice in CPD and on professional self-reflection. Learning and development on end of life care will be promoted in the 'app';

- an interactive decision-making tool to guide doctors through the process of making decisions with patients who lack the capacity to make a decision about treatment and care. The tool is due to be launched in autumn 2015;

- a new dedicated section of the GMC website that links together all of its end of life care content and signposts to helpful external resources, to make relevant tools and guidance more easily identifiable to doctors and other users;

- a pilot outreach programme in which the GMC will work with partner organisations to deliver a programme of combined guidance, training and follow-on support to groups of doctors on the front line who are seeking to improve the standards of end of life care delivered to their local population of patients; and

- support for NHS e-Learning for Healthcare in its work to update e-learning content on end of life care.

6.3   NMC work to update its pre-registration education standards

The NMC has made good progress in evaluating its pre-registration education standards and recently received an interim evaluation report from IFF Research, which is carrying out this work on the NMC's behalf. The NMC anticipates receiving the final evaluation report towards the end of 2015. The evaluation findings will set out which elements of the pre-registration education standards need to be reviewed and revised and enable NMC to progress to a review of NMC's current standards and requirements around end of life care, hydration and nutrition.

6.4　Royal College of Physicians (RCP) work on education and training

The Chair of the Specialty Advisory Committee for Palliative Medicine (a standing committee of the RCP and the Association for Palliative Medicine) has produced new guidance on training junior doctors in non-palliative care in end of life issues for the Joint Royal Colleges Postgraduate Training Board (JRCPTB). The guidance was published in August 2014 and revised in November 2014. *Training in palliative and end-of-life care: Guidance for trainees (and their trainers) in non-palliative medicine training posts* has been distributed to the relevant specialty advisory committees, and is available on the JRCPTB website.

Many specialty curricula now specifically mention care at the end of life, and each speciality advisory committee has been asked to consider this advice in the context of their own curricula to see if any further revisions are needed following the publication of *One Chance to Get It Right*.

6.5　Organisations working together to improve education and training

6.5.1　Royal College of General Practitioners (RCGP), GMC and Royal College of Nursing (RCN) - End of Life Care Training Workshops

The RCGP is working with the GMC and the RCN to run a series of pilot workshops to support GPs with issues such as advance care planning. The first of these, "Delivering Effective End of Life Care", was held in September 2014 and received positive feedback. The series has included workshops on pain control, advance care planning, palliative care emergencies, GMC guidance, and nutrition and hydration. Marie Curie, Macmillan, the GMC and the RCN have all worked with the RCGP to deliver this. As part of its 2015 outreach programme, the GMC is now planning next steps for this work as a longer term means of engaging with groups of GPs, in addition to the ongoing work of GMC regional teams.

As an example, the workshop on nutrition and hydration covers:

- understanding the physiology of food and fluids in dying patients;
- understanding and minimising the situations in which patients are managed inappropriately;
- understanding of situations that cause problems;
- understanding communication issues around end of life;
- knowing how and when to ask for specialist support; and
- being aware of any locality-specific challenges.

The GMC is working with the National Council for Palliative Care (NCPC) to explore the possibility of producing a range of short films during 2015 to help doctors with key aspects of end of life care and to contribute to the NCPC's work supporting the Dying Matters Coalition.

6.5.2　RCN Workshops

The RCN has also held a number of workshops in individual work settings to discuss the Priorities for Care and will continue to support nurses, including non-registered nurses, to understand how the Priorities can be translated into wider practice and implemented effectively. The RCN has a long term commitment to support nurses to feel better equipped to deliver end of life care in all settings and has emphasised it is particularly aware of the needs of nursing staff in non-NHS settings.

6.5.3 HEE group on education, training and workforce issues

HEE has established a small group including representation from HEE Central and its LETBs, the RCP and the RCGP, to progress joint initiatives on workforce planning and education and training to support the Priorities for Care. HEE is also working with NICE and the APM in developing e-learning tools to support high quality end of life care.

6.5.4 Sue Ryder - Human rights approach to end of life care

Sue Ryder has an ongoing commitment to supported personalised approaches to individuals and their families and continues to invest in training in personalised care for its staff. Sue Ryder is working with the British Institute of Human Rights to develop an educational resource which can support staff through a human rights approach to end of life care.

6.5.5 Chaplaincy involvement in education and training

Across the country, chaplains have been providing doctors and nurses in individual local areas with education and training on spiritual care at the end of life, in line with the Priorities for Care.

7. Sharing knowledge and good practice

7.1 NHS Improving Quality

7.1.1 Refresh of End of Life Care Publications

NHS Improving Quality (NHS IQ) is currently refreshing all end of life care publications to reflect recent changes and ensure that all relevant documents clearly map to the Priorities for Care requirements. Progress is being made in reviewing and editing the 34 documents currently in the portfolio and making them available across the system.

The following publications have already been completed and republished on the NHS IQ End of Life Care web pages on the NHS IQ website at: www.nhsiq.nhs.uk/capacity-capability/advancing-change/publications.aspx:

- *Capacity, care planning and advance care planning*;

- *A guide to capacity, care planning and advance care planning* – full report and executive summary;

- *Training Needs Analysis report* - communication skills for end of life care (with all key phrases within the report mapped to the five Priorities for Care);

- *Electronic Palliative Care Coordination System (EPaCCS) Lessons Learnt report*; and

- *Planning Your Future Care* guide.

NHS IQ also provides a monthly bulletin which is circulated through end of life care contacts and networks.

A number of additional publications supporting end of life care delivery have also been collated including: "Considerations of Quality Assurance for Care in the Last Days of Life", "Measurement for Improvement" and "Measuring experience of care in end of life care" fact sheets.

NHS IQ also aims to update and publish the following further documents during 2015:

- *'How To' Guide*

- *The Route to Success* series

- The End of Life Care Commissioning Tool Kit.

NHS IQ has expanded the resources available on the dedicated NHS IQ website linking to or hosting the *One Chance to Get it Right* documentation - see www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care.aspx. A Pinterest board has also been created to share resources and information further on improving end of life care - see www.pinterest.com/nhsiq/end-of-life-care.

7.1.2 End of Life Care Facilitators Network

NHS IQ has been providing support to the end of life care facilitators and social care champions network, and forged links between facilitators. As there remains wide variation in how end of life care facilitators are employed and deployed, NHS IQ's input is aimed at:

- supporting knowledge curation and sharing good practice;

- helping facilitators to support effective networking across the country both regionally and nationally; and

- supporting updates for e-ELCA.

A significant proportion of training needs are addressed through end of life care facilitators and social care champions, especially as many hold individual roles that might include an expectation to reach out and connect across the whole system: for example into hospitals, primary care settings and care homes. NHS IQ will work closely with the facilitator networks to build and strengthen links, support learning exchange and knowledge sharing. It will also work through the Strategic Clinical Networks (SCNs) to reach out to care providers more widely.

