

# **Actions for End of Life Care: 2014-16**

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**Document Status**

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## Foreword

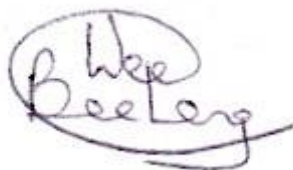
*“You matter because you are you, and you matter to the end of your life”*

Dame Cicely Saunders (1918 - 2005)

More and more people are living with long term conditions – partly due to those acquired in adult life, partly because more babies and children with life-limiting conditions can now live into adulthood and mostly because we are all living longer. But ultimately we all die. This means that care as we approach the end of our life has to matter to everyone – in health care, social care and in the wider community.

Thanks to the success of the first national End of Life Care Strategy (2008), there is much to build on. Because of its success, some of the more deep-seated inadequacies of end of life care are now exposed. For example there is inequity of access to high quality care for those whose end of life needs are harder to define or who may be disadvantaged for a variety of reasons. Inconsistencies in care may lead to the erosion of trust and confidence in professionals and ‘the system’. Furthermore, increasing expectations and pressures on ‘the system’ can lead to demoralisation of the workforce. Of course this does not apply to end of life care alone – they are part of wider issues with which the whole system is grappling.

This document – *Actions for End of Life Care: 2014-16* – sets out NHS England’s commitments for adults and children. It is one component of a wider ambition to develop a vision for end of life care beyond 2015. This can only be achieved in partnership with all those in health and social care. The 2008 Strategy managed to reverse the upward trend of people dying in hospital. We now need to ensure that living and dying well is the focus of end of life care, wherever it occurs. This is the challenge: together we can and must achieve it.

A handwritten signature in blue ink, reading "Bee Wee" on the top line and "Beeler" on the bottom line, enclosed in a circular scribble.

Dr Bee Wee  
National Clinical Director for End of Life Care

## Executive summary

The first national End of Life Care Strategy (2008) generated significant momentum and energy, which led to significant improvements in end of life care. However population demographics and statistics about access to high quality end of life care show that much more remains to be done. The 2008 Strategy needs to be refreshed to align it with current needs of the population and the changing health and social care landscape. Over the next year, NHS England will work in partnership with individuals and organisations both statutory and voluntary, with professionals and the public, and across health and social care, to develop an ambitious five year vision and plans for end of life care beyond 2015.

In the meantime, this document – *Actions for End of Life Care: 2014-16* - sets out NHS England's commitments to end of life care for adults and children. Here we retain the definition of 'end of life care' used in the original Strategy, i.e. 'the last year of life', but we fully acknowledge that the period in which such care is needed ranges from a few years to a matter of months, weeks or days, and into bereavement.

The NICE Quality Standard for End of Life Care (2011) provides a comprehensive picture of what high quality end of life care should look like. In addition, 'Every Moment Counts', the narrative developed for us by National Voices and other partners, adds an important perspective of what person centred coordinated care means. These have both been crucial in helping us to define commitments to end of life care, which are aligned with NHS England's role, mandate and ambitions set out in Everyone Counts: Planning for Patients 2014/15 to 2018/19.

We use a House of Care model (developed for long term conditions) as a framework for setting out our commitments to end of life care. The four interdependent components of the framework are:

1. Engaged, informed individuals and carers – through providing information and seeking feedback and engagement from them.
2. Health and care professionals committed to partnership working – through developing capability and communities of practice.
3. Organisational and supporting processes – through maintaining a focus on developing and refining processes that improve consistent, coordinated care.
4. Commissioning – through development of resources and commissioning approaches which incrementally improves end of life care.

Within each component, we have included specific actions to identify inequalities and seek to address these. Whilst a public health approach to palliative care is not a primary remit of NHS England, we recognise that living and dying well takes place within the context of the wider society, and we have specified the actions we will take in working with Public Health England, Social Care and our Strategic Partners to promote communities which are engaged, involved and compassionate.

# 1 Introduction

The first national End of Life Care Strategy for England (2008) set out a whole systems approach to the commissioning and delivery of end of life care<sup>1</sup>. Envisaged as a ten year strategy, it has generated considerable momentum and improvement, which we must now build upon. Many of the principles still hold but there remain inconsistencies in the quality of care experienced by people who need end of life care, and those important to them<sup>2</sup>.

The End of Life Care Strategy needs to be revisited and refreshed so that national actions align with both the current needs of the population and arrangements in the health and social care system following the Health and Social Care Act 2012. But improving end of life care involves a wide range of people and organisations, across the health and social care, professional and public, and statutory and voluntary, spectrum. Over the next year, we will work with colleagues and individuals across that spectrum to develop an ambitious five year plan for end of life care beyond 2015.

