



Department  
of Health

# Our Commitment to you for end of life care

The Government Response to the Review of Choice  
in End of Life Care

July 2016

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# Our Commitment to you for end of life care

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# Foreword

## By the Parliamentary Under-Secretary of State for Care Quality



The more we have become proficient at extending life, the less we venerate death. We can hardly bear to bring ourselves to say the word, preferring to frame our language of death with awkward euphemisms and the clichés of a greetings card. How we speak reflects what we do. Death is now a muffled admission of failure, an afterthought in a world that celebrates little other than exuberant life. It is a world away from the end that our ancestors would have actively sought: the good death.

It is hardly surprising that our discomfort with death has affected the way we look after the dying person. Whilst we have a proud tradition of palliative care in this country, most notably the modern hospice movement founded by Dame Cicely Saunders, we all know that good care for the dying is far from universal. There are too many who have witnessed for themselves the tragedy of a dying relative or friend neglected simply because it was considered that there was nothing more to do to sustain their life. Each of these experiences points to the same conclusion: that we do not sufficiently value the care of those for whom there is no cure. As healthcare has become more successful, our health systems have become focused more on the curative sciences than the caring arts. The result is that when science has reached its limit, our care of dying people is – as recent reports have shown – variable, haphazard and at times shockingly poor.<sup>1</sup>

This is an inversion of how things, properly ordered, should be. If our National Health Service and our care system is to be what we all wish it, we must all put the care of the person at the centre of all that it does. The time, effort and attention that we devote to a dying patient should not depend on whether we have the ability to extend their life. Care should be the foundation on which cure is provided. For those for whom no cure is available, we should recover our determination to ensure that the dying person has a good death.

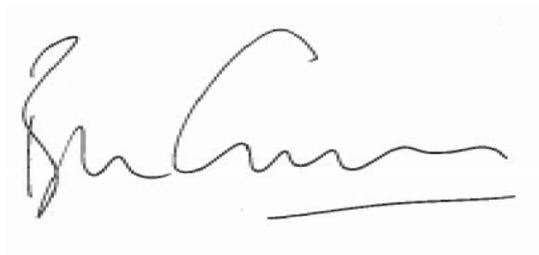
Providing the opportunity of a good death lies at the heart of this document – our commitment to you for end of life care. It is born of HM Government's response to the Review of End of Life Care, a report presented in 2015 at the request of Ministers concerned at the state of care for the dying person in our country. The Review was a seminal piece of work, a culmination of many years of research into the components of providing exceptional palliative care to the dying person. I am very grateful to all the partners who contributed to the Review, in particular the End of Life Care Coalition of charities and the Ambitions for End of Life Care Partnership, led by the National Clinical Director for End of Life Care, Professor Bee Wee. We accept the recommendations of the Review, which form the basis of the broader commitment we give in this response.

## Our Commitment to you for end of life care

Our commitment is that every person nearing the end of their life should receive attentive, high quality, compassionate care, so that their pain is eased, their spirits lifted and their wishes for their closing weeks, days and hours are respected. We shall ensure that all the needs of the dying person – spiritual, physical and familial – are provided for in a way that is as that person and those closest to them wish them to be.

By making this commitment, we will address poor care where it exists and accelerate improvement across the health and social care system in England. Already there are exemplary models of good care operating across the NHS and social care system: we will ensure that where care is not so good we can learn from what is best and translate it to where it is needed most. A universal provision of good care will make possible what we should expect from our health and care system – a universal expectation of a good death.

Cicely Saunders was articulating an ancient truth when she described her mission: that ‘we should see the last stages of life not as a defeat but as life’s fulfilment’. A good death – peaceful, dignified, reflective, compassionate, in the loving embrace of those closest to the dying person – is already a happy end for hundreds of thousands of people across our nation. In making this commitment, we make that promise universal, so that every dying person in England can live in anticipation of a good death.

A handwritten signature in black ink, appearing to read 'Ben Gummer', with a horizontal line underneath.

**Ben Gummer MP**  
**Parliamentary Under-Secretary of State for Care Quality**

# Introduction

Around 470,000 people die each year in England and this is projected to rise by 20% over the next twenty years.<sup>2</sup> We also expect more people to die at an older age and have more complex needs. At the same time, 40,000 children and young people in England now live with a life-shortening or life-threatening health condition.<sup>3</sup> As a country, we face an unprecedented challenge to ensure that the NHS and care services can respond to these changes and provide high quality, personalised care to everyone approaching, or at, the end of life.

In recent years, we have made great strides in improving and raising the importance of end of life care. The Department of Health's *End of Life Care Strategy*<sup>4</sup> set us on this path in 2008 and was soon followed by a series of key documents that have charted our progress in understanding and improving end of life care in recent years. These have included the NICE Quality Standard for End of Life Care<sup>5</sup>, the Independent Review of Palliative Care Funding<sup>6</sup>, and *One Chance to Get it Right*<sup>7</sup>, the system-wide response to the review of the Liverpool Care Pathway.<sup>8</sup>

Finally, the *Ambitions for Palliative and End of Life Care*<sup>9</sup>, published in September 2015, has built on this progress and provided a framework for national and local health and care system leaders to take action to improve end of life care.

According to the recent assessment of global end of life care performance by the Economist Intelligence Unit, our end of life care is rated as the best in the world.<sup>10</sup> We know, however, that not everyone receives the best possible care. For instance, a 2015 survey showed that more than 30% of people who died in hospital were reported by their families and carers to have received "poor" or "fair" care and 40% did not always receive the dignity and respect they deserved at the end of life. We also know that only 19% of people dying at home received complete relief from pain, all of the time. We know that too many people are not involved enough in decisions about their care and do not receive end of life care in their preferred place.<sup>11</sup> Recent reports have shown that, in too many instances, care is not sufficiently focused on the person's individual needs and preferences.<sup>12 13</sup> This is not acceptable.

Our ambition is for everyone approaching the end of life to receive high quality care that reflects their individual needs, choices and preferences. Everyone, including children, should be able to be involved in decisions about their own care and develop care plans, together with those important to them and the health and care professionals responsible for their care.

The Government commissioned the Review of Choice in End of Life Care<sup>14</sup> ("the Review") to provide independent advice on improving the quality and experience of care for adults at the end of life, their carers and others who are important to them, by expanding choice.

The Review, which was focused on adults, demonstrated clearly that high quality care and personalised care based on people's choices and preferences are inseparable. People want to

## Our Commitment to you for end of life care

be given the opportunity to make choices relating to their end of life care, but they want their choices to be real choices, based on high quality end of life care services being available in all areas of the country and in all settings.

This response outlines the actions we are taking, led by organisations across the health and care system, to meet our ambition for all people to have high quality, personalised end of life care built around their needs. A full response to each of the Review's recommendations can be found at Annex A.

Our approach is founded on a national Commitment for end of life care. To deliver this, we will support the system to achieve better, more personalised care for all through a combination of improvements and innovations in the way end of life care is delivered and provided. At the same time, we will spread the lessons and good practice we know exist across the system, ensuring that everyone can benefit from quality improvements.

We will also ensure that end of life care is central to wider reform and transformation being delivered under the *NHS Five Year Forward View*. This means ensuring that end of life care is firmly embedded as core business for the NHS and in all major NHS transformation programmes in the future. It is also why we have included children and young people in the Commitment and in this response as a whole even though they were not explicitly included in the Review.

Finally, through our system leadership role, the NHS Mandate<sup>15</sup> and the new Clinical Commissioning Group Improvement and Assessment Framework<sup>16</sup>, we will hold the NHS to account for the quality improvements needed to deliver our vision of personalised end of life care for all.

Part One of this response sets out our Commitment and a summary of the actions we will take to deliver it. Part Two sets out the detail of our vision to support and deliver the Commitment through greater personalisation, improvements to quality in all settings and strengthened accountability and transparency.

# Part One - Our Commitment to you

## Our Commitment for end of life care

The Review's extensive public consultation made clear what people want. People want to have control over the care they receive and to shape it around their personal preferences. This must, however, be underpinned by high quality care. Without this foundation, personalised care would not be achievable.

We want to set a clear expectation of the standard of care that everyone should be offered as they approach the end of their life and what the health and care system should be doing to ensure that care is both high quality and personalised.

We are making the following commitment to everyone so that the care every person approaching the end of life receives is personalised and focused on their individual needs and preferences:

**Our commitment to you is that, as you approach the end of life, you should be given the opportunity and support to:**

- have honest discussions about your needs and preferences for your physical, mental and spiritual wellbeing, so that you can live well until you die;
- make informed choices about your care, supported by clear and accessible published information on quality and choice in end of life care; this includes listening to the voices of children and young people about their own needs in end of life care, and not just the voices of their carers, parents and families;
- develop and document a personalised care plan, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness;
- share your personalised care plan with your care professionals, enabling them to take account of your wishes and choices in the care and support they provide, and be able to provide feedback to improve care;
- involve, to the extent that you wish, your family, carers and those important to you in discussions about, and the delivery of, your care, and to give them the opportunity to provide feedback about your care;
- know who to contact if you need help and advice at any time, helping to ensure that your personalised care is delivered in a seamless way.

## Introduction

This Commitment encapsulates what everyone should be offered as they approach the end of their life. It is the basis of the high quality, personalised care that many people are already being offered but which is not yet universal. It is aligned with the five Priorities for Care of the Dying Person we set out in 2014 and the *Ambitions for Palliative and End of Life Care* outlined by the National Palliative and End of Life Care Partnership in 2015.

To support this Commitment we will publish information on quality and choice in end of life care so that transparency about care will drive improvement, spread lessons across the country and reduce variation in quality of care.

In making this Commitment, we are sending out the message that high quality personalised care has to be universal. We are determined to end variation in care due to geography, age, diagnosis, background or means. This is a national commitment to high quality care for all.

# Summary of actions to deliver the Commitment

Our Commitment for end of life care is not made lightly. We know how important end of life care is, and how important it is to ensure that this care is the best it can possibly be. However, we also know that there are challenges to overcome before this Commitment can be fulfilled everywhere.

The Review set out the elements of end of life care that people most care about and where people felt choice should play the greatest role. Its advice to Government was comprehensive and has informed our proposals to improve care. Above all, the Review sent the clear message that, for most people, choice is inextricably bound up with quality. The Review emphasised that the offer of choice is only real when there is universal access to high quality services in all settings, when care is coordinated well, and where staff, services and infrastructure combine to enable effective discussion and implementation of people's preferences. The Review also recognised the challenges we face in reducing undesirable variations in care.

We know there are many areas where we need to see improvement. Working together with national organisations across the health and care system, our programme of work will deliver service improvements to ensure that our Commitment for end of life care is achieved for everyone.

In this response we have set out all the measures we will be taking to support the Commitment. These are organised under themes that characterise our vision of high quality care: personalising care; improving care quality; identifying and spreading innovation; leadership and commissioning; improving end of life care education, training and workforce provision and planning; partnership working; and strengthening accountability, measurement and transparency.

**In summary, the actions we will take to support and implement the Commitment are as follows:**

## 1. We will develop more personalised care for people approaching the end of life

We will put in place measures to ensure everyone's preferences are recorded and shared digitally. We will look to expand the availability of options for greater personalisation and control at the end of life enabling more people to decide how money should be spent to meet their needs. We will explore the potential for care coordinators at the end of life. We will pilot a new way of planning care which links up long-term conditions management with end of life care, through "serious illness conversations". We will ensure progress on personalisation can be tracked by developing new measures of success for personalisation.

### 2. We will put in place measures to improve care quality for all across different settings

We will ensure end of life care is part of all the major programmes to transform the NHS, including in the development of local plans and the focus on urgent and emergency care and seven day services in hospitals. Working with our partners, we will continue to improve hospital care through the Transforming End of Life Care in Hospitals programme and ensure that the Care Quality Commission continues to focus on end of life care in all settings where it is delivered. We will develop urgent care clinical advisory hubs to improve access to urgent clinical advice and support for end of life care, including expert advice from specialist palliative care services. We will explore improvements in end of life care for care home residents and implement new ways of delivering effective end of life care in community settings. We will work with our partners to address inequality and variation of access to end of life care services.