The online network for the end of life care facilitators and social care champions network is now hosted by the University of Hull, Centre for End of Life Care Studies and functions to link people across the network, enable discussion forums and promote a proactive approach to sharing and learning. NHS IQ is currently undertaking a survey actively seeking feedback on the network and will act on the results.

7.1.3 National End of Life Care Event

A national event was held in June 2014 for end of life care facilitators and social care champions providing an opportunity for organisations to present case studies and examples of work they had been doing to prepare for the Priorities for Care publication, and its anticipated requirements.

The work focused on building capability and maturity within the networks and raising awareness of the need to consider local and regional development of facilitators' roles. Conversations were also carefully linked to the 'Commitment for Carers' work that the NHS IQ's Experience of Care programme is leading on. The event slide set is available on Pinterest via www.pinterest.com/nhsiq/end-of-life-care.

7.1.4 End of Life Care Facilitator Events

NHS IQ, the National Council for Palliative Care (NCPC) and Hospice UK worked together to hold a series of regional end of life care events between January and March 2015. Delegates included end of life care facilitators, social care champions, palliative care network leads, hospice directors and staff, clinical leads, nurse directors and GPs. In total, around 500 people attended. The aim was to:

- share knowledge and best practice, as well as ways to share this widely across the sector by developing a set of case studies from the plenary and workshop sessions across the five locality events;

- provide more substantial links to palliative care and hospice networks;

- explore how to build in sustainability, capability and improvement for the networks as a whole;

- support Health Education England's review of e-learning for end of life care.

7.2   NHS England

7.2.1   National Palliative and End of Life Care Network

NHS England has established and provides secretariat support to a National Palliative and End of Life Care Network. The overall aim of the Network is:

- to support and ensure implementation of the relevant components of the system-wide response of the Leadership Alliance for the Care of Dying People;

- to provide input to the development of forthcoming system-wide Ambitions for End of Life Care, ensuring that the objectives and actions remain relevant and responsive to the needs of people approaching the end of life;

- to endorse and raise the profile of the proposed system-wide Ambitions within each individual organisation and the wider system including monitoring, challenging and supporting progress on delivery of agreed objectives and actions of the networks in relation to the Ambitions;

- to raise the profile of end of life care at a local level and support this at national level; and

- to ensure efforts to improve end of life care, are coordinated as far as possible, using the architecture of the strategic clinical networks and other informal networks to facilitate maximum impact and avoid duplication and wastage.

NHS England continued to support the national network throughout 2014/15. Over that period, the networks both at local and national level demonstrated their ongoing commitment to implementing *One Chance to Get it Right* and other improvements to the care dying people receive. The networks have provided implementation case studies for this One Year On report, supported and advised local initiatives to implement the Priorities and provided a consistent message nationally on improving care in the last days of life. A huge amount of work has been done nationally to learn from *One Chance to Get it Right* and to embed the Priorities for Care. In this way, the networks have played a crucial role in sharing good practice and providing informed support and advice.

7.2.2   Regional events with commissioners

Working with NHS Improving Quality, NHS England held a number of regional events during March and April 2015 with a specific focus on commissioners of end of life care. These events were co-designed to provide local commissioners with updates on recent national developments on end of life care (for example, on NHS England's *Actions for End of Life Care: 2014-16*), alongside providing an opportunity for commissioners to engage and network locally and share good practice.

7.2.3   Publication of *'Safer Staffing: A Guide to Care Contact Time'*

As a broader development, in November 2014, the Chief Nursing Officer for England published the above guide, which sets out the expectations of commissioners and providers to optimise nursing, midwifery and care staffing capacity and capability so that they can deliver high quality care and the best possible outcomes for their patients.

7.3 General Medical Council

7.3.1 GMC 'Sharing Good Practice' Programme

Following the "Review of approach to the quality assurance of medical education and training", the GMC is enhancing its approaches to sharing areas of good practice to support and drive improvement in local systems. It has developed a programme to promote, identify and share areas of good practice in medical education and training.

Working with medical schools, postgraduate training bodies, and local education providers, the aim is to develop case studies which will be published on the GMC website. As part of this work, the GMC will be exploring what initiatives exist to improve end of life care in the context of medical education and training.

7.3.2 Role of GMC Regional Liaison Service in promoting end of life care

The GMC's regional teams throughout the UK continue to promote end of life care in relation to GMC guidance and the key challenging themes in end of life care for doctors. The GMC is frequently asked to present on end of life care topics and has developed a training package to meet this need.

8. Research

8.1 Progress on the work of the James Lind Alliance

The James Lind Alliance, which is funded by the National Institute of Health Research, supports patients and clinicians in working together to agree which are the most important treatment uncertainties affecting their particular interest.

The palliative and end of life care James Lind Alliance Priority Setting Partnership (PSP) was initiated in October 2013 by Marie Curie, and co-funded by Marie Curie, the NIHR 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 the staff who work with them.

This work is now complete. The initial survey was launched in November 2013 and gathered responses from 1,403 patients, carers, family members and professionals.

In November 2014, 24 patients, current and bereaved carers, clinicians and health and social care professionals met to discuss the resulting shortlist of the 28 highest priority questions and agree the 'Top 10' uncertainties for the PSP. The PSP published a report outlining these 'top 10' research questions at the Public Health England Palliative and End of Life Care Research Summit, hosted by the National End of Life Care Intelligence Network and NHS England, on 15 January 2015.

The 'top 10' research questions are set out in Box 2 below. The work of the PSP will help guide researchers and research funders towards important research questions in palliative care.

8.   **Research**

Box 2: Top 10 Research Questions in Palliative and End of Life Care

1. What are the best ways of providing palliative care outside of working hours to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families.

2. How can access to palliative care services be improved for everyone regardless of where they are in the UK?

3. What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?

4. What information and training do carers and families need to provide the best care for their loved one who is dying, including training for giving medicines at home?

5. How can it be ensured that staff, including healthcare assistants, are adequately trained to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?

6. What are the best ways to determine a person's palliative care needs, then initiate and deliver this care for patients with non-cancer diseases (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), AIDS, multiple sclerosis, Crohn's disease, Parkinson's disease, dementia, and stroke)?

7. What are the core palliative care services that should be provided no matter what the patient's diagnoses are?

8. What are the benefits, and best ways, of providing care in the patient's home and how can home care be maintained as long as possible? Does good coordination of services affect this?

9. What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case coordinator improve this process?

10. What are the best ways to assess and treat pain and discomfort in people at the end of life with communication and/or cognitive difficulties, perhaps due to motor neurone disease (MND), dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer, for example?