In the meantime, this document, ***Actions for End of Life Care: 2014-16***, sets out NHS England's commitments (actions) for adults and children. But this is just the first component of developing the wider ambitions for end of life care.

*Actions for End of Life Care: 2014-16* has been informed by comments and feedback from people who have experience of end of life care – as individual patients, carers, families, volunteers or staff; organisations representing the interests of these people; those with wider professional or societal interest. Importantly, we signal a shift in focus from 'place of death' to the broader 'experience' of end of life care. Wherever people are, we want to enable them to live and die well.

For the purpose of this document, we have retained the working definition of 'end of life care' used in the original Strategy, i.e. 'the last year of life'. In doing so, we fully acknowledge that the trajectory of different conditions mean that for some, 'end of life care' refers to the last few years of life, whereas for others, this could be a matter of months, weeks, days or hours. In the case of sudden unexpected death, the predominant focus of 'end of life care' may be on the period following death.

As far as possible, the commitments in this document are aligned with existing plans and programmes of work within NHS England and partner organisations. They link to key developments, such as the NHS Five Year Forward View<sup>3</sup>, the Better Service Integration Project and NHS England's Commitment to Carers<sup>4</sup> to ensure that excellent end of life care permeates the whole system and reflects death as an inevitable part of life.

## 2 Background

### 2.1 Demographics

- In England, approximately half a million people die each year. The number is expected to rise by 17% from 2012 to 2030<sup>5</sup>. The percentage of deaths occurring in the group of people aged 85 years or more is expected to rise from 32% in 2003 to 44% in 2030.
- Approximately three quarters of deaths are expected, so there is potential to improve the experience of care in the last year and months of life for at least 355,000 new people, and those close to them, each year<sup>6</sup>. High quality generalist end of life care is required for all these people, and can be delivered by non-specialist health and care staff as part of their core work, provided they have adequate time, education and training, and support, to do so.
- A proportion of these people will have complex needs requiring access to advice and/or direct care from professionals trained in specialist palliative care. Currently up to 170,000 people receive specialist palliative care each year<sup>6</sup> but this is likely to be an underestimate as there is growing recognition of unmet need, especially for those with non-cancer conditions and harder-to-reach population groups.
- Currently there are 15 million people in England with a long term condition (LTC)<sup>7</sup>. By 2025, the number of people with at least one LTC will rise to 18 million. The number with two or more LTC is projected to increase from 5 million to about 6.5 million. Most of these people will need end of life care as they approach their last years, months and days of life.
- An estimated 10-11% of people over 65 years, and 25-50% of those over 85 years, have frailty. Frailty is strongly linked to adverse outcomes, including increased mortality.
- Around half a million carers provide support to people dying at home of a terminal illness. The cost to family carers may include lost earnings, 24 hour care and physical and mental health consequences, some of which may be permanent<sup>8</sup>. Between 2001 and 2011, the number of unpaid carers has grown by 600,000<sup>9</sup>, with 1.4 million people providing fifty or more hours of unpaid care per week<sup>10</sup>.

### 2.2 Current context

#### Key data

- The number of people dying in their 'usual place of residence', i.e. at home or in care homes has risen from under 38% in 2008 to 44.5% now<sup>11</sup>.

- Population-based studies of preferences for place of death indicate that over 60% of people (including those who were not facing life-threatening illness at the time) would prefer to die at home<sup>12,13</sup>. Whilst this has been an important driver for improving end of life care at home, the 'place of death' is not necessarily the highest priority for everybody. In a population-based study involving just under 10,000 adults across England, only 34% ranked 'dying in preferred place' as their top care-related priority: the rest were split fairly evenly between the other two options of 'having as much information' as they wanted and 'choosing who makes decisions' about their care<sup>12</sup>. In the 2012 British Social Attitudes survey, 60% of those who stated that they would prefer to die at home would change their mind if sufficient support from family, friends or social and medical professionals were not available<sup>13</sup>. The need to be pain free (24%) came a close second to the presence of family and friends (28%), in terms of the most important aspects of their end of life care.
  
- Key findings from the 2013 National Survey of Bereaved People (VOICES-SF)<sup>2</sup> which collected feedback from bereaved people between 8-11 months after the person's death included:
  - overall quality of care across all services in the last three months of life was rated as outstanding or excellent by 43% of respondents.
  - pain relief was reported to be inadequate for 53% of those who died at home, as compared to 32% in hospitals, 25% in care homes and 13% in hospices.
  - almost 16% of respondents reported that services were not well coordinated in the last three months of life.
  - over 16% of carers and families did not receive adequate support despite asking for more help.
  - 82% of respondents felt that the person had died in the right place.
  