### 3. We will identify and spread innovation in the delivery of high quality care

NHS England will lead on identifying, adapting, promoting and sharing effective models of end of life care for dying people, including lessons from innovative 'Vanguard' sites and new models of care. We will conduct a series of roadshows to exhibit effective approaches and establish a central website as a shared knowledge resource for all.

### 4. We will lead on end of life care nationally and provide support for local leadership, including commissioners, to prioritise and improve end of life care

Working through our commitment to end of life care in the Mandate to the NHS, we will promote and support the *Ambitions for Palliative and End of Life Care* Framework. We will also engage with clinical commissioning groups and Health and Wellbeing Boards on improving end of life care provision through local strategic planning and commissioning. We will provide commissioners with data, tools and palliative care currencies to help identify palliative care needs in local areas and the best ways to commission services to meet those needs.

### 5. We will ensure we have the right people with the right knowledge and skills to deliver high quality personalised care

We have agreed deliverables on improving end of life care education, training and workforce provision and planning with Health Education England (HEE). HEE will develop a refreshed competency framework for end of life care, implement a national action plan to promote good practice and work with its partners to review end of life care within undergraduate and postgraduate curricula. HEE will also include end of life care in its work to develop Community Education Provider Networks, and its work on the future of the nursing workforce. HEE will explicitly include end of life care in its wider workforce planning to deliver the NHS *Five Year Forward View*.

### 6. We will work together with system partners and the voluntary sector to deliver this commitment

We will continue to work closely with our voluntary sector partners including on specific projects to improve end of life care in hospital and out-of-hospital settings, promote a national conversation about death and dying and develop local volunteer networks.

7. Finally, we will **strengthen accountability and transparency to drive improvements**

We will hold the NHS to account for improvements to end of life care through the Mandate to the NHS and we will hold HEE to account through its own Mandate. For the first time, we will develop a robust set of metrics that capture care quality, patient experience and personalisation in end of life care to track progress nationally on delivering high quality, personalised care. We will publish performance against key measures for every clinical commissioning group to drive up standards in every part of the country.

A number of organisations across the health and care system have committed to actions in this response to make the Commitment for end of life care a reality. As part of our responsibility to ensure the commitment is supported, we will ensure that progress against these actions is made publicly available in a year's time.

# Part Two - How we will deliver the Commitment

# 1. Better, personalised care for people approaching the end of life

The Review rightly focused on the importance of providing personalised care, which is based on the needs of the dying person, and takes into account the views of family members, carers and those important to the person.

The five Priorities for Care of the Dying Person have already set out what this means for people who are dying and those caring for them. However, we know that unacceptable variation in quality and personalisation exists and that this can undermine the effective implementation of the five Priorities for Care.

We believe that personalised care, built around individualised care planning, must be central to any improvements to end of life care services. We agree with the Review that now is the time to deliver the improvements to achieve high quality personalised care for all.

The reality of choice at the end of life is not always straightforward. It depends on informed, sensitive, two-way conversations with dying people and their relatives and carers about what is important to them. Not all options will be desirable or clinically appropriate. Preferences change over time, often reflecting changing needs and circumstances. People may have different views and priorities from those close to them. Every dying person needs to have on-going opportunities to have these conversations, express what is important to them and make informed choices about the options available.

To support this process, all staff involved with dying people must be capable of having difficult conversations about death and dying, taking the time to listen carefully to what dying people and those important to them say, and provide opportunities for developing, reviewing and updating personalised care plans with dying people. Health and care providers delivering this care must ensure that staff have the time and space to achieve this.

At the same time, it is important that all dying people have access to spiritual support as well as physical and psychological support and that their loved ones will be supported to access bereavement support.

Making good end of life care happen is not the responsibility of one person or organisation: it happens because professionals and organisations work together, record and share information and focus on individual needs. We want to create a future for end of life care where cooperation and information-sharing between staff and organisations are seamless so that everyone responsible for a dying person's care has the right information at their fingertips and can implement and update individual care plans and preferences.

**To support greater personalisation of end of life care, we will take the following action:**

- NHS England will ensure that shared digital palliative and end of life care records, such as Electronic Palliative Care Coordination Systems (EPaCCS), have been rolled out to the majority of local areas by 2018 and all areas by 2020, to support the sharing of information and to promote personalised care. To support the rollout of shared digital records, NHS England will work with GP system suppliers to open up their systems to support interoperability. In areas currently without shared digital records, the Summary Care Record (SCR) will be promoted as the minimum requirement to enable electronic sharing of end of life care preferences.
- In line with the recommendations of the National Information Board, by 2018, digital solutions will be developed to enable people to access their own records and add information about their care, including their end of life care preferences.
- NHS England will work with a small number of interested areas to assess rapidly the options for personalising services and improving choice and control for individuals at the end of life, using the learning from the delivery of personal health budgets and integrated personal commissioning in end of life care. NHS England will also ensure that more people across the country who receive fast track NHS Continuing Healthcare have the option to have more choice and control over the services they receive.
- NHS England has studied the potential role of “care coordinators” to help people express their preference, make informed choices and navigate their way through the complex health and care system. The National Council for Palliative Care will take this work forward by developing optimal models for a care coordinator scheme and will host a stakeholder event to obtain feedback and test feasibility.
- New Care Model sites Airedale and Southend have been selected to test an innovative approach to ‘serious illness conversations’ in which clinicians are trained to support people with serious illnesses to discuss what is important to them, treating these discussions as a clinical intervention which delivers patient-centred care. The approach will be evaluated to ensure the final training products are tested, meaningful and value-driven, with existing pioneers and Vanguards set up to respond quickly to the evaluation.
- Public Health England (PHE) recently published its report *Faith at the End of Life*<sup>17</sup>, a resource for professionals on delivering holistic care at the end of life. The NHS will be able to use this resource in its work to deliver a holistic approach to end of life care planning and assessment of people’s needs that includes a focus on dying people’s spiritual needs and bereavement services for family members and others close to the dying person. This is also important for dying children and their families.
- As part of its new inspection approach, which includes end of life care as a core element, the Care Quality Commission’s (CQC) will continue to inspect whether healthcare Trusts and community services address people’s spiritual needs at the end of life and whether they are well-coordinated with bereavement services.
- NHS England has commissioned the National Council for Palliative Care to develop an educational film that will provide advice and guidance to help prepare individuals with

## Part Two - How we will deliver the Commitment

advanced disease and long term conditions, and those important to them, for their consultations with clinicians. The film will be available on NHS Choices and the 'Dying Matters' website and will provide vital advice and guidance for people at a challenging point in their lives.

- As part of its work to support the commitment for end of life care, NHS England will lead a public-facing campaign to promote choice and personalisation in end of life care.

## 2. Improving the quality of end of life care in all settings

Enabling choice and improving quality go hand in hand. Real choice for people approaching the end of life depends on the confidence they have that they will receive the right care in whatever place they choose to die. This means that in all settings, high quality, personalised care is delivered to meet the person's needs and preferences as far as possible and to support them to live as well as possible until they die.

Many people do experience excellent care but we know that specific problems persist in certain settings. We know that too many people who die in hospital do not receive the level of attentive care, compassion and respect they deserve.<sup>18</sup> At the same time, too many people who opt to die at home do not have their pain adequately managed.<sup>19</sup> We also know that residents in care homes often experience difficulties getting the right care at the right time.<sup>20</sup>

Dying people's informed choices about place of care and death and other issues must be supported by services offering high levels of care, dignity and respect in all settings. Whether a dying person is being cared for at home, in a hospital, a care home or in a hospice, they have the right to expect that their pain will be managed actively at all times, whether at day or at night; that they will be treated with respect and compassion; that they and those important to them will be listened to and given the advice, support and care they need.

Good care is also about identifying people approaching the end of life earlier so that there is time and opportunity to prepare, discuss and plan care, and time to put that care in place to meet people's individual needs and preferences.

We know that this does not always happen as well as it should and that there is unacceptable variation in access to round-the-clock advice, support and care, especially when people are dying in community settings, in a care home or in their own home.

All dying people and those important to them must have access to palliative care advice whenever and at whatever level of expertise is needed. Every local area must adopt effective models of care to ensure that services provide people with round-the-clock access to the reassurance, support, advice and care that they need, regardless of setting or condition.

Finally, we also know that certain groups, including people from black and minority ethnic communities, people living in deprived areas, homeless people and people in secure and detained settings report poorer quality end of life care experiences.<sup>21 22 23</sup> At the same time, we know that people with learning disabilities or dementia or people in isolated or rural areas can find it more difficult to access the end of life care they need.<sup>24 25</sup> The Care Quality Commission's (CQC's) recent report on inequality and variation in end of life care underscores these challenges.<sup>26</sup> These unacceptable variations must be acknowledged and action taken to ensure all people have high quality care.

### To achieve the quality improvements we want to see, we will put in place improvements tailored to hospital, community and care home settings:

- To deliver improvements in all settings, NHS England will ensure that all relevant major programmes contain end of life care as a key component and the scope of all new national initiatives is explored to consider how they can contribute to improving quality and choice of end of life care. End of life care is an intrinsic thread within several of NHS England's corporate priority areas, including Urgent and Emergency Care, Cancer and Dementia and we expect to see end of life care improvements identified and realised as part of these programmes.
- *Delivering the Forward View: NHS planning guidance 2016/17 – 2020/21*<sup>27</sup> asks local systems to address how they will close the health and wellbeing gap and include, within their Sustainability and Transformation Plans (STPs), plans for a 'radical upgrade' in patient choice and control. It also asks local systems to account for how they will manage implementation of choice, particularly at end of life, as part of their programme to hand power to patients.
- NHS England and NHS Improvement have established joint oversight arrangements for the Transforming End of Life Care Programme. They will work to support statutory and voluntary sector partners to extend the use of the Programme's key enablers, as in the case of the National Council for Palliative Care (NCPC) and Macmillan Cancer Support's *Building on the Best* programme, Guy's and St Thomas's Hospital's *AMBER care bundle* and the Point of Care Foundation's *Patient and Family Centred Care* programme. The Oversight Board for this work includes voluntary sector members and patient representation.
- The intention is for these arrangements to include acute and community hospitals and focus on service and quality improvement which supports compassionate, personalised care. Additionally, where Trusts have been rated as 'Inadequate' or 'Requires Improvement' in CQC inspections of end of life care, NHS Improvement will work with these Trusts and community services to improve the delivery of end of life care in these areas.
- In addition to these hospital improvements, a number of clinical commissioning groups (CCGs) around the country are being supported to test new community end of life care services, such as 24/7 specialised nursing services, backed by socially motivated investment. These services will deliver improved quality and choice in community-based end of life care.
- To improve access to urgent clinical advice and support for end of life care, including expert advice from specialist palliative care, clinical advisory hubs being developed as part of NHS England's Urgent and Emergency Care plan will include clear and explicit processes for access to palliative care through each hub across the country, and will be accessible to individuals who need the service, their families and professionals involved in their care.
- To improve the end of life care being delivered in care homes, NHS England will work with care home partners to support improvements in end of life care for care home residents and spread lessons from existing Vanguard sites that include care homes.