8.2   National Institute for Health Research call for research

In May 2015, the NIHR Health Technology Assessment (HTA) Programme put out a call for clinical and applied health research into end of life care, with a particular interest in interventions in the last 30 days of life and the evaluation of interventions for the management of end of life care in people with non-cancer and cancer related conditions. The NIHR HTA Programme funds research to assess the effectiveness of technologies within the NHS.

The call for research includes symptom management, supporting informed decision-making, the use of technologies or interventions that support patients' ability to die at home if they wish, and developing the knowledge, skills and confidence of patients, carers and health professionals in care delivery. Full research proposals will be reviewed in February 2016 with expected start dates for research in late 2016.

8.3   Research on medically assisted nutrition and medically assisted hydration

The two updates in medically-assisted nutrition and hydration were published in April 2014 by the Pain Palliative Care and Supportive (PaPaS) Cochrane Group. These can be found online at: www.ncbi.nlm.nih.gov/pubmed/24760679 and www.ncbi.nlm.nih.gov/pubmed/24760678.

Both updates concluded that there remain insufficient good-quality trials to make any recommendations for practice on the use of medically-assisted nutrition or hydration in palliative care patients.

8.4   Research on the impact of opioids

The NIHR commissioned the PaPaS Cochrane Group to undertake a rapid review of the impact of opioids on consciousness, appetite and thirst. This was published in May 2014 and is available online at: www.ncbi.nlm.nih.gov/pubmed/24874470).

The authors found no direct evidence that opioids affected patient consciousness, appetite or thirst when used to treat cancer pain. However, somnolence, dry mouth, and anorexia were common adverse events in people with cancer pain treated with morphine, fentanyl, oxycodone, or codeine. The review highlights the problems that exist with adverse event measurement, reporting, and attribution. Together with the known complications concerning other accompanying medication, data collection and reporting, and nomenclature, this means that these adverse events cannot always be attributed unequivocally to the use of opioids, and so they provide only a broad picture of adverse events with opioids in cancer pain. The review identifies a research agenda that includes developing definitions for adverse events that have a spectrum of severity or importance, and the development of appropriate measurement tools for recording such events to aid clinical practice and clinical research.

8.5   'Mapping review' of evidence requirements

The PaPaS Cochrane Group, supported by the NIHR, has completed a 'mapping review' of the requirements in *One Chance to Get it Right* for research evidence. The result is a library of published palliative care and end of life research outputs, which became available in March 2015 as a searchable online research database at: http://papas.cochrane.org/palliative-care-library.

The database summarises the evidence currently available. It contains over 1800 entries, which includes systematic reviews, randomised controlled trials, quasi-experimental studies, descriptive studies, and expert opinion. Each item is classified against the Priorities for Care in

One Chance to get it Right. The database represents an invaluable tool for those seeking information about the existing research evidence for palliative and end of life care.

8.6   Health Education England research on education and training

Health Education England (HEE) commissioned The Democratic Society to lead a review into the efficacy of education and training resources, which began in March 2015. The outcome of the review will inform HEE which resources should be promoted and embedded in education and training curricula across the healthcare workforce and help target HEE spending on activities which drive high quality outcomes.

The review has completed its qualitative and quantitative research phase and seeks to examine:

- the effectiveness of education and training resources on care for the dying for trainee and experienced healthcare staff;

- practice in the planning and implementation of resources into education and training methods and programmes;

- the existence of systemic barriers to embedding education and training resources across curricula in a more streamlined way; and how mobile and accessible existing education and training material are to the health workforce; and

- the extent to which education and training resources, methods and programmes improve and sustain quality of care for the dying.

This review will also inform the decision on whether further research into the development and evaluation of education and training methods and programmes is required through the Department of Health Policy Research Programme.

The review report will be submitted to HEE during summer 2015 and HEE will carefully consider its findings and recommendations and how these can be taken forward in partnership with NHS England.

8.7   Marie Curie Research Activities

As part of its new research strategy, Marie Curie has committed to doubling the amount it spends on research into end of life care by 2019. The new strategy focuses on strengthening collective understanding of the experiences of people with different conditions and from different communities.

8.7.2   Research Projects Funded by Marie Curie

For its research strategy in 2015, Marie Curie is funding five academic research projects which will explore key aspects of care and support for terminally ill people and their families. The research projects cover a range of care settings and conditions and were announced in March 2015. They are:

- a study to test whether a drug called mirtazapine can help relieve breathlessness. This study is a feasibility trial – it aims to find out if the trial methods and drug are acceptable to those taking part and whether researchers can recruit enough people to a future trial;

- a study to develop and test a toolkit of "rules of thumb" for end of life care. "Rules of thumb" are ways of condensing knowledge into useful plans of action;

- a project to develop and evaluate a simple bedside tool for community use to identify who is most likely to benefit from palliative radiotherapy for cancer-induced bone pain;

- a review of the evidence on the role and outcomes of clinical nurse specialists - how services can be best organised to improve symptom relief and the experience of palliative care quality and continuity across hospital and community care for patients who are diagnosed with advanced cancer in an emergency situation; and

- an investigation of whether or not paracetamol improves pain control in people already taking strong pain killers for cancer-related pain.

8.7.3   Other Marie Curie research activities

- As mentioned above, working with the James Lind Alliance, Marie Curie has brought together a partnership of more than 30 stakeholder organisations to identify the research priorities of terminally ill people, carers and health and social care professionals. The top ten priorities were announced in January 2015 and these will be used to help shape future research into end of life care and inform future Marie Curie funding.

- Marie Curie has also funded research which explored palliative and end of life care for black and minority ethnic communities.

- The charity has funded a new chair in palliative care at University College London.

- In 2013/14, Marie Curie funded and worked with The Royal College of Physicians and Public Health England to undertake the National Care of the Dying Audit of Hospital Care and is similarly involved in the new 2015 audit.

9. Work to promote the Priorities for Care

All the organisations involved in the Leadership Alliance committed to work to promote, publicise and support the approach to care in the last days and hours of life, including the Priorities for Care, in the course of their work. Some of those activities undertaken so far are set out below.

9.1   General Medical Council

The General Medical Council (GMC) has continued to promote its guidance on end of life care, at the local and national level, focusing on the key themes doctors find challenging and which were highlighted in the *More Care, Less Pathway* and *One Chance to Get it Right* reports. GMC regional teams in England regularly engage with doctors, medical students and patients, Clinical Commissioning Groups and other organisations involved in local healthcare services.

As well as making its guidance for doctors more accessible and user-friendly, the GMC has added content to its website about the work of the Leadership Alliance and has published each of the commitments it made as a member of the Alliance.

The GMC has promoted its guidance and resources on end of life care at the RCGP annual conference, talking to doctors about the major challenging themes and surveying them on their experiences of delivering end of life care and the common challenges they face.

The GMC has refreshed the presentation of its end of life care guidance and supporting resources on its website, to make them more prominent, easy to use and accessible. It is also exploring with E-Learning for Healthcare the scope for updating GMC content available through their website. The GMC is running a campaign throughout 2015 to raise awareness of these online resources, and how they can support doctors to deliver the Priorities for Care.