- Inequitable access to consistent, high quality of end of life care for certain groups of people remain:
  - Homeless people die at more than three times the rate of aged matched controls in the general population. The average age of death in the UK for single homeless people is between 40 and 44 years<sup>14</sup>. Almost half of those cared for by the charity St Mungo's died from multiple organ failure and over a third died in hospital<sup>15</sup>.
  - Amongst the black and minority ethnic population, there is a lower uptake of palliative and end of life care services compared to white/majority groups and evidence of poorer outcomes<sup>16</sup>.
  - People with learning disabilities are less likely to have access to specialist palliative care services, receive inadequate pain control in their final illness and are more likely to have their deaths described as not being planned for, uncoordinated and poorly managed<sup>17</sup>.



- Approximately one third of people aged over 60 years will die with dementia, many with complex physical and psychological needs. Yet many receive poor quality care towards the end of life<sup>18</sup>.

### Funding of palliative care

- In 2010-11, the total expenditure on adult and end of life care was £460 million but there was a wide variation of expenditure on specialist palliative care between Primary Care Trusts across the country, ranging from £186 to £6213 per death<sup>19</sup>. A considerable proportion of funding came from the voluntary sector through fund-raising.
- In July 2010, the Secretary of State for Health commissioned an independent review of the funding of dedicated palliative care for adults and children with the aim of creating a fair and transparent per-patient funding system, based on an NHS tariff to meet NHS responsibilities, regardless of the choice of provider. The review recommended a pilot programme to collect data to build the evidence base for such a tariff<sup>19</sup>. Based on this information, NHS England and Monitor will develop a national development currency available for use from April 2015.

### Liverpool Care Pathway and Care in the last days of life

- Following concerns by bereaved relatives, an independent review of the Liverpool Care Pathway (LCP) was commissioned by the Minister for Care and Support and chaired by Baroness Julia Neuberger<sup>20</sup>. The review 'More Care Less Pathway' acknowledged that where the LCP was used well, it facilitated good care of dying people, but found many instances where its use was associated with poor experiences of care. The panel made 44 recommendations, including the phasing out of the LCP within 6-12 months.
- In June 2014, the Leadership Alliance for the Care of Dying People published a system-wide response to that independent review. The Alliance consisted of the Department of Health, NHS England and other statutory bodies responsible for healthcare commissioning and delivery, health and social care regulation and professional regulation, royal colleges, National Institute for Health Research, National Institute for Health and Care Excellence (NICE) and national charities. The system-wide response, entitled *One Chance to Get it Right*, articulated a vision of what good care in the last days to hours should look like, in the form a five Priorities for Care, and was accompanied by a set of commitments made collectively and by individual organisations<sup>21</sup>.

## 3 What should high quality End of Life Care look like?

### 3.1 NICE Quality Standard

The NICE Quality Standard for End of Life Care for adults (2011) provides a comprehensive picture of what high quality end of life care should look like<sup>22</sup>. Delivered collectively, this should contribute to improving the effectiveness, safety and experience of care for adults approaching the end of life and the experience of their families and carers. This is described through the 16 quality statements set out in Box 1.

#### 3.1.1 Box 1: NICE Quality Standard for End of Life Care<sup>22</sup>

##### **Quality Statements:**

1. People approaching the end of life are identified in a timely way.
2. People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
3. People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
4. People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
5. People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.
6. People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
7. Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
8. People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
9. People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
10. People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.
11. People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.