## Improving the quality of end of life care in all settings

- The Association of Palliative Care Social Workers, in collaboration with Hospice UK and others, has published a comprehensive resource to support and develop palliative care within social work practice.<sup>28</sup> The resource is fully aligned with the *Ambitions for Palliative and End of Life Care* outlined by the National Palliative and End of Life Care Partnership in 2015 and sets out the increasing role of social care workers in end of life care settings. The resource supports the priority of the Chief Social Worker for Adults to achieve greater clarity and recognition for the role of social workers in support for people with complex health and care needs, including end of life and palliative care.
- Public Health England has commissioned a project to assess the role of care homes for people and their families at the end of life. The project will identify examples of best practice and innovative models of care, consolidate the existing evidence and information about palliative and end of life care delivered by care homes, and explore how health and social services engage with care homes and support residents. It will identify where further information is needed, and propose guidance for care delivery.
- Guy's and St Thomas's Hospital, working with NHS England and NHS Improvement, is continuing to implement and evaluate the use of the *AMBER care bundle*. The *AMBER care bundle* is a simple approach used in hospitals when there is clinical uncertainty of recovery. The approach supports staff, patients and families who wish to continue with treatment in the hope of a recovery, while encouraging open conversation about people's wishes and preferences should things get worse rather than better. It was adopted as a key enabler within the pre-existing Transforming End of Life Care Programme and remains an important approach to improving care planning with earlier conversations and shared decision-making about end of life care preferences.
- The CQC's new inspection approach, which has been in place since October 2014, includes a clear focus on end of life care and applies in all services where end of life care is delivered. The approach includes acute hospitals, community settings, GP services, hospices and care homes. For acute hospitals, end of life care is one of the eight core services which the CQC will always inspect, by asking five key questions, namely, whether the service is safe, effective, caring, responsive to people's needs, and well-led. The CQC publishes a rating for the end of life care service in each acute hospital it inspects.
- The CQC has defined and published the Key Lines of Enquiry which inspection teams always follow to answer the five key questions for every service. In addition the CQC has developed service specific guidance, including specific guidance on its end of life care inspection approach, which was published earlier this year.<sup>29</sup>
- During 2016, the CQC will review its inspection approach and, as part of this process, will be considering whether choice in end of life care can be incorporated into its refreshed inspection regime.
- In May 2016, the CQC published *A different ending: Addressing inequalities in end of life care*, a review of inequalities and variation in the provision of end of life care.<sup>30</sup> The report calls for action to reduce inequalities and undesirable variation in end of life care quality, and echoes the *Ambitions* framework's call to action to CCGs and Health and Wellbeing Boards to ensure that local needs assessments and strategic planning fully consider end of life care.

## Part Two - How we will deliver the Commitment

The Department of Health will work with the CQC, NHS England, NHS Improvement, Health Education England and Public Health England to address the issues raised by the review.

### 3. Learning from the best: identifying and spreading innovation in end of life care delivery

Our plan for the future of end of life care in England will be implemented in the context of wider changes to how healthcare is delivered as set out in the *NHS Five Year Forward View*.<sup>31</sup>

Central to these changes will be a range of New Care Models which will enable services to work together more efficiently and deliver better outcomes for patients. Innovation in service design is a key element of this work and there is a real opportunity over the next few years to ensure innovative ideas on the design and delivery of end of life care services are put to work to deliver better outcomes for dying people. We know that local areas around the country, like Airedale, Bedfordshire and Hull, are already providing innovative models of community and integrated end of life care.<sup>32</sup> In these areas, services have reduced unnecessary emergency admissions and provided the reassurance, support and responsive, timely care dying people, carers and family members need.

Over the course of this Parliament we will ensure that national leadership, local leadership and innovation combine to identify, promote and spread the models of care that achieve the best outcomes for dying people. We will also ensure that end of life care expertise, knowledge and support are accessible to local innovators to support service improvement.

#### **To achieve this:**

- NHS England will work with local commissioners and leaders in end of life care innovation to identify effective models of end of life care for dying people and support work on how to adapt those models to local needs or develop new approaches. This work will be supported by national and regional clinical leads who will continue to identify innovative models and share lessons nationally.
- NHS England will work with the National Council for Palliative Care (NCPC) and the National Palliative and End of Life Care Partnership, during 2016, to expand the *Ambitions for Palliative and End of Life Care* website. The website will be a single central point of reference for professionals and organisations around the country with an interest in end of life care innovation to share and spread lessons about successful models of end of life care provision.
- As part of the development of Sustainability and Transformation Plans (STPs), NHS England will assess plans being produced by local systems, and where new models are being considered, offer support by sharing examples of innovative models already in existence and spread the lessons learned.
- NHS England will continue to learn from the New Models of Care around the country and will spread the lessons from these sites, with a particular focus on the six care home Vanguard.

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- During autumn 2016, NHS England and the Department of Health will hold a series of end of life care roadshows across England to exhibit innovative practice in delivering high quality, personalised end of life care.
- The NCPC is completing an evaluation for NHS England describing different models in use across the country that enable round-the-clock care for palliative and end of life care. The intention is for local commissioners to be able to use this evaluation to understand which models could best work for their local population.
- Public Health England has commissioned a piece of research on palliative and end of life care with the following overarching aims:
  - to apply existing evidence on the cost-effectiveness of end of life care to service delivery models;
  - to identify gaps in evidence; and
  - to identify whether there are specific patient or disease groups that will benefit from different models or where there is potential for greater benefits.

The plan is also to produce a user-friendly tool to support commissioners and planners in delivering cost-effective care.

- The National Institute for Health Research (NIHR) Health Technology Assessment programme has selected three end of life care research projects. The projects are as follows:
  - the Namaste Care intervention to improve the quality of dying for people with advanced dementia living in care homes;
  - ImproveCare: the management of clinical uncertainty in end of life care; and
  - carer-administration of as-needed sub-cutaneous medication for breakthrough symptoms in home-based dying patients.

In addition, several research applications relating to end of life care have recently been awarded funding under other NIHR programmes, including the Research for Patient Benefit programme.

## 4. Leadership and commissioning: a system-wide commitment to improving end of life care

We have demonstrated our commitment to end of life care through the Mandate to the NHS, setting out specific goals to improve quality and choice in end of life care. NHS England will lead on improving end of life care nationally along with NHS Improvement, Public Health England, the Care Quality Commission and Health Education England.

We believe that end of life care can improve the most where leaders at both national and local levels champion the importance of caring for dying people and drive quality improvement. We also believe that end of life care is most likely to improve where local commissioners and Health and Wellbeing Boards have explicitly valued and prioritised end of life care and recognised that getting end of life care right is a fundamental part of improving their local health economy.

We believe in and strongly support the vision set out in the *Ambitions for Palliative and End of Life Care* framework.<sup>33</sup> The framework sets out what high quality end of life care looks like and the building blocks to make this happen in local areas. It also calls on leaders from every part of the health and care system – clinicians and managers in acute Trusts and community services, decision-makers within clinical commissioning groups (CCGs) and Health and Wellbeing Boards, staff in care homes and GPs looking after dying people in out of hospital settings - to put the framework into practice and lead on making end of life care services work for people approaching the end of life.

In particular, we want to ensure that every local area commissions services that support the implementation of the *Ambitions* framework. Every CCG Board should consider whether local end of life care services are delivering the kind of high quality, personalised end of life care set out in the *Ambitions*, in every setting. They should have a clear vision of what package of services locally will deliver these goals and actively seek out commissioning resources to achieve this.

At the same time, local health system leaders, including CCGs, should consider how end of life care can form an integral part of the transformation of local health economies which will be necessary to delivering the NHS *Five Year Forward View*.

Improvements to end of life care should not occur in isolation. They should be threaded through the most effective New Models of Care that will deliver the new, transformed NHS.

Sustainability and Transformation Plans (STPs) should fully take into account the contribution that sustainable, efficiently designed end of life care services can make to achieving better outcomes for dying people.

In making this happen, all CCGs should also be clear about the efficiency gains to be made when people are able to make plans and express preferences early about their care so that

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unnecessary hospital admissions are avoided. We know that people's experiences of care are better and services more coordinated and efficient when clinical staff can identify people's needs earlier and share and implement end of life care plans more easily.<sup>34</sup>

The role of national leadership will be to support and engage with commissioners and providers of services on how end of life care can be improved and offer advice on service models that work well in different areas.

### **To achieve this and support the implementation of the Ambitions for Palliative and End of Life Care:**

- NHS England published, in April 2016:
  - information for commissioners about specialist level palliative care which they will be able to use as the basis for commissioning and promoting local collaborative working across the country. This includes a sample service specification for commissioners to use;<sup>35</sup> and
  - a new end of life care commissioning toolkit which will support the task of identifying local end of life care needs and commissioning end of life care services in each local area according to local needs.<sup>36</sup>
- NHS England will also publish a definitive set of palliative care currencies to help categorise people receiving palliative care according to level of complexity and resource need. This will be available for use from April 2017. NHS England will engage with key partners during 2016 to review and consider a range of approaches to palliative care funding for children and adults, all of which will require the use of the palliative care currencies as the 'building blocks' for any funding model. This will allow commissioners and providers of specialist end of life care to ensure the best services are being provided to meet people's needs regardless of care setting.
- NHS England is working with Public Health England to produce, in 2016, an individual-level clinical dataset for adult specialist palliative care. Once published, this dataset can be adopted by commissioners and providers to understand the current clinical provision of specialist palliative care and evaluate outcomes.
- NHS England is developing an end of life care commissioning tool to inform the development of an Optimal Value Pathway (OVPs) for end of life care as part of the Rightcare commissioning programme. The OVPs will be used extensively by delivery partners with CCGs to support local optimal service design and delivery.
- The Chief Social Worker for Adults is committed to raising the profile of social workers and social care within end of life care provision and leading on improving the delivery of end of life and bereavement care within social care.<sup>37</sup> Her priorities for developing the social care workforce over 2016/17 include making progress on developing clearer role and capabilities for social workers in end of life and palliative care as outlined in the recently published resource *The role of social workers in palliative, end of life and bereavement care* and reinforcing the importance of professional leadership in the social work and social care professions to improve provision of end of life care.

## Leadership and commissioning: a system-wide commitment to improving end of life care

- We will also promote end of life care leadership through publicising this response and continuing to emphasise, including through the Mandate to the NHS, the importance we place at a national level on improving end of life care. This will include engaging with the Chairs of Health and Wellbeing Boards through appropriate mechanisms, ensuring that this vital policy area is at the forefront of their thinking as they work on local strategies and priorities, and as local STPs are being implemented in local areas.

## 5. The right people with the right knowledge and skills to deliver high quality, personalised care

There should be no doubt that looking after people approaching the end of life with compassion and competence is a highly demanding and often challenging role, requiring specific knowledge and expertise.

High quality end of life care requires multi-disciplinary teams working in partnership to deliver high quality and safe care to patients. Highly effective palliative care specialists are experts, not only in identifying and treating people nearing the end of their lives, but also in managing uncertainty, being open to changes in a person's condition, and tailoring care to individual needs.

Underpinning this care is the ability to have the most difficult conversations about death, dying and the course of a disease or condition. Getting those conversations right can result in high levels of patient satisfaction and high quality delivery of clinical care.

There has been a growing recognition over recent years that in order to achieve high quality end of life care in all settings there must be a concerted effort to improve the education and training in end of life care-specific issues that all doctors, nurses and other health and care staff receive. This is important both for adults and children receiving palliative care. Providing high quality palliative and end of life care depends on specialist advice and support to professionals both on an individual patient level and through more generic education and training.

We want to ensure that end of life care is fully reflected in undergraduate and postgraduate curricula for doctors and nurses, in continuing professional training programmes and professional competency frameworks. Good education and training are not just about curricula and competencies, however. We also want to ensure that the lessons staff receive translate into effective behaviours and high quality outcomes for people approaching the end of life.

We must ensure that all staff responsible for the care of people nearing the end of life are skilled not only in specific clinical interventions and procedures relating to the end of life, but also receive training to support the often difficult and sensitive conversations they will need to have with dying people and those important to them.