The GMC is developing an online user-friendly decision making tool which will helps doctors assess their patients' capacity to make key decisions about their care. During 2015, GMC is also producing a set of theme-specific checklists to provide doctors with some quick tips against each of GMC's priority areas.

9.2   Health Education England

Health Education England (HEE) continues to promote *One Chance to get it Right* through its 13 Local Education and Training Boards (LETBs). All LETBs have developed bespoke approaches to promoting the *One Chance to Get it Right* glossary terms in their respective regions. These include workshops and utilising local stakeholder networks and hubs. .Each of the four geographical Directors has reported on how this is being achieved across each region.

HEE has also commissioned NHS Employers to disseminate key messages via its websites and other communication channels. This was delivered over summer 2014, with links to resources on end of life care included on the NHS Employer website.

HEE also commissioned NHS Employers, in January 2015, to circulate an HEE briefing note on the Priorities for Care. HEE plans to refresh its communication to NHS employers on the system-wide response glossary terms as part of its dissemination of the findings of the HEE Review into the efficacy of end of life care resources. This will begin in autumn 2015.

9.3   Nursing and Midwifery Council

The NMC has published the Priorities for Care guidance document for healthcare professionals document on a dedicated page on its website. The revised NMC Code reflects and places greater emphasis on many of the issues highlighted in the Priorities for Care, and was promoted through the consultation process accompanying its development and on its publication in January 2015.

9.4   Health Care Professions Council

The HCPC has promoted the Priorities for Care among registrants and other stakeholders through the following activities:

- a news story on the HCPC website highlighted publication of the *One Chance to Get It Right* response document and the five Priorities for Care and directed readers to the full document and commitment statements. The publication was also announced via HCPC's social media channels;

- publication, in August 2014, of an article in the HCPC newsletter *In Focus* aimed at registrants and key stakeholders drawing attention to the duties and responsibilities of health and care staff to deliver the Priorities for Care; and

- publication of an article on the work of the Leadership Alliance and the Priorities for Care was published in the HCPC *Education Update* in October 2014, aimed at education providers. This can be found at www.hcpc-uk.org/assets/documents/10004908HCPCEUIssue17d.pdf.

9.5   Royal College of General Practitioners

The RCGP:

- has promoted the End of Life Care 'app' in the *RCGP Clinical News*;

- ran an hour long session at the 2014 RCGP national conference with a session looking at developments from the *One Chance to Get it Right* report; and

- has developed improved web resources to signpost GPs to educational resources.

9.6   Royal College of Nursing

The RCN held an event in June 2014 at the RCN Congress to discuss the work of the Leadership Alliance and to inform members that the RCN would be taking forward a specific project to support nurses to deliver better care for people approaching the end of life. Two further events at the RCN Congress in 2015 highlighted the work the RCN has done to date following the *One Chance to Get it Right* report. They set out the RCN's ongoing commitment to foster partnerships with other organisations and work with and support nurses to provide end of life care confidently and skilfully.

9.7   College of Health Care Chaplains - End of Life Care Resource Group

The College of Health Care Chaplains (CHCC) has reinstated its End of Life Care Resource Group and is using this to inform and to educate its members. Chaplains continue to be part of

the multi-disciplinary team and their contributions mean they can promote, support and help the Priorities for Care to become embedded in their organisations. CHCC is working in partnership with the National Council for Palliative Care to promote the improvement of spiritual care at the end of life and is contributing to the revision of the NICE guidelines for the management of care for dying adults, in the field of spiritual care.

9.8   Macmillan

Macmillan has communicated the Priorities for Care and the system wide response through its e-newsletter (reaching 7600 Macmillan professionals).

Macmillan has also:

- reviewed its written content to incorporate the Priorities for Care and its support, including educational support, for Macmillan end of life care professionals in the light of the Priorities for Care, and will be implementing the outcomes of this review throughout 2015;

- developed an e-learning toolkit on advance care planning for healthcare professionals. It is hoped this toolkit will be a valuable resource for those professionals who are involved in end of life care conversations with their patients; and

- supported local educational events. For example, one training event "Take the Chance" was held in Devon and planned in collaboration with two local Clinical Commissioning Groups. It included topics such as "Communication – the root of it all" and "The Real Priorities in End of Life Care."

Macmillan is continuing to advocate and influence nationally and locally on achieving real improvements in services and greater choice for people approaching the end of life.

9.9   Marie Curie

Marie Curie has developed and continues to roll-out the Marie Curie Helper Service in a number of areas of the country, with trained volunteers supporting terminally ill people and their families in their own homes.

Marie Curie has published a number of policy reports which seek to improve care for terminally ill people. These include *Difficult conversations with dying people and their families* and *Next Steps: Improving end of life care for Black, Asian and Minority Ethnic people in the UK.*

10. Other work by the Department of Health, NHS England and others

10.1 NHS mandate

The mandate to NHS England for 2015/16 was published on 11 December 2014. It was developed following targeted stakeholder engagement during 2014 and consultation with NHS England and Healthwatch England.

The updated mandate carries forward all 25 objectives in the 2014/15 mandate to ensure the NHS continues to deliver the care that people need and expect. The mandate continues to include improving the quality of care for people at the end of their lives, and the NHS Outcomes Framework continues to monitor bereaved carers' views on the quality of care in the last 3 months of life (through the VOICES-SF survey).

In response to the NHS Five Year Forward View, the Government announced additional funding to support the NHS through the mandate, totalling an overall increase to frontline spending of £1.98billion.

10.2 Five Year Forward View

NHS England has used the NHS Five Year Forward View Vanguard Programme site visits as opportunities to further raise the profile of *One Chance to Get it Right* and the Priorities for Care.

10.3 The Responsible Clinician Role

The Academy of Medical Royal Colleges has led on work, with the professional community, to produce guidance on the role of the responsible clinician in inpatient settings. The final guidance was published in June 2014 and describes the purpose of the responsible clinician role and named nurse with some key considerations for implementation including:

- the overall responsibilities for the coordination and continuity of a patient's care during their hospital stay including discharge, any transfers within hospital and readmission;

- the role as a point of contact for the patient, their carers and family (the guidelines include a set of key messages to patients that hospitals might wish to use);

- the role of the named nurse recognising the need for more flexibility because of shift working arrangements; and

- displaying information about accountable clinicians including the importance of patient consent.

The Department of Health and wider system agrees that it would be important to send a further message to the NHS supporting the adoption of this guidance. The planning guidance for the NHS which has been produced jointly by system leaders makes it clear that during 2015/16 commissioners and providers are expected to work together to embed the practice of clear clinical accountability, with a named doctor responsible for a patient's care, within and across different care settings. The Department has asked the Academy to produce further guidance that could apply to other healthcare settings. This will be published by the Academy in due course.