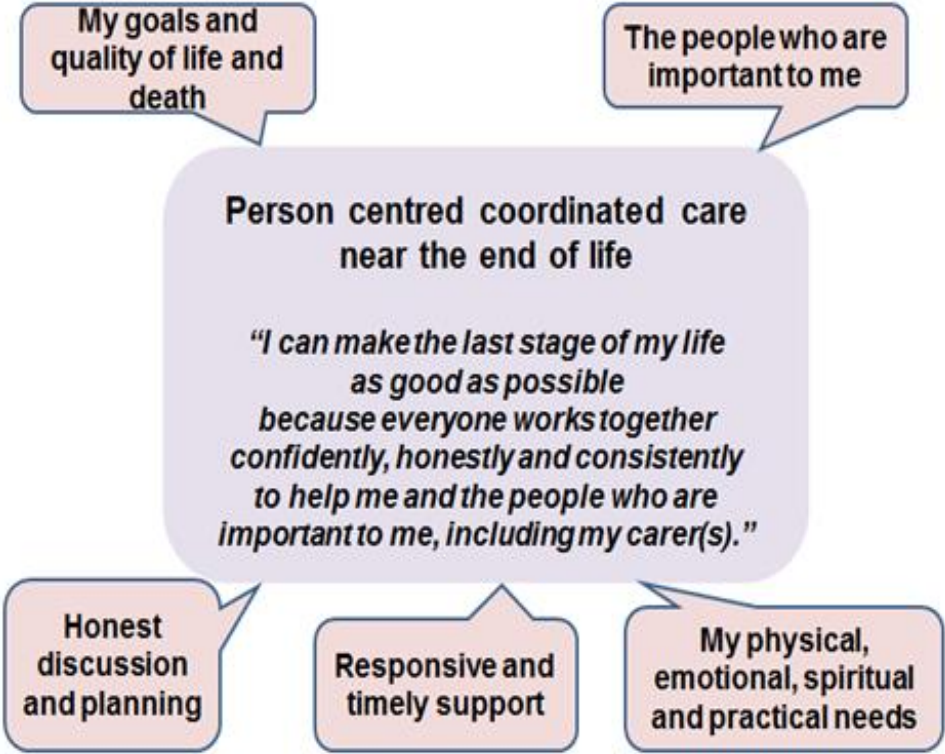
12. The body of a person who has died is cared for in a culturally sensitive and dignified manner.
13. Families and carers of people who have died receive timely verification and certification of the death.
14. People closely affected by a death are communicated with in a sensitive way and are offered immediate and on-going bereavement, emotional and spiritual support appropriate to their needs and preferences.
15. Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
16. Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

### 3.2 Development of Priorities and Actions for End of Life Care

In addition to the NICE Quality Standard, a number of other developments have contributed to the thinking and development underpinning this document. These include:

- themes which emerged from a workshop hosted by NHS Improving Quality and NHS England in July 2013 involving 53 individuals and organisational representatives of stakeholders.
- feedback from a workshop involving members of the public at the NHS England Annual General Meeting in September 2013, and discussions on social media immediately following that meeting.
- feedback from targeted communication with statutory and voluntary organisations with specific involvement in end of life care between December 2013 and March 2014.
- 'Every Moment Counts', the narrative for 'person-centred coordinated care' produced for NHS England by National Voices in 2014, in conjunction with its partners, ([see Fig 1](#)) which sets out critical outcomes and success factors in end of life care, support and treatment, from the perspective of the people who need that care, and their carers, families and those close to them.
- feedback about wider end of life care issues received through an engagement exercise carried out by the Leadership Alliance for the Care of Dying People in relation to care in the last days of life between October 2013 and January 2014.

3.2.1 Figure 1- 'Every Moment Counts' - narrative of what 'person centred coordinated care' means in the context of end of life care



## 4 How will NHS England lead and support the new commissioning system to improve outcomes for people approaching the last years of life?

### 4.1 Our Mandate and role

NHS England's Mandate from the Government for 2013-2015 includes an objective 'to pursue the long term aim of the NHS being recognised globally as having the highest standards of caring, particularly for older people and at the end of people's lives'.

NHS England's purpose is to create the culture and conditions for health and care services and staff to deliver the highest standard of care and ensure that valuable public resources are used effectively to get the best outcomes for individuals, communities and society for now and for future generations.

We have a dual role:

- Providing leadership and support to Clinical Commissioning Groups as commissioners of secondary and community services for end of life care services, including specialist palliative care.
- Direct commissioning of services which incorporate end of life care, e.g. in primary care and for people in secure and detained settings.

The commitments we set out in this document support the delivery of a number of NHS England's ambitions, as set out in Everyone Counts: Planning for Patients 2014/15 to 2018/19<sup>23</sup>, particularly:

- Improving the health related quality of life of the 15+ million people with one or more long-term condition, including mental health conditions.
- Reducing the amount of time people spend avoidably in hospital through better and more integrated care in the community, outside of hospital.
- Increasing the number of people with mental and physical health conditions having a positive experience of hospital care.
- Increasing the number of people with mental and physical health conditions having a positive experience of care outside hospital, in general practice and in the community.
- Reducing health inequalities.

See Annex A for more detailed mapping of the commitments in this document against the ambitions in Everyone Counts: Planning for Patients 2014/15 to 2018/19.

## 4.2 A Framework for End of Life Care, using the 'House of Care' model

NHS England and its partners are using a simple organising framework to deliver person-centred coordinated care for people with long-term conditions. We have adopted this model as the framework for End of Life Care because this framework helps to focus attention on the elements that need to be in place to enable high quality person-centred end of life care to be experienced, and it provides a continuum from long term conditions through to end of life care.

The 'walls', 'roof', and 'foundation' of the House of Care represent four interdependent components which, if present, provide the greatest opportunity for person-centred and coordinated care (see Fig 2). The framework assumes an active role for patients and carers in individual care planning, working with health and social care staff, services and other support agencies.