**To ensure staff are equipped and supported to deliver the high quality care that people want and need as they approach the end of their lives, we are taking the following action:**

- We have asked Health Education England (HEE) to set a clear requirement that all staff involved in the delivery of end of life care will have appropriate education and training. Under this agreement, HEE will work with its key partners to ensure that all staff delivering end of life care are appropriately trained, particularly in the five priorities for care. HEE will work with its Medical and Nursing Advisory Groups to review progress in strengthening the

undergraduate and postgraduate curricula to support patient choice and improving quality in end of life care. HEE will also ensure workforce planning delivers the right people with the right skills to support improved quality and greater choice in end of life care, in both hospital and out-of-hospital settings.

- The Department's Mandate to HEE reflects strategic objectives around workforce planning and health education, training and development. The Mandate looks at how the healthcare workforce can be supported through excellent education and training to deliver the very best care to patients. We expect these objectives on end of life care to be reflected in the HEE Mandate for 2016/17.

**To deliver these agreed objectives:**

- HEE will work with Skills for Care and Skills for Health to develop a refreshed core competency framework to standardise end of life care training and education.
- Through a lead local area, HEE will deliver a national action plan to promote best practice in workforce education and training in end of life care.
- HEE will work with NHS Employers to promote best practice on employer-led training, demonstrating the benefits to employers to incentivise further investment in end of life care training.
- HEE will work with both the Medical and Nursing HEE Advisory Groups, which comprise over 20 partners from the respective professions, to review progress in strengthening undergraduate and postgraduate curricula to support patient choice and improving quality in end of life care and how these developments can be embedded in HEE's national delivery plan.
- Following publication of the Shape of Caring Review,<sup>38</sup> HEE is working closely with the Nursing and Midwifery Council in its fundamental review of the skills and competencies that future nurses will be expected to meet to ensure these respond to the needs of patients at the end of life.
- In developing its national workforce plans, HEE is committed to remain focused on requirements for staff groups required to deliver high quality end of life care. Under the overall plans for the NHS workforce, proposed training levels will provide for over 70,000 growth in nurses, midwives, allied health professionals, and scientists over the next five years, as well as over 10,000 consultants and GPs.
- HEE is working with NHS England and the wider system through its Workforce Advisory Board to better understand the wider health and social care workforce needs in the context of the NHS *Five Year Forward View*, to ensure that we are growing the wider workforce, including community and district based nursing, to keep pace with the growth of GP numbers and to deliver the new models of care, including those relating to end of life care.
- NHS England, HEE, the Royal College of General Practitioners (RCGP) and the British Medical Association GP committee are working closely together to ensure that we have a skilled, trained and motivated workforce in general practice. They have jointly produced a ten point action plan to address immediate issues, and to take the initial steps in building the

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workforce for the future and new models of care. The plan is designed to complement and support HEE in its delivery of its mandated aim of recruiting 3,250 GP trainees by 2016.

- HEE will also develop Community Education Provider Networks (CEPNs) to provide the infrastructure necessary for multi-professional training and education in primary care. End of life care education and training will be an integral part of this approach. CEPNs will also support the recruitment, retention and 'return to practice' of all staff groups. The aim is for CEPNs to enable HEE to work across a wide range of providers, CCGs and higher education institutions, to support delivery of the objectives of the NHS *Five Year Forward View* and the HEE Mandate.
- In response to a recent Primary Care Workforce Commission report,<sup>39</sup> HEE is planning to develop the GP and community nursing workforces. The Transforming Nursing for Community and Primary Care project is working in partnership with the Royal College of Nursing, RCGP and NHS England to develop a comprehensive and realistic plan for the future of primary care nursing services. The programme aims to ensure the 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.
- In 2015, HEE published the *District Nursing and General Practice Nursing Service: Education and Career Framework*, which provides clear education and career pathways for district and general practice nursing for the current and future workforce.<sup>40</sup> The Framework supports standardisation of roles within both disciplines across England and sets out the required skills and education for both – enabling practitioners to plan and develop careers and assist workforce planning, service and educational commissioning. The Framework is supported by an education commissioning service specification which defines educational standards and continuing professional development requirements, including end of life care.
- The Chief Social Worker for Adults in the Department of Health has included capability in working with end of life issues in the *Knowledge and Skills Statement for Social Workers in Adult Services*, published in March 2015.<sup>41</sup> The Statement informs the qualifying and post graduate requirements for social workers. The Association of Palliative Care Social Workers and the British Association of Social Workers have recently published best practice guidance for social workers in palliative, end of life and bereavement care to support raising the standards of practice in social work. From 2018, a new system for social work regulation will be established, which will support the development of further specialisms and advanced practitioner status models, helping raise the quality and profile of social work in arrangements for people in key areas, including end of life and palliative care.

## 6. Working in partnership to improve care and increase community resilience

Our vision of high quality, personalised end of life care for all rightly focuses on the care delivered by the NHS and social care to dying people in all settings. But death and dying are issues that involve and affect family members, carers and wider support within local communities – they are not simply medical issues with medical solutions.

People consistently tell us that their solace at this all-important time comes not only from the effective treatment of their physical symptoms and broader support from statutory services, but also from the networks of family, friends, carers and volunteers that support them.

The voluntary sector plays a key role in our communities and is at the forefront of end of life care innovation and delivery. Everyone recognises the role it plays both in improving care and in developing ways for local communities to respond to the needs of dying people.

Harnessing this community support forms part of the approach set out by the *Ambitions for Palliative and End of Life Care* framework. We will continue to learn from the best the voluntary sector has to offer and work with our voluntary sector partners, including Macmillan Cancer Support, Marie Curie, Sue Ryder, Hospice UK and the National Council for Palliative Care (NCPC) on developing better services and building stronger community networks for dying people. We will also continue working with partners that focus on children and young people, including Together for Short Lives, CLIC Sargent and The Teenage Cancer Trust.

### **To take this forward:**

- the Department will work with the National Partnership for Palliative and End of Life Care and the End of Life Care Coalition of charities to promote the implementation of the *Ambitions for Palliative and End of Life Care* framework in local areas.
- NHS England and NHS Improvement will work with voluntary sector partners on specific projects to improve the quality of end of life care in acute hospitals as part of the programme to transform end of life care in hospitals, including:
  - the NCPC and Macmillan Cancer Support, working with NHS England and NHS Improvement, are testing out the *Building on the Best* programme in ten acute hospital Trusts across the country. This will focus on supporting improvements in outpatient consultations, shared decision-making, handover of information and records as people move between acute and community care settings, and pain and symptom management.
  - The Point of Care Foundation, working with NHS England, is leading on a project on *Patient and Family Centred Care*, funded by The Health Foundation, in nine acute and community settings. This is a quality improvement collaborative programme to support

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NHS staff to deliver more compassionate care to people at the end of their lives, improving experiences of care for dying people and their families, and to spread the lessons about patient and family centred care collaborative methodology to colleagues across the service.

- Public Health England (PHE) and the NCPC are piloting community resilience approaches, including on bereavement, based on the Dying Well Community Charter in eight local pathfinder sites around the country.
- the Department of Health (DH) and system partners will work with voluntary sector partners to develop the work of end of life care volunteer networks, including on bereavement care, and strengthen the bonds that support dying people in their own communities.
- the DH and NHS England will work with voluntary sector partners to raise public awareness nationally of issues around death and dying and the importance of individuals making end of life care plans in advance. This will include support for the Dying Matters Coalition and Campaign, which is run by the NCPC. The Coalition leads on initiatives to promote a national conversation about death and dying.
- the DH funds, and jointly manages with NHS England and PHE, the Health and Care Voluntary Sector Strategic Partner Programme. The programme enables voluntary sector organisations to work in equal partnership with the DH, NHS England and PHE to help shape and deliver policies and programmes, for the benefit of the sector and improved health and well-being outcomes, and provides a way for policymakers to reach thousands of voluntary sector organisations across England through the extensive depth and reach of the partners' networks.
- the NCPC (together with Hospice UK and Marie Curie) is taking forward a number of end of life projects as part of their Strategic Partner role in 2016/17, including:
  - pain management for people at home at the end of life;
  - raising public understandings and expectations about sharing records in end of life care;
  - public health - palliative care and the Dying Well Community Charter;
  - "People in Partnership at the end of life" - Developing the voice and involvement of people with personal experience in end of life care.
- Other strategic partners are also developing plans for end of life care projects: for example, Age UK are working on a project to improve patient and carer experiences of nutrition and hydration at the end of life and National Voices are developing a project on public understanding and expectations about sharing records in end of life care.

## 7. Strengthening accountability and transparency to drive improvements

We hold the NHS to account for progress against its objectives through the NHS Mandate. In our Mandate for 2016/17, we explicitly refer to end of life care and ask NHS England to significantly improve patient choice and quality in end of life care, including on people's choices about where they would like to be cared for and die.

NHS England has issued planning guidance for the NHS to deliver the NHS Mandate commitments and have asked clinical commissioning group (CCG) clusters to submit local Sustainability and Transformation Plans to set out how they will improve and transform services locally. NHS England and partner organisations will review the plans during summer 2016 and we expect that these plans will set out proposals which will lead to improvements in the full range of NHS services, including end of life care.

Similarly, we hold HEE to account for delivery against the Government's Mandate to HEE. We have asked HEE to set requirements to deliver the right education, training and workforce planning to support improved quality and choice in end of life care and we expect these to be reflected in the HEE Mandate for 2016/17.

NHS Improvement (the new working arrangement between Monitor and the NHS Trust Development Authority), Public Health England and the Care Quality Commission each have important contributions to make to deliver the Government's commitments on end of life care and are held to account by the Department of Health.

Over and above these formal accountability arrangements, we will ensure that progress against the actions each organisation has committed to in this response is made publicly available in a year's time.

In addition, to support our Commitment for End of Life Care we will publish information on quality and choice in end of life care so that transparency about care will drive improvement and spread lessons across different areas.

In March 2016, NHS England published its new CCG Improvement and Assessment Framework (CCG IAF), which will measure the performance of each CCG against key national indicators of quality improvement.<sup>42</sup> Currently, the new Framework includes a key indicator which will track changes to the percentage of deaths that take place in hospitals within each CCG as a proxy for end of life care quality.

The intention of the CCG IAF is to introduce greater transparency regarding the performance of CCGs and to enable there to be a focus from NHS England on supporting CCGs to be the best they can. The Framework and ratings will be publicly available in a clear format on the MyNHS website from summer 2016.

**To support continuing quality improvement through the Framework, and to ensure we have the right data and information about end of life care nationally, we will:**

- develop and implement a suite of new metrics to measure progress against the NHS Mandate on both quality and choice in end of life care. These measures will provide comprehensive information on performance at CCG level so that we can track progress and variation around the country. The new metrics will cover both quality and patient experience at end of life, including how involved people felt in their conversations and decisions about their own care and treatment, taking account of the new Commitment for end of life care. As a first step towards developing the new metrics, NHS England are conducting a feasibility study into possible new ways of capturing the experience of people approaching the end of life and their carers. Local areas will also be able to use the new metrics for service improvement.
- include, by June 2018, a new Clinical Priority Area for End of Life Care in the CCG Improvement and Assessment Framework. Once the new metrics are developed, new indicators for end of life care will be included under the End of Life Care Clinical Priority Area to give a clear demonstration of the quality of end of life care in each CCG, in every part of the country.
- contribute to a new system-wide Governance Board, hosted by NHS England and involving statutory and voluntary partners. This Board will oversee delivery of the Commitment and wider improvements in end of life care. It will provide a forum for debate, challenge and assurance that improvements in end of life care are being realised.

## 8. Conclusion

Our vision for the future of end of life care is the culmination of many years of work to provide better, more personalised experiences of care for dying people, supported by high quality services and robust system leadership.

The *Ambitions for Palliative and End of Life Care*, published in September 2015, set a clear direction for change and issued a call to all those involved in the care of dying people at both the national and local level. Our Commitment for end of life care and the plans we have set out in this response build on the *Ambitions* through a set of actions to deliver improvements in end of life care for all dying people in all care settings.