10.4 The Review of Choice in End of Life Care

An independently-led Review of Choice in End of Life Care was established in July 2014 as part of the Government's commitment to enable greater choice and high quality care for people at the end of their lives. The Review considered what choices were most important to people at the end of life and should form part of a "choice offer". The review also examined the changes to services required to enable a choice offer, the major barriers and enablers relating to choice and the cost of these changes.

The review published its advice in February 2015 and set out, in particular, how more people can be cared for and die in their own home, as this was found through the review's public engagement to be a key choice for many people approaching the end of their lives. It also set out the savings that more out-of-hospital care might achieve in acute care, as well as the additional investment needed in community health and social care services.

The Government's initial response to the review in February 2015 supported the Review's vision of choice. The Government is working with NHS England to see how best this vision can be achieved and the full Government response will be published later in 2015.

10.5 VOICES-SF Survey

The National Survey of Bereaved People (VOICES-SF, Views of Informal Carers – Evaluation of Services: Short Form) is conducted by the Office for National Statistics and collects information on bereaved peoples' views on the quality of care provided to a friend or relative in the last three months of life, for England. The survey has now been run for four years and was commissioned by the Department of Health in 2011 and 2012, and NHS England in 2013 and 2014. DH and NHS England continue to identify areas of concern and measure progress on improving end of life care by assessing the results of this survey. In particular the VOICES-SF survey is a key part of the way NHS England and DH continue to monitor bereaved carers' views on the quality of care as part of the NHS Outcomes Framework.

A summary of the findings of the 2014 survey (published in July 2015) is as follows:

- 3 out of 4 bereaved people (75%) rate the overall quality of end of life care for their relative as outstanding, excellent or good; 1 out of 10 (10%) rated care as poor.

- 7 out of 10 bereaved people (69%) whose relative or friend died in a hospital, rated care as outstanding, excellent or good. This is significantly lower than outstanding, excellent or good ratings of care for those who died in a hospice (83%), care home (82%) or at home (79%).

- Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (30%) compared to the least deprived areas (21%).

- 1 out of 3 (33%) reported that the hospital services did not work well together with GP and other services outside the hospital.

- 7 out of 10 (73%) respondents felt hospital was the right place for the patient to die, despite only 3% of all respondents stating patients wanted to die in hospital

As part of its work to drive improvements in end of life care services, NHS England arranged for the 2014 version of the VOICES survey to be modified explicitly to include questions relating to hydration, nutrition and communication and supplement a number of other questions relating specifically to elements of care in the last two days of life.

These results have a bearing on some of the issues identified in the *One Chance to Get it Right* report, although they relate to care delivered in 2014 only.

For the last two days of life they show that:

- 81% of bereaved relatives agreed or strongly agreed the dying person had received sufficient pain relief, 6% did not agree.

- 75% and 78% of bereaved relatives agreed or strongly agreed the dying person had received support to eat and drink respectively, 7% did not agree.

- 75% of relatives felt doctors and nurses had treated the dying person with dignity and respect all of the time.

- 79% of bereaved relatives agreed or strongly agreed they were kept informed about the dying person's condition and care, 8% did not.

- 76% of bereaved relatives agreed or strongly agreed they had enough time to ask questions and discuss the dying person's condition and care, 9% did not.

- 74% of bereaved relatives agreed or strongly agreed they had a supportive relationship with health care professionals in the last two days of life, 8% did not.

NHS England is also exploring different options for improving the measurement of patient and family experience, and outcomes, of end of life care that can be used for service improvement and benchmarking. The next VOICES-SF survey is due to be published in July 2016.

10.6 National Clinical Audit of the Care of Dying People

The Healthcare Quality Improvement Partnership (HQIP) and NHS England agreed to commission the Royal College of Physicians (RCP) to undertake a further National Clinical Audit on the Care of Dying People during May 2015, focusing on the recommendations from the 2013 audit (published in May 2014) and the five Priorities for Care. The RCP is leading this work in collaboration with the Association of Palliative Medicine and a wide range of other professional bodies and voluntary groups. The results of the audit are due to be published in May 2016.

10.7 The End of Life Care Ambitions Partnership

NHS England has developed an End of Life Care Ambitions Partnership, a partnership working group composed of 25 organisations with an interest in end of life care. This includes CQC, PHE and third sector organisations, as well as organisations representing the patient and carer voice. The Partnership group is co-chaired by the National Clinical Director for End of Life Care and the Chief Executive of Marie Curie.

Throughout 2015, this group will focus largely on the forthcoming Ambitions for End of Life Care document, ensuring that its objectives remain relevant and responsive to the needs of people approaching the end of life.

10.8 Public Health England: the use of intelligence to improve end of life care

Since the publication of *One Chance to Get it Right*, Public Health England (PHE) has undertaken a range of activities to produce intelligence on end of life issues, including:

- In line with its commitments, PHE's National End of Life Care Intelligence Network (NEoLCIN) continues to produce profiles and reports using routine data sources to inform

frontline practitioners, commissioners, policy makers and patients and their families about patterns of care.

- PHE is working with NHS England, academic partners and Hospice UK to develop a new minimum (patient centred) data set for palliative care which should cover all caregivers and enable a better assessment of the type and quality of care being received.

- From September 2014, the NEoLCIN has undertaken a programme of visits to each Strategic Clinical Network across the country, meeting with palliative care specialists, commissioners, GPs and other staff. The aims are to expand palliative care and public health practitioners' and commissioners' awareness of the work of the NEoLCIN and listen to their needs. The meetings have also highlighted how networks can use data sources to plan and monitor improvements in care and have introduced the Dying Well Community Charter and Toolkit to commissioners.

- The NEoLCIN continues to work with academic partners and held a Research Summit in January 2015, with more than 150 researchers, funders and policy makers.

- Work is ongoing to improve quarterly reporting on place of death and additional reports will be published to better support the monitoring of quality improvements.

10.9 Health Education England Working Group

HEE is using its workforce and education commissioning leverage and strategic partnership working to promote joined-up holistic approaches to improving education and training in end of life care. HEE has established an End of Life Care Working Group comprising health stakeholders (including NHS Employers, RCGP, and RCP) actively involved in research and policy work on care for the dying. The Group is used as a sounding board and has helped inform HEE's approach to embedding best practice and learning on End of Life Care across the health workforce through joint working.

The HEE End of Life Care Working Group is the key vehicle through which HEE is taking a system wide approach to embedding and implementing the five Priorities for Care. The working group has:

- reviewed submissions from each of its four geographical Education and Quality Directors to identify gaps in education and training commissioning and curricula and is considering how these gaps can be addressed with other statutory partner bodies.