In Section 5, we set out our priorities and actions under the heading of each of these four components and the broader context of the community in which the House of Care sits.

### 4.2.1 Figure 2 - End of Life House of Care framework



## 5 Our commitments for 2014-16

This section sets out commitments which are within our gift to lead or directly influence. To improve end of life care for all, many more actions are required across the system, including in social care, public health and education. We will continue to work with our partners across the system in these endeavours but those plans and aspirations go beyond the scope of this document.

The commitments in this document do not represent the entirety of our work over the next two years. They do not spell out what we would regard as our core duties and responsibilities, nor do they include ideas which are as yet aspirational, in early stages of development, or those which will have been completed by the time of publication. The commitments are set out in the order of the time by which we hope to have achieved or made progress on them: they are not ordered by importance or priority.

Not everything in end of life care is measurable. Whilst we will take steps to seek innovative ways of evaluating impact, we will also do our best to avoid doing only what is measurable. The impact of some of these actions is likely to be incremental and occur over a longer period of time.

### 5.1 Engaged, informed individuals and carers (House of Care Left Hand Wall)

People who are living with progressive, life-limiting conditions must be at the centre of any decision, plan or action for their care or treatment. Often they want their families, carers and others who are important to them, to be involved too. For this to be achieved, they need to be able to find information in the way that best suits them at that particular time, through a variety of formats including print, audio and online materials.

The needs and preferences of each person, and the ways in which those are best met – whether through information, support, care or treatment – fluctuate throughout the course of their illness, and vary from person to person. Their personal beliefs, and faith, ethnic and cultural identity will all influence the choices they make. Some people will want to be in complete control of decisions and actions – others will not want, or be able, to take this on for themselves, but their interests must always remain at the centre of any decision or action.

We will undertake the following actions to improve the ways in which individuals and those close to them can feel informed, supported and engaged in their own care:

What we will do	By when
1. Publish and promote the use of 'Every Moment Counts': the narrative for 'person-centred coordinated care', developed by National Voices and other partners.	December 2014
2. Provide clinical advice and support for the independent review of 'choice in end of life care' commissioned by the	February 2015

Department of Health.	
3. Support the National Council for Palliative Care in their development of a new guide for individuals and those close to them about what to expect in the last days of life.	March 2015
4. Update and improve the range and quality of information about palliative and end of life care provided on NHS Choices about care, treatment and support options, including advance care planning.	June 2015
5. Ensure that the Priorities for Care of the Dying Person (as set out in <i>One Chance to Get it Right</i> ) are addressed in the care of people in secure and detained settings, where NHS England has direct commissioning responsibility.	June 2015
6. Review the National Survey of Bereaved People (VOICES-SF) to ensure that this continues to measure the experience of the bereaved person in a way that is meaningful and facilitates service improvement.	September 2015
7. Through NHS England's Commitment to Carers, identify and raise awareness of the particular needs that certain groups of carers may have, during caregiving and in bereavement, in particular: <ul style="list-style-type: none"> <li>a. those who are particularly young or particularly old</li> <li>b. those caring for people with dementia</li> <li>c. those caring for people with learning disability</li> <li>d. those who have physical or mental ill-health or frailty themselves</li> <li>e. those who are isolated.</li> </ul>	March 2016
8. Identify groups of people, across all age groups, who do not have equitable access to high quality end of life care, and develop plans for addressing this, working with the National End of Life Care Intelligence Network, NHS England's Local Area Teams, Care Quality Commission, Local Government, service users and other stakeholders.	March 2016



## 5.2 Health and care professionals committed to partnership working (House of Care Right Hand Wall)

Living with a progressive, life-limiting condition, and its physical and psychological consequences, is hard for the person concerned, and those close to them. Providing person-centred coordinated care for these individuals can be challenging for health and care staff and volunteers too. The intellectual, practical and emotional demands on them mean that they need support, education and training, if they are to be effective in what they do, and to remain compassionate and resilient. They need to be able to work efficiently and effectively within a resource-constrained context. They also need: time to learn and to care; opportunity to listen to, and interact with, people and their families; time and skills for reflection, relationship-building and team working across health and social care boundaries, all of which help to build resilience and capability.