Our vision is also one of transformation and transparency for end of life care. We have ensured that end of life care will gain a new prominence within a health and care system moving towards new, more effective models of care. For the first time, our plans will also ensure that this progress can be measured. Performance around the country will be assessed based on indicators of quality and patient experience in end of life care. The strengthened accountability we have put in place through the CCG Improvement and Assessment Framework will ensure the NHS delivers these improvements and meets the Mandate commitments we have laid down. Finally we pledge to make available an update on the progress all organisations have made towards achieving these goals, in a year's time.

Our national Commitment for end of life care is a central tenet of this vision for personalised care. However, we want to go further than this. The plans we have set out will not only enable health and care services to deliver this Commitment; they will create the conditions for continuous improvement in end of life care in England.

For many years, we have led the world in developing and providing the best quality care to people at the end of life. To build on this legacy, over the course of this Parliament our aim is to embed end of life care in the core business of the NHS and social care services. By 2020, we will aim to include the Commitment in the NHS Constitution, making a pledge to all that the care people receive at this most significant time in life, whether they are children or adults, truly offers every individual the chance to live well until they die.

## 9. A note on palliative and end of life care for children and young people

Our Commitment to end of life care is for people of all ages: children, young people and adults. Similarly, most of the measures we have set out to deliver the Commitment apply equally to people of all ages needing end of life care. Children and young people with the most complex needs should be able to live their lives as they and their parents wish, and enjoy the same independence and choice which we all expect. As we have reflected in our Commitment, it is essential that the voices of children and young people are heard so that they are involved in their care, able to express their needs and preferences and make informed choices about their care.

While the scope of the Review itself did not include children, we felt it was important to recognise the importance of end of life and bereavement care for children and young people and to highlight some of the particular needs of children and young people with life-threatening or life-limiting conditions, as well as some of the challenges faced by children's palliative care services.

There are recognised differences between adults' and children's end of life care. Often, the type and complexity of the condition, the duration of illness, the involvement of the whole family, the need for ongoing access to education and employment and the changing development of the child throughout present particular challenges for children's end of life care. On top of these difficulties, care delivery can be more challenging as there are fewer patients over a larger geographical area.

Moreover, thanks to improvements in medical science, children with complex needs and life-limiting conditions are now living into adulthood in ways which were seldom possible in the early years of the children's hospice movement. As a result, without necessarily requiring end of life care, children and their families can benefit immensely from access to expert care and support, including respite care, delivered in a children's hospice setting, by community palliative care services, or 'hospice at home' services.

Children's palliative care is particularly dependent on good collaboration between different clinical and non-clinical services across a variety of different settings. These might include community children's nursing, paediatric inpatient services, specialist palliative care consultant-led teams, hospices, GPs and the wider network of supporting services such as school services and the voluntary sector, including Together for Short Lives, CLIC Sargent and the Teenage Cancer Trust. Community-based services and forms of support for children and their families can provide the kind of flexibility, responsiveness, continuity of care and care coordination that support children to have independence and choice. As children with life-threatening or life-

limiting conditions live more and more into adulthood, continuity and coordination are all-important in ensuring that the transition from child to adult end of life care services is smooth.

A further critically important component of palliative and end of life care for children and their families is support around bereavement, both before and after a child dies. The death of a child at any age is a tragedy and can have a long-term lasting impact on their families. The care and support parents and families, especially siblings, receive at this time is, of course, critically important.

To support high quality personalised care for children and young people, commissioners and providers of services must prioritise children's palliative care in their strategic planning so that services can work together seamlessly and advance care planning can be shared and acted upon.

Commissioners should also consider how they can structure services that offer accessible, high quality respite and bereavement support for children and their families. In the case of maternity and neonatal services, hospitals should ensure they are providing the right facilities and staff with the right skills to provide emotional and psychological support, as well as privacy and compassion when a child dies.

### **To address the challenges of children's palliative and bereavement care and loss during pregnancy:**

- We will explore with commissioners, NHS providers and the hospice sector how best to encourage a dialogue on commissioning well-coordinated palliative and respite care, and different approaches to funding locally commissioned services, using the palliative care currencies as 'building blocks.'
- NHS England will explore the scope for Integrated Personal Commissioning (IPC) to include end of life care services. IPC is a new way to support both adults and children with complex needs by joining up health, social care and other services at the level of each individual. The approach focuses on person centred care and support planning, facilitating an earlier more personalised discussion of end of care for those with the most complex needs.
- NHS England will work with a small number of interested areas to assess rapidly the options for personalising services and improving choice and control for individuals at end of life, using the learning from the delivery of personal health budgets and integrated personal commissioning in end of life care, including for children.
- We are currently exploring how maternity and neonatal bereavement services can be improved. We know that many maternity and neonatal services across the country provide excellent care to support bereaved parents but there is more that can and should be done to reduce the variation in the provision of bereavement care across the country.
- NHS England have established a Maternity Transformation Programme Board to bring key partners together to oversee the implementation of a broad range of policies to deliver significant improvements to maternity care in England, including implementation of the recommendations of the National Maternity Review *Better Births, Improving outcomes of maternity services in England* (2016).<sup>43</sup> The Transformation Programme includes a broad

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range of workstreams impacting on provision of bereavement care including supporting local transformation of maternity services, promoting best practice for safer care, transforming the workforce and reforming the payment system.

- We will also work with NHS England and system and voluntary sector partners to identify bereavement care pathway exemplar models to be shared widely across the NHS, so that for instance, a hospital in the east of England can learn from and implement the good bereavement practice of a service in the west.
- We will work with system partners to explore the idea of identifying a maternity bereavement champion for each regional network.
- We will work with NHS England and the Royal College of Midwives to agree a competency framework for ensuring that all midwifery staff have basic bereavement training and skilled midwifery bereavement staff are available to support parents following a loss.
- We will consider also the implications of bereavement care when a child or young person dies, and how national leadership can be provided for different forms of bereavement support.

# Annex A: Table of Review recommendations and Government responses

	Choice Review advice text	Details of actions in response
1.	<p><b>Each person who may be in need of end of life care is offered choices in their care focused on what is important to them and that this offer is:</b></p> <ul style="list-style-type: none"> <li>• <b>made as soon as is practicable after it is recognised that the person may die in the foreseeable future.</b></li> <li>• <b>based on honest conversations with health and care staff, which supports the person to make informed choices.</b></li> <li>• <b>consistently reviewed through conversations with health and care staff.</b></li> </ul>	<p><i>Our Commitment for end of life care makes clear what every person should expect in their care as they approach the end of life. This means that everyone who wants to have honest discussions and develop a personalised care plan based on their preferences will be supported to do so. This plan will also be shared with others to enable joined up care.</i></p> <p><i>The commitment also makes clear that the people important to the dying person will be involved in their care as much as the person would want and that there will be access to support whenever needed.</i></p> <p><i>The actions detailed in this response will ensure that the commitment will be offered to all people as they approach the end of their lives to build an ongoing dialogue and ensure each person’s end of life care is high quality and personalised.</i></p> <p><i>NHS England will launch a social media campaign to support implementation of the commitment for end of life care (from summer 2016) and will be hosting several roadshows across the country to promote the commitment to commissioners &amp; providers during autumn 2016.</i></p>
2.	<p><b>That each person who has consented to and wishes to specify choices and preferences in their end of life care has these recorded in their individual plan of care, with its details held on an Electronic Palliative Care Coordination System (EPaCCS) or equivalent system.</b></p>	<p><i>‘Personalised care planning’, ‘honest conversations’ and ‘shared records’ are all foundations or building blocks of the Ambitions for Palliative and End of Life Care framework, set out in in 2015. We fully support the Ambitions, which all local health leaders should take into account when planning and commissioning services.</i></p> <p><i>The Commitment for end of life care puts the creation of a personalised care plan, based on individual needs and preferences, at the centre of our vision of high quality, personalised care.</i></p> <p><i>NHS England is supporting the Integrated Care Pioneers to participate in the Serious Illness Care Programme UK. This project looks at systems change and training to support clinicians to initiate and have honest and meaningful discussions with patients who have serious illnesses about their values, preferences, and priorities. The project has now commenced work on ensuring the materials developed and tested in the</i></p>

		<p><i>USA are fit for purpose with the UK population. This is being developed and tested through the Clatterbridge Cancer Centre. Two sites (Airedale and Southend) have also been identified to participate in the pilot of the programme which began in May 2016.</i></p> <p><i>Other work within NHS England is taking place to promote the use of personalised care plans. For example,</i></p> <ul style="list-style-type: none"> <li><i>• raising awareness with GPs and the public about the use of the enhanced Summary Care Record (which now has improved functionality to make it easier for patients and GP practices to include end of life care preferences); and</i></li> <li><i>• Electronic Palliative Care Coordination Systems (EPaCCS) are in place in many areas of the country. NHS England is committed to ensure 100% national coverage by 2020 so that end of life care plans can be recorded and shared through these systems.</i></li> </ul>
<p><b>3.</b></p>	<p><b>That each person in need of end of life care has a named responsible senior clinician who would have overall responsibility for their care and their preferences.</b></p>	<p><i>All people, including those approaching the end of life, want effective, compassionate and co-ordinated care, and rightly expect to know who is responsible for their care overall, wherever they are being cared for.</i></p> <p><i>For people being cared for in hospital, the Academy of Medical Royal Colleges (AoMRC) produced guidance (published June 2014) setting out the role and responsibilities of a responsible consultant or clinician in England.<sup>44</sup> The guidance describes the purpose of the responsible clinician role and named nurse with some key considerations for implementation.</i></p> <p><i>To embed the AoMRC guidance, NHS England published Delivering the Forward View: NHS Shared Planning Guidance 2016/17-2020/21<sup>45</sup> in December 2015. The planning guidance makes clear that, during 2016/17, 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 planning guidance states that delivery of this policy is a key element of local areas’ Sustainability and Transformation Plans for the next five years. The Department has also asked the Academy to produce further guidance that could apply to other healthcare settings. This will be published by the Academy in due course.</i></p> <p><i>For people being cared for in community settings, the 2015/16 GP contract required a named accountable GP to take responsibility for the co-ordination of all appropriate services and ensure they are delivered where required to each of their patients. This requirement builds on the 2014/15 GP contract to provide a named accountable GP for the over-75s.</i></p>

<p><b>4.</b></p>	<p><b>That each person in need of end of life care is offered a care coordinator who would be their first point of contact in relation to their care and their preferences.</b></p>	<p><i>Whilst a specific person cannot be nominated as a care coordinator due to the practicalities of the same person being available 24/7, care coordinators do already exist in the NHS and aim to address the challenges of complex systems, usually directed at those with long term conditions. Social care workers, including palliative care social workers, also currently have an important role to play in supporting people and connecting up services.</i></p> <p><i>Core components of the care coordinator role should include:</i></p> <ul style="list-style-type: none"> <li>• <i>delivering support to people with long term conditions and/or to their carers;</i></li> <li>• <i>delivering care via referral from the primary care team;</i></li> <li>• <i>providing information about health, social services, third sector or other community provisions in equal measure;</i></li> <li>• <i>supporting personal budgets and being available whether the client qualifies for benefits and personalised budgets or not;</i></li> <li>• <i>providing “live” feedback on service quality to the commissioner.</i></li> </ul> <p><i>NHS England has studied the potential role of “care coordinators” to help people express their preference, make informed choices and navigate their way through the complex health and care system. The National Council for Palliative Care will take this work forward by developing optimal models for a care coordinator scheme and will host a stakeholder event to obtain feedback and test feasibility.</i></p>
<p><b>5.</b></p>	<p><b>That each person who wishes to express their end of life care choices and preferences in advance is offered a way to do this through access to their own medical records and plans of care and the ability to add and amend information on personal choices and preferences.</b></p>	<p><i>By delegation from the Department of Health, the National Information Board (NIB) defines and agrees strategy, requirements and priorities for informatics across the system, ensuring that system leaders work collectively to guarantee the successful delivery of the system wide strategy. Allowing people the ability to view and write into their own medical records and edit information about their preferences and choices is aligned to NIB workstream 1.1 -"to provide patients and the public with digital access to health and care information and transactions". The overall aims of the workstream are:</i></p> <ul style="list-style-type: none"> <li>• <i>to give the public more control of their health and care and to interact with care providers more effectively;</i></li> <li>• <i>to allow patients to view their records online and have the opportunity to create and manage their own personal care record;</i></li> <li>• <i>to ensure online appointment bookings and repeat prescriptions will be available across all care services.</i></li> </ul> <p><i>NHS England is also working through the Code4Health community. The community brings like-minded people together to focus on improving the ways in which people can manage and influence their own care,</i></p>