- secured representation on partner working groups: HEE is a member of NHS England's Ambitions Partnership Working Group and PHE's National End of Life Care Intelligence Network to ensure joined up approaches to end of life care in the context of the NHS Five Year Forward View.

- identified and established a Local Education and Training Board (LETB) network of managers with responsibility for end of life care; and

- collated evidence of LETB activity on end of life care and used the Mandate objectives to communicate national strategy and alignment with LETB workforce strategy.

10.10 College of Health Care Chaplains - evaluation of the Priorities for Care

The College of Health Care Chaplains (CHCC) committed in *One Chance to Get it Right* to ensuring that the most appropriate spiritual, religious and cultural care is being given to people coming to the end of their lives and those who are important to them.

To achieve this, the CHCC has collected and examined case studies provided by chaplains in local areas and used them to monitor the presence of the Priorities for Care in the care people receive. Chaplains have been encouraged to use the case studies to reflect on and improve their own practice.

The CHCC is also analysing the case studies as part of a two-year research project to identify whether the Priorities are discernible in chaplains' narratives of end of life care nationally.

10.11 Work to engage patients on end of life care planning

Following an initial meeting with the National Council for Palliative Care (NCPC) to discuss opportunities for partnership working, the GMC is planning to work together on the production of case studies, opinion pieces and some 'mythbusters' aimed at encouraging patients to engage with issues around end of life care planning. The GMC is also beginning work to produce two short films – one on nutrition and hydration and one on communication skills, with the aim of launching them in December 2015.

10.12 The Dying Well Community Charter

PHE and the NCPC published a Dying Well Community Charter in September 2014. The Charter incorporates the Priorities for Care as well as the Royal College of Nursing and Royal College of General Practitioners' 2011 End of Life Care Patient Charter. PHE also commissioned a "Public Health Approaches End of Life Care Toolkit" to support implementation of the Dying Well Charter. To catalyse the implementation of the Charter, the NCPC and PHE have launched a scheme inviting organisations to be one of six Pathfinder Communities to pioneer a public health approach to end of life care in England.

11. Implementation of the Priorities for Care

This section includes:

- details of work by NHS Improving Quality (NHS IQ) to support and engage on how the Priorities are being implemented locally;

- a summary of themes identified from case studies submitted by Strategic Care Networks (SCNs) and Palliative Care Networks (PCNs) to illustrate how the Priorities are being put into practice and evaluated locally; and

- four case studies setting out coordinated action to improve care at the hospital and regional levels.

11.1 NHS Improving Quality provider engagement and support offer

NHS IQ has been working across the system to support planning and implementation of the Priorities for Care as part of NHS England's Priorities for Care implementation support offer. NHS IQ has also engaged directly with multiple service providers, SCNs and end of life care facilitators at regional stakeholder events on the impacts of phasing out the Liverpool Care Pathway, and the development of strategic plans to incorporate the five Priorities for Care within end of life care delivery, commissioning, and education and training domains.

This was combined with a request from NHS England to SCN and PCN leads for a position statement on organisational states of readiness for the Priorities for Care implementation.

NHS IQ's support package has included 'critical friend' review visits to care providers in order to assist them in planning for and implementing the Priorities for Care. The support team consisted of a Senior Service Improvement Fellow and clinician, accompanied by the designated NHS IQ end of life care delivery support manager for the region.

When this process began in 2014, the majority of sites had transition plans in place and requested support to review their planning or implementation of care based on the Priorities for Care.

To date, support has been provided to over 50 organisations. Visits began in August 2014 and continued through to the end of January 2015. The focus for the visits was on establishing how organisations have phased out the LCP and what plans are being put in place to build on the Priorities for Care requirements.

NHS IQ is currently collating key learning points from the visits to provide an overview of implementation progress to date, key lessons learnt and what ongoing implementation support might be required.

It is notable that a large percentage of visits to care providers were Trusts participating in the Transforming End of Life Care in Acute Hospitals programme. This programme began in 2011 with 25 acute Trusts signing up to the first wave. There are currently 76 acute trusts (over 100 hospitals) taking part in the programme with expressions of interest from other Trusts pending.

The majority of 'critical friend' visits were concentrated in the North and the South of England. Support visits with host organisations have seen high levels of positive engagement from different sectors, with involvement of community, primary and social care colleagues in the planning review meetings. A number of sites have made good progress with their implementation plans and are offering peer support across their localities.

11.2 Summary: case studies on implementation

In October 2014 and May 2015, the Department of Health issued calls to Strategic Clinical Network and Palliative Care Network Leads for case studies to illustrate how the Priorities for Care have been and are being implemented locally.

The case studies received show widespread engagement with the Priorities across the country. They also evidence the significant amount of work completed over the last year, especially in acute hospitals. They show the dedication of staff involved in end of life care to adapt the care being delivered locally, in light of the Priorities, and identify and overcome the challenges of doing so. Four of the case studies are included in more detail at section 11.3 below.

While recognising this is not a comprehensive picture of national practice, the overall impression is of a major effort across the country to absorb fully the lessons from *One Chance to Get it Right* and incorporate them into the day-to-day practice and outlook of staff, organisational systems and culture.

The key messages from the case studies are as follows:

- Across all locations, the case studies show a high level of engagement with the Priorities for Care and significant progress in designing and implementing care for dying people based on the Priorities – there is a marked focus on delivering individualised care.

11.2.1 Education and training

- Several studies describe the arrangements put in place to educate staff about the Priorities and how to implement them. One SCN in the North West has developed recommended core education standards for care and support for the dying person in the last days and hours of life. This is underpinned by the Priorities for Care, supports individual professional development plans, builds on mandatory training and identifies further sources of support such as e-ELCA.

- Other examples include:

  - development of simulation sessions for clinical staff, with specific emphasis on the Priorities for Care. Existing aspects of the education programme were updated to incorporate key messages about the Priorities for Care, including placements for undergraduate and postgraduate medics, student nurse placements, nursing and care worker development programmes, unqualified staff and an extensive Care Homes End of Life Care Programme (6 Steps).
  - development of a network of palliative care link nurses to support education and clinical support for implementation of the Priorities for Care at a ward level.
  - updating of end of life care standards within the Nursing Assessment and Accreditation System in both the hospital and community settings to maintain high quality care in the last days of life with emphasis on aspects of the Priorities for Care.
  - setting up of an assertive Emergency Admissions Unit in-reach project involving a dedicated palliative care CNS screening and triaging all admissions to EAU daily. This provided direct clinical support for staff in the implementation of the Principles of Care and resulted in earlier identification and review of patients with palliative care needs.
  - recording of significant conversations with patients in a dedicated section of the electronic patient record. Information is also shared electronically across key care

> providers using the 'Communicate My Care' Electronic Palliative Care Coordination System.
> - the use of Schwartz rounds and regular training, discussion and reflection in 'virtual ward' multi-disciplinary team meetings to build staff confidence and skillsets in conducting difficult conversations with families.