We will undertake the following actions to help health and care professionals build and sustain their commitment to working in partnership with each other, and with the people they care for and those close to them:

What we will do	By when
1. Provide guidance to care practitioners on how to deliver personalised care planning, including advance care planning.	November 2014
2. Foster and support local leadership, facilitate sharing of best practice and promote development of communities of practice through palliative and end of life care networks.	March 2015
3. Build and strengthen leadership through our commitment to facilitate 10,000 nurses to participate in leadership courses by 2015 (Compassion in Practice Action Area 4).	March 2015
4. Work with professionals and organisations who are currently participating in the Transforming End of Life Care in Acute Hospitals programme to identify and address specific areas for improvement.	March 2015
5. Develop a way of sustaining local communities of practice through the network of end of life care facilitators and social care champions supported by NHS Improving Quality.	September 2015
6. Work with Public Health England, Health Education England, the Association of Directors of Adult Social Services, the Care Quality Commission, Monitor and other partners to enhance health and care professionals' understanding and use of data and intelligence. This will enable them to develop their own ability to monitor, assess and understand people's experience in order to improve services, and to identify and address: <ul style="list-style-type: none"> <li>a. unwarranted variations in practice</li> <li>b. the needs of groups of people whose access to high quality end of life care is inequitable, and</li> <li>c. the variations in response that are needed to</li> </ul>	March 2016

support and respect faith and cultural differences.	
7. Support positive experience and encourage a sense of personal responsibility to deliver compassionate care in line with 'making explicit the links between good staff experience and quality outcomes for patients' which is a key deliverable of Compassion in Practice Action Area 6.	Ongoing
8. Work with commissioners in areas where NHS England has direct commissioning responsibility, to empower and enable professionals to recognise, assess, communicate and provide individualised care and support for those who are likely to die within the next few hours or days, as set out in the report One Chance to Get it Right.	Ongoing
9. Work with Health Education England and commissioners to enable staff to receive the necessary education, training and support to address the 5 Priorities for Care for the dying person, as set out in the report One Chance to Get it Right.	Ongoing
10. Work with Health Education England, Skills for Care, Royal Colleges, professional bodies and voluntary organisations to enhance the capability of health and care staff, specifically in: <ul style="list-style-type: none"> <li>a. recognising when the individual is approaching the last year(s) of life and in communicating about this and other difficult issues in a sensitive manner</li> <li>b. using skills of shared decision-making to engage and empower those for whom they care in coming to decisions about health and social care that best fit with the person's needs and preferences</li> <li>c. using evidence-based principles of medicines optimisation to improve clinical outcomes and patient experience</li> <li>d. assessing and addressing the needs of carers, including in bereavement.</li> </ul>	Ongoing

### 5.3 Organisational and supporting processes (House of Care Roof)

Consistent, coordinated care is a crucial component of person-centred care, especially for people with progressive, life-limiting conditions, and those close to them. They need to feel confident that organisational processes will be effective, efficient and accessible whenever needed, without the person or those close to them having to spend excessive time or energy orchestrating everything. Safe, accurate and effective handovers of care between health and care staff, and across teams and organisational boundaries, are critical to ensure that the experience of care is not fragmented, frustrating or unsafe. Much of this lie in the hands of individual health and care staff, service providers and local commissioners.

We will undertake the following actions to support staff, service providers and commissioners to develop or gain access to systems and processes that help them to deliver as good as possible experience of person-centred coordinated care for people in the last years of life, and those close to them.

What we will do	By when
1. Provide a knowledge hub of up to date information, resources and links to support health and care staff, commissioners and patients and carers, through the House of Care toolkit and all networks and portals available through our partners.	March 2015
2. Submit a referral to the National Institute for Care and Excellence for updating service guidance for palliative care (last version 2004).	March 2015
3. Work with Care Quality Commission in their thematic review of inequalities and variations in the provision of end of life care, including taking forward the recommendations of the review where these are relevant to NHS England's role.	March 2015
4. Support the Association of Ambulance Chief Executives in developing guidelines for end of life care to be included in next iteration of Ambulance National Clinical Guidelines.	April 2015
5. Work with the Royal Colleges, regulatory bodies and other professional organisations to embed the Priorities for Care of the Dying Person into daily practice through dissemination of the Duties and Responsibilities of Health and Care Staff, as set out in <i>One Chance to Get it Right</i> .	June 2015
6. Work with NHS England's Regional and Area Teams, Strategic Clinical Networks and Clinical Senates, and with the NHS Commissioning Assembly, Health and Wellbeing Boards, Monitor and Trust Development Authority to encourage the use of the Priorities for Care of the Dying Person: Implementation Guidance for service providers and commissioners, as set out in <i>One Chance to Get it Right</i> .	June 2015