		<p><i>treatment and support towards the end of their life. The community will work together to share knowledge and expertise, and work with those who have the skills to develop the necessary tools in a way that has the greatest impact for people to exert more personal control and choice over their own care. The overall aim of the work is to support the Code4Health community to develop criteria for patient facing digital solutions and act as a catalyst for digital innovations. The Code4Health community will then stimulate the market to develop solutions in line with these criteria and endorse them on NHS Choices.</i></p> <p><i>Summary Care Records (SCRs), which have achieved 96% coverage so far across England, already provide the ability for GPs to record the individual's preferences and priorities on their health records with their consent, and to share this with a wide range of health care professionals who have access to SCR.</i></p> <p><i>Furthermore, the SCR now has improved functionality to make it easier for patients and GP practices to include end of life care preferences as part of SCRs with additional information. This initiative enables preferences that have been recorded on the GP record to be automatically included when a patient consents to an enriched SCR. This provides health communities with an immediate and cost effective solution to enable the sharing of preferences to complement EPaCCS, or when EPaCCS are not in place.</i></p>
<p><b>6.</b></p>	<p><b>That carers for people at the end of life should be formally identified as such by the relevant services, that their eligible needs for support be met in line with the provisions of the Care Act 2014, and that support be provided for carers following bereavement.</b></p>	<p><i>The Care Act 2014 sets out carers' legal rights to assessment and support and came into force in April 2015. Under its provisions, local authorities have a legal responsibility to assess a carer's need for support, where the carer appears to have such needs.</i></p> <p><i>Local authorities will assess whether the carer has needs and what those needs may be. This assessment will consider the impact of caring on the carer, and other important issues such as whether the carer is able or willing to carry on caring, whether they work or want to work, and whether they want to study or do more socially.</i></p> <p><i>The Ambitions for Palliative and End of Life Care: National Framework for Local Action recognises the importance of recognising carers' needs and in particular, bereavement through the building block 'Good end of life care includes bereavement'.</i></p> <p><i>NHS England, through its 'Commitment to carers strategy' has committed to support the relevant bodies, including Health Education England, to support the use of packages for health care staff that increase carers awareness, and support staff to identify, involve and recognise carers as experts, and as individuals with their own needs, choices and aspirations. It has also committed to supporting the relevant bodies in signposting carers to information and advice about</i></p>

		<p><i>support available.</i></p> <p><i>The five Priorities for Care of the Dying Person form the core of the approach to care in the last days and hours of life. The fourth priority is that ‘The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.’ The extent to which the five priorities are being implemented in acute and community settings forms part of Care Quality Commission inspections.</i></p>
<p><b>7.</b></p>	<p><b>That family members, carers and/or those important to the individual should be involved in discussions about care preferences where the dying person has said they should be, if this is appropriate and helpful.</b></p>	<p><i>The new Commitment for end of life care includes an explicit commitment that the person would have ‘the opportunity and support to involve, to the extent that they wish, their family, carers and those important to them in discussions about, and the delivery of, their care, and to give them the opportunity to provide feedback about their care’.</i></p> <p><i>Involving family members, carers and/or those important to the individual in discussions about care preferences, if this is the wish of both the individual and the carer, is already established in the following guidance:</i></p> <p><i>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. In particular ‘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.’</i></p> <p><i>One of the foundations of the Ambitions for Palliative and End of Life Care is ‘Involving, supporting and caring for those important to the dying person’.</i></p> <p><i>NHS England’s Commitment to carers strategy outlines its commitment to involve and recognise carers as experts, by working through the relevant bodies. In, and through developing the House of Care toolkit, NHS England has brought together relevant national guidance and published evidence, local case studies and information to support carers to be informed and engaged in care.</i></p> <p><i>The Nursing and Midwifery Council’s revised code came into effect in March 2015 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 and providing support for families, carers and others identified as close to the dying patient.</i></p> <p><i>The Government has committed to publishing a new National Carers Strategy by the end of 2016, and is currently consulting widely to underpin the development of the Strategy. A key part of the strategy will be to ensure that services improve the way that they identify,</i></p>

		<p><i>support and involve carers in planning care - including at end of life.</i></p>
<p><b>8.</b></p>	<p><b>That Health Education England, Local Education and Training Boards and Skills for Care ensure that staff responsible for the delivery of end of life care have training focused on the key elements of their roles which enable choice such as early identification of needs, advance care planning, communications skills, shared decision-making, the use of coordination systems (e.g. EPaCCS) and working in partnership with people and other organisations to design and deliver person-centred care.</b></p>	<p><i>We have asked Health Education England (HEE) to set a clear requirement that all staff involved in the delivery of end of life care will have appropriate education and training.</i></p> <p><i>Under this agreement, HEE will work with its key partners to ensure that all staff delivering end of life care are appropriately trained, particularly in the five priorities for care. HEE will also work with its Medical and Nursing Advisory Groups to review progress in strengthening the undergraduate and postgraduate curricula to support patient choice and improving quality in end of life care. We expect these objectives on end of life care to be reflected in the HEE Mandate for 2016/17.</i></p> <p><i>To deliver these requirements, HEE will work with Skills for Care and Skills for Health to develop a refreshed core competency framework to standardise end of life care training and education.</i></p> <p><i>Through a lead local area, HEE will deliver a national action plan to promote best practice in workforce education and training. HEE will also work with NHS Employers to promote best practice on employer-led training, demonstrating the benefits to employers to incentivise further investment in end of life care training.</i></p> <p><i>HEE will work with both the Medical and Nursing HEE Advisory Groups, which comprise over 20 stakeholders from the respective professions, to review progress in strengthening the undergraduate and postgraduate curricula to support patient choice and improving quality in end of life care and how these developments can be embedded in HEE's national delivery plan.</i></p> <p><i>Following publication of the Shape of Caring Review, HEE will work closely with the Nursing and Midwifery Council in its fundamental review of the skills and competencies that future nurses will be expected to meet to ensure these respond to the needs of patients at the end of life.</i></p> <p><i>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 non-palliative care junior doctors in end of life issues for the Joint Royal Colleges Postgraduate Training Board (JRCPTB).</i></p> <p><i>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.</i></p>

<p>9.</p>	<p><b>That there be greater joint working between palliative care specialists and other clinical staff, and between secondary care and primary care staff, to identify people who may need end of life care as early as possible.</b></p>	<p><i>The GMC and the Academy of Medical Royal Colleges (AMRC) have jointly consulted on a draft framework for generic professional capabilities (GPCs), which would apply to all specialty training. The framework described the human qualities required of doctors, such as being able to: communicate effectively; work as part of or lead a team; share decision-making with patients; and 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 results from the consultation have since been analysed and indicate strong support for the framework, which has informed the drafting process. The Council will shortly be considering the final draft of the framework.</i></p> <p><i>During 2016, the GMC will be consulting on revised standards for curricula and assessment which will include new requirements for colleges and faculties to integrate and contextualise the GPC framework into the 65 curricula for UK postgraduate medical specialty training. The GMC will be working with the Academy of Medical Royal Colleges to develop guidance to support implementation of GPCs in order that colleges and faculties can begin to develop new curricula from 2017 in line with the framework.</i></p> <p><i>NHS England is also supporting the Integrated Care Pioneers to participate in the Serious Illness Care Programme UK. This project looks at systems change and training to support clinicians to have meaningful discussions with patients, who have serious illnesses, about their values, preferences and priorities. The project has now commenced work on ensuring the materials developed and tested in the USA are fit for purpose with the UK population – this is being developed and tested through the Clatterbridge Cancer Centre. Two sites (Airedale and Southend) have also been identified to participate in the pilot of the programme which began in May 2016.</i></p>
<p>10.</p>	<p><b>That Health Education England, in planning for future workforce numbers, should:</b></p> <ul style="list-style-type: none"> <li>● <b>work with commissioners and providers to agree both specialist and non-specialist palliative care workforce requirements, in acute</b></li> </ul>	<p><i>We have asked Health Education England (HEE) to set a clear requirement on workforce planning for end of life care.</i></p> <p><i>Under this agreement, HEE will ensure workforce planning delivers the right people with the right skills to support improved quality and greater choice in end of life care, in both hospital and out-of-hospital settings.</i></p> <p><i>We expect this objective on end of life care to be reflected in the HEE Mandate for 2016/17.</i></p> <p><i>In developing its national workforce plans, HEE is committed to remain focussed on requirements for staff groups required to deliver high quality end of life care. Under the overall plans for the NHS workforce, proposed training levels will provide for over 70,000 growth in nurses,</i></p>

<p><b>and community settings, to deliver improvements in end of life care.</b></p> <ul style="list-style-type: none"> <li>• <b>take into account how breaking down organisational boundaries can allow staff working in acute settings to play a greater role in delivering care in community settings.</b></li> </ul>	<p><i>midwives, AHPs, and scientists over the next 5 years, as well as over 10,000 consultants and GPs.</i></p> <p><i>To deliver its objective on end of life care workforce planning, HEE is working with NHS England and the wider system through its Workforce Advisory Board to better understand the wider health and social care workforce needs in the context of the NHS Five Year Forward View, to ensure that we are growing the wider workforce – such as community and district based nursing – sufficiently to keep pace with the growth of GPs and to deliver the new models of care, including end of life care.</i></p> <p><i>NHS England, HEE, RCGP and the BMA GPs committee (GPC) are working closely together to ensure that we have a skilled, trained and motivated workforce in general practice. They have jointly produced a ten point action plan to address immediate issues, and to take the initial steps in building the workforce for the future and new models of care. The plan is designed to complement and support HEE in its delivery of its mandated aim of recruiting 3,250 GP trainees by 2016.</i></p> <p><i>HEE will also develop Community Education Provider Networks (CEPNs) to provide the infrastructure necessary for multi-professional training and education in primary care. End of life care education and training will be an integral part of this approach. CEPNs will also support the recruitment, retention and 'return to practice' of all staff groups. The aim is for CEPNs to enable HEE to work across a wide range of providers, CCGs and Higher Education Institutions, to support delivery of the objectives of the NHS Five Year Forward View and the HEE Mandate.</i></p> <p><i>In response to the Primary Care Workforce Commission report, HEE is planning to develop the general practice and community nursing workforces. The Transforming Nursing for Community and Primary Care project is working in partnership with the Royal College of Nursing, the Royal College of General Practitioners and NHS England to develop a comprehensive and realistic plan for the future of primary care nursing services. The programme aims to ensure the supply of highly skilled, competent nursing staff to improve individual outcomes and support the move to care closer to, or in, people's homes, including people in the last stages of their life.</i></p> <p><i>HEE has developed the HEE District Nursing and General Practice Nursing Service Education and Career Framework which provides clear education and career pathways for district and general practice nursing for the current and future workforce. The framework is supported by an education commissioning service specification which defines educational standards and continuing professional development requirements.</i></p>
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<p><b>11. That all key decision-makers and commissioners at every level, including in Clinical Commissioning Groups, Health and Wellbeing Boards and providers ensure a universally good end of life care service exists in all relevant settings as a platform for delivery of a national choice offer to all dying people.</b></p>	<p><i>The Ambitions for Palliative and End of Life Care framework calls for leadership from clinical commissioning groups (CCGs) and Local Authorities and, in particular Health and Wellbeing Boards, to create the circumstances necessary for action to improve end of life care. Today, the emphasis is on local decision-making and delivery, thus the purpose of the document is to provide a national framework for local action. The Partnership’s vision is that these bodies will come to a local arrangement where there is clear responsibility either from one organisation or a number of organisations, to oversee the process to improve end of life care.</i></p> <p><i>The Department of Health will promote end of life care leadership through publicising this response and continuing to emphasise, including through the Mandate to the NHS, the importance we place at a national level on improving end of life care. This will include engaging with the Chairs of Health and Wellbeing Boards through appropriate mechanisms, ensuring that this vital policy area is at the forefront of their thinking as they work on local strategies and priorities.</i></p> <p><i>The recently published Delivering the Forward View: NHS planning guidance 2016/17 – 2020/21 asks local systems to address how they will close the health and wellbeing gap and include, within their Sustainability and Transformation Plans (STPs), plans for a ‘radical upgrade’ in patient choice and control as well as how they will manage implementation of choice – particularly in end-of-life, as part of their programme to hand power to patients. NHS England, and NHS Improvement (via Monitor and the NHS Trust Development Authority) have produced ‘how to’ guides and advice to support the development of STPs.</i></p> <p><i>As part of the development of Sustainability and Transformation Plans (STPs), NHS England will assess plans being produced by local systems and where new models are being considered, offer support by sharing examples of innovative end of life care models already in existence and spread the lessons learned.</i></p> <p><i>NHS England is also supporting commissioners through the RightCare programme (originally the Quality, Improvement, Prevention and Productivity programme initiated by the Department of Health in 2009). The primary objective for the NHS Right Care programme is to maximise value, which can be defined as:</i></p> <ul style="list-style-type: none"> <li><i>• the value that the patient derives from their own care and treatment</i></li> <li><i>• the value the whole population derives from the investment in their healthcare</i></li> </ul> <p><i>As part of the programme, Public Health England, NHS England and NHS</i></p>
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**Part Two - How we will deliver the Commitment**