11.2.2 Documentation

- Several case studies describe the development and use of local documentation and resources to support the delivery of the Priorities. These include:

    - individual plans of care for the last days of life including a focus on identification and communication;
    - an "End of life conversations" form to capture a range of relevant information including the dying person's wishes and preferences and to support and guide staff in identifying dying, decision-making and sensitive communication when having difficult conversations;
    - a guidance document for staff covering decision-making, diagnosing dying, mental capacity, communication, advance care planning, preferred place of care. This sits in the patient's notes;
    - a nursing initial and on-going symptom assessment tool including guidance on treatment, recordkeeping and communication with family/carers;
    - a carers diary – a communication tool to enhance dialogue between the clinical teams and the family/carers;
    - an information pack for carers/relatives;
    - a communications booklet developed in direct response to Priority 4 (sensitive communication), to facilitate professional communication and aid staff in having difficult conversations;
    - a multi-disciplinary team decision document with prompts around the core care principles expressed in the Priorities for Care;
    - intranet quick guides and on-ward teaching sessions;
    - a set of core education standards to support staff education and training around the Priorities and the new approach to care in the last days and hours of life.

11.2.3 Evaluation

- All the case study locations have begun to evaluate, or have plans in place to evaluate, the effectiveness of the care being delivered. Some locations piloted and evaluated the services before fully rolling them out and one began a second phase of piloting and evaluation in September 2014. Some of the earliest formal audits began in October/November 2014. Evaluation will be achieved through a variety of methods in different locations, including:

    - individual case reviews and event analysis;
    - care plan audits and audits of care in the last days of life;
    - analysis of data on hospital admissions and dying in place of preference;
    - feedback from healthcare providers;
    - involvement of ward sisters in reviewing care;
    - focus groups across different settings;
    - reviews focusing on the education and training delivered on the Priorities and their use;
    - staff surveys;
    - feedback on out-of-hours provision; and

- bereaved carers' views on the care the dying person receives.

- A comprehensive evaluation approach in Cheshire took place in January 2015. This sought to evaluate the local delivery of the Priorities for Care by determining baseline levels of implementation across all settings, the effectiveness of staff training and levels of staff confidence in applying the care plan to practice; gaps in professional knowledge; any barriers to using the new resources developed from the Priorities for Care; and patient outcomes.

11.2.4 Other themes emerging from case studies

- At the regional level, strategic clinical networks are performing the function of disseminating information to localities and coordinating local strategy groups, providers and commissioners in developing local solutions.

- Some of the studies emphasise the continuity with what had gone before (because care was already being delivered along the lines of the principles expressed by the Priorities for Care), while some areas point to distinct differences with the new arrangements (for instance the shift of focus from documents and processes to the dying person and individualised care).

- Certain areas are developing integrated care models to coordinate and deliver care based on the Priorities across multiple settings. This includes an example of an acute Trust implementing a rapid discharge process to ensure dying people can be in their preferred setting and arrangements to ensure the plan of care follows the patient effectively.

- One area stressed the importance of the proactive support of clinical leadership to deliver the Priorities effectively, and the negative effect on outcomes when this support is lacking.

- In some areas, the work being done has had a positive knock-on effect of improving the completion rates of documentation on ceilings of treatment, including DNACPR forms.

- While progress is being made to implement the Priorities in acute settings, there is more work to do, in some areas, to embed it in community settings. However, some areas have highlighted the Priorities as a lever for change more widely in end of life care.

- Some areas have strongly emphasised that successful implementation depends on good levels of involvement from primary care, particularly from expert generalist GPs. Where there is high turnover in primary care (potentially due to funding issues), implementation is threatened.

- Some areas felt it should be recognised that the concentration on the Priorities for Care, though the Priorities represent a good approach, has necessarily replaced other quality improvement work, which is also vital to the care of patients at the end of life. In one case, work was set aside on promoting earlier discussions with patients and their families, something that has been identified locally as a priority.

- One area stated there was initial reluctance to lose the previous system which staff felt was working well. Staff felt that replacing tickboxes with more comprehensive documentation was time-consuming, less efficient and more difficult to audit. However, at the same location audits of care demonstrated improved communication and improved documentation around nutrition, hydration and mouth care. It was also found that region-wide, education in the

11.   Implementation of the Priorities for Care

Priorities for Care had reached 2217 staff, 677 of which worked in care homes and that 72 percent of district nurses and 72% of GPs had been trained in the Priorities. As a result staff reported that their confidence had grown and they felt more empowered to make individualised care plans. The audits also found staff understanding had increased and there was more consistency of approach across the workforce.

11.3 Implementation case study examples

The following four case studies illustrate in more detail the scope of work being undertaken in local areas to implement the new approach to care in the last days and hours of life. They are included to give insight into key elements of the implementation work, namely:

- the role of Strategic Palliative Care Networks in offering support locally and in reviewing and evaluating progress; and

- work on education and training, and on evaluation and audit, within acute Trusts.

Case study example 1: The work of a regional Strategic Palliative Care Network (SCN)

The SCN is committed to making an impact in the implementation of the recommendations from the report *One Chance to Get it Right*, and to helping organisations procure project management resource to help them plan, identify gaps in the service and how those gaps could be closed.

An offer of help was sent to all providers – acute, community and primary care explaining the assistance to be provided and expectations of them. The philosophy underlying *One Chance to Get it Right* is that providing end of life care is everyone's business.

To support providers (acute, community and primary care) and to progress the embedding of this fundamental work in a meaningful and robust way we offered funds for providers to: undertake a scoping/assessment of their organisation's current level of provision; identify the gap between current provision and what is required to deliver against all the recommendations; and develop a comprehensive action plan to deliver against all the recommendations.

The application had to include: lead contact details; proposed timescales for commencing and completing the scoping exercise; date for completion of action plan; requested number of days of project support (maximum of 5 days, at band 7 or 8a); confirmation of agreement to aspects below and had to agree to:

- produce a robust action plan covering all 34 recommendations of the *One Chance to Get it Right* report.

- include timescales for delivery of actions

- carry out a review and evaluate the impact of the actions

- commit to share the action plan with the host CCG and locality colleagues.

- commit to work collaboratively with locality colleagues and host CCG in delivering the plan.

The offer was reinforced with a 'masterclass' session to focus on the recommendations and how those who attended could make a difference back in the workplace.

The offer was made to four acute trusts, three community providers and 11 CCGs (for the primary care response). The uptake was three acute, two community and nine CCGs, making a total of 14 out of 18 organisations. Organisations had until the end of March 2015 to complete the review.

Case study example 2: Review and evaluation in a Strategic Clinical Network region

The South West Strategic Clinical Network has undertaken an extensive programme of survey and review of the implementation of the new approach to care in the last days and hours of life, including the Priorities for Care.