7. Work with Healthcare Quality Improvement Partnership to commission a national audit of the care received by people who die in acute hospitals.	March 2016
8. Support the continuing implementation of digital record-sharing systems to improve care coordination, including: <ul style="list-style-type: none"> <li>a. the ability and willingness to share data across care settings</li> <li>b. ensuring that systems are capable of capturing and making explicit the individual's preferences and goals, and how they wish these to be achieved, and</li> <li>c. working with Public Health England to ensure that the National Information Standard for the content of Electronic Palliative Care Coordinating Systems (EPaCCS) remains up to date, fit for purpose and is in alignment with the proposed Information Standard for personalised care planning.</li> </ul>	Ongoing
9. Work with Public Health England to identify variations in practice and inequitable access to high quality end of life care for disadvantaged groups of people, and work with relevant stakeholders and partners to identify mechanisms for translating the requirements of these groups of people into meaningful actions and outcomes.	Ongoing

## 5.4 Commissioning (House of Care Foundation)

End of life care is locally commissioned and locally provided. The whole spectrum of care must be commissioned, from generic end of life care and support such as that delivered by primary care teams, non-specialist hospital teams and social services, through to hospice care and specialist palliative care services. Currently a simple meaningful set of metrics for end of life care does not exist. These need to be developed and carefully selected to ensure that they can be used safely as levers and incentives. They will need testing and adjustment to guard against unwanted unintended consequences.

We will undertake the following actions, alone or in partnership with others, over the next two years, to develop resources and mechanisms to improve the commissioning of palliative and end of life care services so that people living with progressive, life-limiting conditions, and those close to them, can receive the best possible care which matches their level of need and, as far as possible, preference:

<b>What we will do</b>	<b>By when</b>
1. Produce guidance for commissioners on personalised care planning to help them understand how 'personalised' care planning is different, how it can be delivered, and how it fits into the wider system.	November 2014
2. Identify blocks and potential solutions for people who are in their last years of life to have their end of life care needs met whenever necessary, through contribution to the Better Services Integration Project (part of the Seven Day Services programme).	December 2014
3. Incorporate into the NHS Standard Contract a requirement for due regard to be paid to the Priorities for Care of the Dying Person: Implementation Guidance for service providers and commissioners, as set out in <i>One Chance to Get it Right</i> .	January 2015
4. Publish national development currencies (units of care) for specialist palliative care to support the development of a new palliative care funding model, and support further testing and development of the currency over the following year, working closely with Monitor.	March 2015
5. Continue to explore how personalised care planning, including personal health budgets, can support individuals and their carers to design care packages specific to their needs at end of life. In the longer term, we will also explore the potential and impact of Integrated Personal Commissioning (from April 2015).	April 2015
6. Examine a range of methods for capturing the insights of patients and those close to them about their experience of end of life care, and the extent to which these can be used for service improvement and to enhance commissioning practice.	April 2015
7. Update the commissioning toolkit for end of life care, previously published by the National End of Life Care	June 2015

Programme, and make this available through the House of Care toolkit.	
8. Encourage commissioning of peer support services in local communities to help meet the social and emotional needs of people approaching the end of their lives, and their carers, and produce guidance on how to commission these services, demonstrating the benefits, and providing best practice examples.	July 2015
9. Publish a service specification for specialist palliative care which can be used as a basis for commissioning and for peer review or service accreditation.	September 2015
10. Work with commissioners to ensure that the services they commission have the right staff with the right skills and knowledge in the right place in part through our work to develop a tool for workforce planning and staffing levels for community nursing (Compassion in Practice Action Area 5).	September 2015
11. Work with direct commissioning leads (including specialised commissioning) and National Clinical Directors to ensure that commissioning of services includes considerations about how attention to end of life care can be incorporated into service specifications. An initial specific focus will be given to the following groups of people: <ul style="list-style-type: none"> <li>a. people who have dementia</li> <li>b. people with severe frailty</li> <li>c. people with learning disability</li> <li>d. people from black and minority ethnic backgrounds</li> <li>e. people in secure and detained settings</li> <li>f. people who are homeless.</li> </ul>	March 2016
12. Work with Public Health England to develop a palliative care clinical dataset to provide the foundations for further work on outcomes and indicators.	March 2016
13. Work with Hospice UK to improve the relevance and sensitivity of mechanisms for contracting for hospice and specialist palliative care services.	Ongoing
14. Review and develop metrics and commissioning levers and incentives suitable for use in end of life care, using the NICE Quality Standard for End of Life Care and 'Every Moment Counts', the narrative for person-centred coordinated care, and test these to ensure that their use is meaningful, safe and do not result in widening variation in practice or further inequity.	Ongoing
15. Improve and disseminate evidence about interventions that are safe, effective, and improve the experience of those approaching the last years of life, and those important to them, working with Public Health England, National Institute for Health Research, and the research and academic communities.	Ongoing

## 5.5 Broader context: Engaged, involved and compassionate communities

Death is an inevitable part of life. Living with a progressive, life-limiting illness, dying, death and bereavement involve not only the individual, their families, carers and those close to them, but also the communities within which they live. Wider societal attitudes to death, dying and bereavement influence the way conversations occur about different aspects of end of life care, and the way we shape our personal and communal response – voluntary and statutory. It is particularly important to recognise the diverse needs of different groups of people within our society, some of whom have limited opportunity or capability to voice their own views or needs, which may differ from the majority position.