		<p><i>RightCare have delivered Commissioning for Value packs to all 209 CCGs in England. The packs seek to demonstrate the extent to which complex patients utilise resources across programmes of care and the urgent care system.</i></p> <p><i>NHS England, Public Health England and NHS Right Care have launched an NHS Atlas of Variation in Healthcare to help commissioners, service providers and health professionals deliver the best healthcare. The Atlas identifies where opportunities to address "unwarranted" variation exist – by revealing the possible over-use and under-use of different aspects of healthcare.</i></p> <p><i>An end of life care commissioning tool is also being developed to support the Optimal Value Pathways (OPVs) work within the RightCare programme. Both the casebooks and OPVs will be used extensively by delivery partners with CCGs to support local optimal design &amp; delivery.</i></p>
	<p><b>That EPaCCS or equivalent system coverage is increased to 100% of localities by April 2018 to enable the recording and sharing of people’s choices and preferences.</b></p>	<p><i>NHS England is committed to ensuring 100% of localities have Electronic Palliative Care Coordination Systems (EPaCCS) in place that enable the recording and sharing of preferences. This goal is to be realised by 2020, in line with the National Information Board framework commitment to make all patient and care records digital, real-time and interoperable by 2020. NHS England is working towards the majority of localities having an EPaCCS in place by 2018.</i></p> <p><i>To support delivery of this commitment, all local health economies were required to produce Local Digital Roadmaps by June 2016 detailing the actions they will take to become 'paper-free at the point of care' by 2020.</i></p> <p><i>To support the rollout of EPaCCS, NHS England will work with GP system suppliers to 'open up' their systems to support interoperability. In areas currently without an EPaCCS, the Summary Care Record (SCR) will be promoted as the minimum requirement to enable electronic sharing of end of life care preferences.</i></p> <p><i>The latest NHS Standard Contract places a requirement on providers to implement EPaCCS and provides guidance for ensuring these systems are interoperable.</i></p> <p><i>However, recognising that current implementation of EPaCCS varies across the country, the Summary Care Record (SCR) now has improved functionality to make it easier for patients and GP practices to include end of life care preferences as part of SCRs with additional information. This initiative enables preferences that have been recorded on the GP record to be automatically included when a patient consents to an enriched SCR. This provides health communities with an immediate and cost effective solution to enable the sharing of preferences to</i></p>

		<i>complement EPaCCS or when EPaCCS are not yet in place.</i>
<b>13.</b>	<b>That EPaCCS or equivalent systems are fully accessible to view and update for all involved in the provision of end of life care services, in particular social care organisations, and that they align with the information on care plans offered to people with long term conditions and any social care assessments.</b>	<p><i>Some local health economies have established their EPaCCS to interact with social care, including residential care homes, but many others have not. Those who have managed to achieve a full or partial solution to this difficult problem will be encouraged and supported to share how they have achieved this. Localities are encouraged to broaden their EPaCCS footprint to social care organisations and NHS England will provide support where possible.</i></p> <p><i>The SCR programme, run by the Health and Social Care Information Centre is proposing to run a 'proof of concept' project providing access to view Summary Care Records to social care professionals working in care homes, which if successful, will provide an easy to use solution for access to records which can be enriched with additional information, including end of life preferences.</i></p>
<b>14.</b>	<b>That by the end of 2019, every local area should establish 24/7 end of life care for people being cared for outside hospital, in line with the NICE quality standard for end of life care, which supports people's choices and preferences.</b>	<p><i>In 2012, NHS England 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.</i></p> <p><i>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 identified that the general reduction of services at weekends, across primary/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 those in their last days and months of life. The NHS 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.</i></p> <p><i>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. Central to this will be the development of a 'Clinical Hub' offering patients who require it access to a wide range of clinicians, both experienced generalists and specialists. The clinicians in the hub will be supported by the availability of clinical records such as 'Special Notes', Summary Care Records (SCRs) as well as locally available systems.</i></p> <p><i>To better understand access to end of life care across the country, NHS</i></p>

## Part Two - How we will deliver the Commitment

		<p><i>England has commissioned a summary evaluation of the different models in place across the country, which will outline their benefits and limitations and can be used to accelerate speed of adaptation and adoption of good practice.</i></p> <p><i>In addition, to deliver improvements in all settings, NHS England will ensure that major programmes contain end of life care as a key component and the scope of all new national initiatives is explored to consider how they can contribute to improving quality and choice of end of life care. End of life care is an intrinsic thread within several of NHS England's corporate priority areas, including Urgent &amp; Emergency Care, Cancer and Dementia and we expect to see end of life care improvements identified and realised as part of these programmes.</i></p>
15.	<p><b>That NHS and social care organisations work in closer partnership with the voluntary sector to support hospices in providing the services required to meet people's choices.</b></p>	<p><i>NHS England and 26 partner organisations across the health and social care system, including the statutory and voluntary sectors, worked together to publish the Ambitions for Palliative and End of Life Care – national framework for local action. This is a 5 year national framework for local action, which emphasises the need for cross-organisational collaborative working. Locally we expect the NHS, social care and voluntary sector to work together to deliver the ambitions and provide services to meet people's choices.</i></p> <p><i>The Department of Health is also working in close partnership with the End of Life Care Coalition of charities in developing effective models of end of life care.</i></p>
16.	<p><b>That local areas who already have the systems and services in place to offer and deliver choice as outlined in the proposed national choice offer do this at the earliest opportunity, sharing their expertise with others through a central knowledge hub.</b></p>	<p><i>The Department of Health and NHS England will take a number of actions to promote effective leadership and commissioning in end of life care, as set out in the above response to advice point '11'.</i></p> <p><i>NHS England will also work with the National Council for Palliative Care and the National Palliative and End of Life Care Partnership, during 2016, to expand the Ambitions for Palliative and End of Life Care website to share and spread lessons learned about successful models of end of life care provision. This will be a single central point of reference for professionals and organisations around the country with an interest in end of life care innovation.</i></p>
17.	<p><b>That Health and Wellbeing Boards consider enabling choice, better coordinated care and integrated models of end of life care in making strategic plans for their local areas.</b></p>	<p><i>Health and Wellbeing Boards are integral to driving improvements in local end of life care services. We will communicate with all Health and Wellbeing Boards through established mechanisms to make them aware of this response and the importance the Government places on this issue.</i></p>

<p><b>18.</b></p>	<p><b>That the potential for the use of personal budgets should be more fully explored and that provider organisations should consider how they can best support people to use personal budgets to enable their choices and preferences to be met.</b></p>	<p><i>The expansion of integrated personal health budgets forms part of the 2016-17 Mandate to NHS England. NHS England will work with a small number of interested areas to assess rapidly options for personalising services and improving choice and control for individuals at end of life, using the learning from the delivery of personal health budgets and integrated personal commissioning in end of life care. NHS England will also ensure that more people across the country who receive fast track NHS Continuing Healthcare have the option to have more choice and control over the services they receive.</i></p> <p><i>To support delivery of this objective, the latest shared planning guidance: Delivering the Forward View: NHS Shared Planning Guidance 2016/17-2020/21 asks local system to address how they will close the health and wellbeing gap and include, within their Sustainability and Transformation Plans (STPs), plans for a ‘radical upgrade’ in patient choice and control as well as how they will manage a major expansion of integrated personal health budgets and implementation of choice – particularly in end-of-life, as part of their programme to hand power to patients.</i></p>
<p><b>19.</b></p>	<p><b>That health and social care commissioners include initiatives aimed at increasing community resilience and involvement in end of life care in their plans.</b></p>	<p><i>The Ambitions for Palliative and End of Life Care recognises the important role of community resilience through the sixth ambition of ‘Communities being willing to help’.</i></p> <p><i>The National Council for Palliative Care (NCPC) and Public Health England are supporting eight pathfinder organisations across England to pioneer a public health approach to end of life care - the ‘Dying Well Community Charter’ (principles which organisations sign up to). NCPC will work with Pathfinders to develop a method for evaluating the impact that Pathfinders are having on awareness and activities around dying, death and bereavement in their local areas, and will share lessons from this over the coming year.</i></p>
<p><b>20.</b></p>	<p><b>That the £130million additional investment identified as needed to enable the national choice offer in end of life care to be made by April 2020 be identified in the next spending review.</b></p>	<p><i>The Government has given detailed consideration to the costing model set out in the Review and, on balance, considers the model does not represent the best way forward to support the introduction of the national Commitment to End of Life Care.</i></p> <p><i>The 2015 Spending Review sets out the Government’s plans to protect spending on the NHS in England and its support for the NHS Five Year Forward View which outlines a plan for a more sustainable, integrated health service that cares for people closer to home.</i></p> <p><i>By committing to increase NHS funding in England by £10billion in real terms by 2020/21, above 2014/15 levels, the Government is supporting the NHS in England to deliver its plan and improve safety, quality and access.</i></p>