The survey received responses from 8 Clinical Commissioning Groups, 4 local authorities, 6 acute Trusts and 6 other care providers. It asked three questions as follows:

a) What processes as an organisation have you put in place to address the five Priorities for Care?

b) What evaluation methods are you using to measure the impact of your processes?

c) What barriers are you encountering in implementing this policy and what help is required to move them?

The survey also requested details of the nominated lead for end of life and the Board Member with responsibility for end of life for each organisation.

Question a) responses showed organisations were using the following processes to embed the Priorities for Care:

- Strategic planning; Personalised care planning; Commissioning; Communication/coordination of services; CQC inspections and guidance; Education, training, resources and workforce development; Tools to aid advance care planning and decision-making; Local policies, guidance and knowledge sharing.

Question b) responses showed evaluation methods in use locally to measure effectiveness of the Priorities for Care, including:

- Complaints used to identify problems and measure improvement; Dashboards and clinical audit; Education and training evaluations; Formal evaluation based on performance metrics and/or NICE guidance; Analysis of monthly reporting data from acute and community providers, EPaCCs data, referrals and carer assessment data; Multi-disciplinary meetings to evaluate progress and identify service gaps; Patient and bereavement surveys

Question c) responses recorded the main barriers in implementing the new approach. These included problems with:

- capacity, resources and funding; interoperability of IT systems; communication and coordination between different organisations; consistency of documentation across providers; and workforce development, including education and training.

Responses also highlighted the importance of organisations' approach to culture of care and culture of working.

The survey responses are being used by the Strategic Clinical Network and other groups locally to identify where providers and commissioners need support to deliver the Priorities for Care and to ensure current practice is aligned to national guidelines.

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Case study example 3: Work on education and training in a specialist acute Trust

Since January 2015, the Trust Specialist Palliative Care Team (SPCT) has implemented a rolling multi-professional education programme covering six core areas:

- *One Chance to get it right*: principles and priorities

- Recognising dying and introduction of new documentation

- Management of pain and agitation

- Management of nausea/vomiting & breathlessness

- Management of hydration/nutrition & respiratory tract secretions

- Care at and after death

The Trust provides education sessions concerning symptom control and end of life care to junior doctors in training three times per four-month rotation, and for Oncology Registrars on an annual basis.

In November 2015, the Trust plans to run a multi-professional study day: *Have we got it right? The experience of care in the last few days and hours of life for patients, families and staff*. The study day will cover areas including managing psychological distress, assessing hydration needs at end of life, and advance care planning. To further enhance staff training and support the Trust offers multi-professional reflection sessions after a person has died within the Trust.

After extensive consultation with staff, the SPCT developed and are piloting an End of Life Care and Communication Record, to support and record conversations with patients who are felt to be dying and their relatives. The document particularly focusses on identifying and recording the preferences for care of individual patients and those close to them.

The SPCT has also implemented 'Care at and after death' documentation, which is completed for all deaths within the Trust. The document supports communication with those close to the patient and also other healthcare professionals after a person's death. It also signposts to referral for bereavement follow-up. Alongside these two documents, the SPCT has developed palliative care resource folders on all wards and relevant clinical areas, which also contain further resources regarding symptom management, and information concerning the Trust's SPCT and local specialist palliative care services.

The Trust also completed a multi-professional survey of staff training needs. This evaluated that confidence levels were good within the Trust overall in terms of caring for patients and families at the end of life. However, the survey also identified particular areas for development including having discussions with dying patients, discussing resuscitation decisions and managing psychological distress.

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Case study example 4: Evaluation and audit in an acute hospital Trust

Use of the individualised End of Life Care Plan has been audited across the Trust on a weekly basis. This information is reported to clinical leaders across all Divisions and regularly shared with the Executive.

A set of Quality Markers have been developed with reference to the Priorities for Care for the Dying Person. These have been used to determine whether key aspects of care and communication for the dying person and those important to them have been clearly recorded and key actions undertaken.

In order to review progress over time, audit of these Quality Markers now forms part of the monthly Mortality Review process for the Hospital Palliative Care Team. At a Trust-wide level, data from the audit of the Quality Markers was presented to the Executive End of Life Care Task Group and the Executive Quality and Safety Committee (data for April 2014) and has been compared to a similar cohort for October 2014. This data has supported the effectiveness of using an individualised end of life care plan to achieve quality markers and maintain consistent high quality care in the last days of life.

The longer term Trust plan is to seek incorporation of the Quality Markers into Mortality Review across individual Directorates and Divisions.

A validated self-completion questionnaire (CODE) was used to gain carer bereavement feedback in 2013 on care delivery in the last days of life. This was repeated for a sample of hospital deaths in 2014. For the Trust, the 2013 sample revealed:

- 97% of those completing the questionnaire reported being very or fairly involved in decisions about care and treatment of their family member (nationally = 76%)

- Clinically Assisted Hydration (CAH) – 59% of bereaved relatives reported being involved in discussions about whether or not there was a need for CAH in the last 2 days of the patient's life (Nationally = 39%)

- 82% reported that the overall level of emotional support given to them by the healthcare team was good or excellent at the Trust.

12. Conclusion

Taken together, the progress organisations across the health and care system have made towards addressing the key issues from *One Chance to Get it Right* has been wide-ranging and substantial.

The Care Quality Commission has inaugurated and implemented major changes in its inspection approach so that end of life care has become an explicit, consistent thread through its inspections of services in all settings.

Professional regulators and Royal Colleges have taken action to address concerns and revise codes of conduct and standards. With Health Education England, they have contributed to getting education and training on care in the last days and hours of life right.

National organisations like NHS England, Health Education England, Public Health England, NHS Improving Quality, the National Institute for Health and Care Excellence and the National Institute for Health Research have made significant progress on the actions they committed to in *One Chance to Get it Right*. In the course of doing so, a number of organisations have taken important steps towards improving care and implementing the Priorities for Care of the Dying Person.

All the organisations involved in the Leadership Alliance for the Care of Dying People, including the charities who continue to advocate for better care at the end of life, have fully embraced, promoted and helped to normalise the Priorities for Care, which were the central focus of the new approach set out in *One Chance to Get it Right*.

With many of the commitments already achieved at the one year on point, there is every reason to be confident that the collective commitment across the system to improve care in the last days and hours of life will drive further and continuing improvement and ensure that any remaining actions are completed to the timescales organisations have agreed.

However, there is still much to do to ensure that everyone receives high quality, individualised and compassionate care at the end of life and it will continue to require vision, perseverance and applied effort to achieve these aims.

What is clear is that the consensus, progress and momentum generated by *One Chance to Get it Right* have galvanised the efforts of individuals and organisations across the health and care system and produced genuine improvements in the care people receive. As a result, one year on from the system-wide response, we are in a better position to achieve our common goal of delivering better care for everyone at the end of life.