Engaging and involving communities – directly, through our Strategic Partners and in collaboration with Public Health England and Social Care – will help to extend the reach and effectiveness of end of life care services. NHS England has produced Participation Guidance which will be used to support our involvement.

We will work collaboratively with our Strategic Partners, community groups and other organisations throughout the health and care system by:

- Facilitating partnership working across the end of life care community through a forum for strategic partners and organisations interested and involved in delivering end of life care, or supporting its delivery, for adults and children.
- Working together to identify inequalities in end of life care, for specific conditions and groups of people, and to develop strategies for reducing these inequalities.
- Promoting the use of ‘Every Moment Counts’, the narrative for ‘person-centred coordinated care’, developed by National Voices and other partners, as a key focus for developing community initiatives in end of life care.
- Supporting the Dying Matters Coalition in its work to promote public awareness and conversations about dying, death and bereavement.
- Supporting Public Health England in its work to promote and assess the impact of the Public Health End-of-Life-Care Toolkit, the Dying Well Charter and Compassionate Communities.

## 6 The way forward

We will work in partnership with our system and stakeholder partners to make progress on these priorities and actions. Wherever the action involves personal information, the key principles for information governance set out in Annex B apply.

NHS Improving Quality will play a major role in supporting the delivery and implementation of these plans. For some of these actions, tangible 'products' will make it obvious that we have achieved what we said we would do; for others, evidence of impact will be harder to demonstrate. Ultimately, the yardstick of our effectiveness will be the experience reported by those who experience end of life care, and we must find ways to find out about this from all groups of people.



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## 8 Annex A - Mapping Actions in End of Life Care (Sections 5.1 to 5.4) against Everyone Counts: Planning for Patients 2014/15 to 2018/19

<b>Ambitions set out in NHS England's Everyone Counts: Planning for Patients 2014/15 to 2018/19</b>	<b>Section 5.1: Actions</b>	<b>Section 5.2: Actions</b>	<b>Section 5.3: Actions</b>	<b>Section 5.4: Actions</b>
Securing additional years of life for the people of England with treatable mental and physical health conditions				
Improving the health related quality of life of the 15+ million people with one or more long-term condition, including mental health condition	1, 2, 4, 7	6, 9, 10	1, 2	2, 4, 6, 7, 9, 12, 13, 14, 15
Reducing the amount of time people spend avoidably in hospital through better and more integrated care in the community, outside of hospital	1, 2, 4	6, 9, 10	1, 2, 4, 8	4, 5, 7, 12, 14
Increasing the proportion of older people living independently at home following discharge from hospital	1, 4, 7	1, 10	2	
Increasing the number of people with mental and physical health conditions having a positive experience of hospital care	1, 2, 3, 4, 6	1, 2, 3, 4, 5, 7, 8, 9	1, 2, 5, 6, 7, 8	2, 3, 5, 6, 7, 8, 9, 14, 15
Increasing the number of people with mental and physical health conditions having a positive experience of care outside hospital, in general practice and in the community	1, 2, 3, 4, 6	1, 2, 3, 5, 7, 8, 10	1, 2, 4, 5, 6, 8	2, 3, 4, 6, 7, 8, 9, 14, 15
Making significant progress towards eliminating avoidable deaths in our hospitals caused by problems in care				
Improving health		6	2	
Reducing health inequalities	1, 2, 3, 4, 5, 7, 8	4, 6, 8	1, 2, 3, 4, 8, 9	3, 4, 6, 7, 8, 9, 15
Parity of esteem	1, 4	6		

## 9 Annex B: Personal Information

The best possible end of life care depends on the best possible use of information relating to that care. That use must also be lawful, but the law and best practice will never impede good care.

This means that for all end of life care programmes:

- A full and accurate record must be made of the care and support, and all the discussions and decisions that go with it, from day to day.
- The person must have full access to this information (unless that is likely to cause him or her harm).
- The person must be fully informed about the intended uses of the information including who it may be shared with, and why.
- The person's wishes must be respected including their decisions about information sharing (unless there is a lawful basis for not doing so).
- If the person wishes it, his or her family or carers should be involved in these decisions.
- If the person lacks mental capacity decisions should be made in their best interest (in the case of children without capacity by those with parental responsibility for them).
- The information must be kept safe and secure, and confidentiality must be maintained at all times.