## Part Two - How we will deliver the Commitment

		<p><i>We are committed to improving quality and choice in end of life care as an intrinsic part of creating a modern fit-for-purpose NHS that delivers what people need from their health services. In our Mandate for 2016/17, we explicitly refer to end of life care and ask NHS England to improve significantly patient choice and quality in end of life care, including on people’s choices about where they would like to be cared for and die.</i></p> <p><i>Our plan for end of life care recognises the changes underway in the NHS over this Parliament and ensures that end of life care is firmly embedded in the major programmes NHS England is putting in place to deliver a transformed NHS.</i></p> <p><i>As a result, we do not believe that the specific costing proposals set out in the Review, which do not take into account the wider transformation agenda, represent the best way to ensure improvements in end of life care.</i></p>
<p><b>21.</b></p>	<p><b>That the national choice offer be supported through a new right in the NHS Constitution for everyone to be offered choice in end of life care and have these choices and preferences recorded and held in their individual plan of care. The offer should be included in the NHS Choice Framework and supporting information for patients should be published on the NHS Choices website.</b></p>	<p><i>Our immediate priority is to ensure that the Commitment for End of Life Care becomes a reality for every person nearing the end of life. Our plans to improve and support the development of end of life care services over the coming years will help embed the Commitment and deliver better, more personalised care. However, over the longer term, we believe there is scope for the Commitment to be included as a pledge in the NHS Constitution by 2020, and we are also considering reflecting the Commitment as a section in the NHS Choice Framework.</i></p> <p><i>Finally, we will publicise and raise awareness of the Commitment on the NHS Choices website.</i></p>
<p><b>22.</b></p>	<p><b>That NHS England’s new guidance for Clinical Commissioning Groups makes explicit reference to enabling preferences at the end of life, and preferences at the end of life be considered in ongoing work on the NHS Standard Contract, new palliative care currencies, the service specification</b></p>	<p><i>Enabling preferences at the end of life is a theme within a number of key documents and guidance issued by NHS England.</i></p> <p><i>The latest shared planning guidance: Delivering the Forward View: NHS Shared Planning Guidance 2016/17-2020/21 asks local health economies to develop Sustainable Transformational Plans. One of the areas they should consider when developing these plans is how implementation of choice in end of life care will be an integral part of their plan to hand power to patients.</i></p> <p><i>Since 2015/16, the NHS Standard Contract includes a requirement for service providers to pay due regard to the Implementation Guidance for the Care of Dying People, to enable the Priorities for Care of the Dying</i></p>

	<p><b>for specialist palliative care and the updated commissioning toolkit for end of life care.</b></p>	<p><i>Person to be addressed. The latest NHS Standard Contract also places a requirement on providers to implement EPaCCS, a key enabler of achieving preferences at the end of life, and includes guidance on ensuring these are interoperable.</i></p> <p><i>NHS England will publish a definitive set of palliative care currencies to help categorise people receiving palliative care according to level of complexity and resource need. This will be available for use from April 2017. The new funding system will support discussions between commissioners and service providers for improving commissioning of palliative care, all of which contribute to enhancing the conditions in which meaningful choice can take place.</i></p> <p><i>In April 2016, NHS England published a refreshed commissioning toolkit for end of life care, which emphasises the importance of enabling preferences as a key theme throughout. Ongoing work at NHS England to produce information for commissioners on the components of specialist palliative care refers to the NICE Quality Standard 'QS13 - End of Life Care for Adults', which prioritises the individual preferences of people at the end of life as a core concern.</i></p>
<p><b>23.</b></p>	<p><b>That, in reviewing the Quality and Outcomes Framework consideration be given to how identification of palliative care needs, people's preferences at the end of life and better coordinated care can be appropriately incentivised, potentially with regard to the use of EPaCCS or equivalent systems.</b></p>	<p><i>The current Quality Outcomes Framework (QOF) contains two items relevant to End of Life Care – to have a register of patients identified as requiring palliative care and to discuss all patients on the register in a multidisciplinary team meeting every three months.</i></p> <p><i>We will review the end of life care items in the QOF once national coverage for electronic systems which can record peoples' needs and choices is achieved.</i></p>
<p><b>24.</b></p>	<p><b>That the work on individual-level outcome and experience measures for palliative care, being led by NHS England and Public Health England, should incorporate real time feedback and also measure the extent to which a person had been offered choice and whether their choices had</b></p>	<p><i>To drive improvement nationally through the new CCG Improvement and Assessment Framework, NHS England will work with the Department of Health, Public Health England and the Health &amp; Social Care Information Centre to develop and implement a suite of new metrics to measure progress against the NHS Mandate on both quality and choice in end of life care. These measures will provide comprehensive information on performance at CCG level so that we can track progress and variation around the country. The new metrics will cover both quality and patient experience at end of life, including how involved people felt in their care and treatment, taking account of the new Commitment for End of Life Care.</i></p>

	<p><b>been met. These measures should also provide meaningful data to monitor the impact of a national choice offer on health inequalities.</b></p>	<p><i>We will also include, by June 2018, a new Clinical Priority Area for End of Life Care in the new CCG Improvement and Assessment Framework. Once the new metrics are developed, new indicators for end of life care will be included under the End of Life Care Clinical Priority Area to give a clear demonstration of the quality of end of life care in each CCG, in every part of the country.</i></p> <p><i>As a first step towards developing the new metrics, NHS England are conducting a feasibility study into possible new ways of capturing the experience of both people towards the end of life and their carers. The study will:</i></p> <ul style="list-style-type: none"> <li><i>• provide NHS England with a clear understanding of the most effective ways to capture feedback on the quality of end of life care;</i></li> <li><i>• provide recommendations regarding questions that can be asked of people and their carers in real time to evaluate and support increased involvement in decision-making (to the extent the person wishes).</i></li> </ul> <p><i>Interim findings of the study will be available in summer 2016. Options on the best ways to provide CCG-level data and will then be considered to decide the best way forward.</i></p> <p><i>NHS England has been working with Public Health England to develop a palliative care clinical dataset, to provide the foundations for further work on outcomes and indicators. As part of the project, data was collected by a number of pilot sites during 2015/16 to understand the feasibility of collecting patient level data, capture learning and evaluate any benefits. This work is shortly drawing to a conclusion and the dataset will be published alongside guidance and an evaluation in autumn 2016.</i></p>
<p><b>25.</b></p>	<p><b>That indicators be developed for the NHS and Adult Social Care Outcomes Frameworks to hold the health social care system to account for delivering choice and improving experience for all at the end of life.</b></p>	<p><i>In March 2016, NHS England published its new CCG Improvement and Assessment Framework, which will measure the performance of each CCG against key national indicators of quality improvement. Currently, the new framework includes a key indicator which will track changes to the number of deaths in hospital within each CCG as a proxy for end of life care quality.</i></p> <p><i>Over the course of this Parliament, NHS England will develop and implement a suite of new metrics to measure progress against the NHS Mandate on both quality and choice in end of life care, with the intention that the new, metrics will feature in a new Clinical Priority Area for End of Life Care in the CCG Improvement and Assessment Framework, by June 2018.</i></p>

<p><b>26.</b></p>	<p><b>That the Government implement a clear policy to make access to social care for people at the end of life fast and free.</b></p>	<p><i>The Government recognises the vital role that social care plays at the end of life and is considering options to ensure that more people are able to access the support they require. Receiving an appropriate health and social care package, in a timely manner, is a key factor in enabling people to achieve any choices and preferences that they may have in their end of life care.</i></p> <p><i>However, the Government considers that the current barriers to timely access to high-quality care will not necessarily be overcome by free social care at end of life. For example, free social care at the end of life will not address problems such as the limited capacity of social care and the delays people experience in commencing a care package. The Department of Health will consider cost-effective approaches to removing these critical barriers.</i></p> <p><i>Individuals with a rapidly deteriorating condition that may be entering a terminal phase, may require ‘fast tracking’ for immediate provision of NHS Continuing Healthcare (NHS CHC). An appropriate clinician should complete the Fast Track Pathway Tool where an individual requires an urgent package of care which addresses their care needs in the most appropriate and timely manner and in the individual’s preferred place of care. Where a recommendation is made for an urgent package of care through fast-track arrangements, this should be accepted and actioned immediately. The National Framework for NHS CHC sets out the arrangements for fast-tracking individuals where the appropriate clinician decides that the individual meets the criteria.</i></p> <p><i>Since October 2014, anyone receiving NHS CHC has had the ‘right to have’ a Personal Health Budget (PHBs). PHBs aim to give patients more choice and flexibility to meet their needs in ways that work for them and agreed with the NHS. NHS England is working to ensure that more people across the country who receive fast track NHS Continuing Healthcare have the option of a personal health budget and is working with a small number of interested areas to rapidly assess the potential for personal health budgets and integrated budgets in end of life care.</i></p>
<p><b>27.</b></p>	<p><b>That the CQC inspection regime for acute and community trusts, primary care and adult social care (which includes hospices and care homes) uses the offer of choice to individuals in end of life care and the ability of organisations to facilitate and support coordinated</b></p>	<p><i>The CQC’s new inspection approach, which has been in place since October 2014, includes a clear focus on end of life care and applies in all services where end of life care is delivered. The approach includes acute hospitals, community settings, GP services, hospices and care homes.</i></p> <p><i>During 2016, CQC will review its inspection approach and consider where improvements can be made, including on incorporating choice in end of life care into its inspection regime.</i></p>

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	care as signifiers of quality.	
28.	<p><b>That there be further work on costs and savings to support implementation of the choice offer, building on both the existing costing work and covering uncosted elements of this advice such as staff training, named responsible senior clinicians and care coordinators.</b></p>	<p><i>The Department of Health is working with key partners, including NHS England, Public Health England (PHE) and voluntary sector stakeholders, to develop understanding of the costs and savings associated with different models of end of life care. This work includes:</i></p> <ul style="list-style-type: none"> <li>• <i>work PHE have commissioned, building on the Choice Review costings to understand the health economics of moving place of care and death from acute hospitals into community settings. The aim of this work is to identify knowledge gaps and develop our understanding of costs associated with different models of end of life care;</i></li> <li>• <i>work being undertaken through socially motivated investment with a number of CCGs around the country to test models of community end of life care provision, which will evaluate costs and savings.</i></li> <li>• <i>work being undertaken by Macmillan Cancer Support to assess outcomes of Macmillan Specialist Care at Home’s six pilot centres. This is a partnership approach, enhancing existing services to deliver effective palliative care to more people in the community. Evaluation work includes case study analysis to look at provision of specialist palliative care services in a local area and estimated costs associated with extending provision; and a formal evaluation of the centres.</i></li> <li>• <i>work that Sue Ryder has undertaken to understand potential costs and savings as a result of its Partnership for Excellence in Palliative Support (PEPS) service in Bedfordshire, a coordination hub which coordinates care and provides advice and support for people at the end of life and their carers 24/7.</i></li> </ul>
29.	<p><b>That the Dying Matters Coalition has a key role to play in widening public understanding and supporting development of choice and so should be encouraged, supported and sustained, as should initiatives aimed at building the confidence of health and care professionals on these issues.</b></p>	<p><i>The Government recognises the key role the Dying Matters Coalition plays in empowering the public to understand and discuss dying, and contribute to a growing national conversation on death and dying, which foregrounds the importance of good, early care planning. The Dying Matters Coalition was funded by the Department of Health in its early years, and NHS England has continued to support the Coalition ever since. NHS England will continue to contribute to the funding of the Coalition during 2016/17 and its work will continue to be promoted and publicised to CCGs and local health economies.</i></p>

<p><b>30.</b></p>	<p><b>That there should be further funding for research into palliative and end of life care, focusing on the priorities identified by the James Lind Alliance.</b></p>	<p><i>The National Institute for Health Research (NIHR) Health Technology Assessment programme launched an open call for research in March 2015. The programme welcomed proposals for the evaluation of interventions for the management of end of life care in people with non-cancer and cancer related conditions, in particular interventions for the last 30 days of life.</i></p> <p><i>Development of the call was informed by the work of the Palliative and End of Life Care Priority Setting Partnership, which was facilitated by the James Lind Alliance and which the NIHR jointly funded. Three research project awards have been made so far, subject to contract, on the following topics:</i></p> <ul style="list-style-type: none"> <li><i>• the Namaste Care intervention to improve the quality of dying for people with advanced dementia living in care homes;</i></li> <li><i>• ImproveCare: the management of clinical uncertainty in end of life care; and</i></li> <li><i>• Carer-administration of as-needed sub-cutaneous medication for breakthrough symptoms in home-based dying patients.</i></li> </ul> <p><i>In addition, several research applications relating to end of life care have recently been awarded funding under other NIHR programmes, including the Research for Patient Benefit programme.</i></p>
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