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# What's important to me.

*A Review of Choice in End of Life Care*



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Programme Board

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## About this review

The Choice in End of Life Care Programme Board was commissioned to provide advice to Government 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. Full details of the Review Board's terms of reference are available online.<sup>1</sup>

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# Foreword and introduction

## Claire Henry MBE, Chair of the Choice in End of Life Care Review Board

Dying, death and bereavement are important parts of everyone's lives. They happen to us all, and many of us will be affected by the death of people close to us. But whilst dying is inevitable, and universal, that is the only certain thing about it. So much else is unpredictable. It is therefore vital to offer people choice and control over the things that are important to them at this point of maximum vulnerability in their lives.

Choices at the end of life affect us all. People have told us during this Review that they want their end of life care to reflect their own individual views and preferences; as one person said, "this is about those unique things that make me, me".

However we still hear too many stories of people's choices relating to end of life care not being heard, shared or met and of people not having control or high quality care. It has often been said, not least in the End of Life Care Strategy (2008), that the way we care for dying people is a measure of our society. At the moment, when it comes to making sure that people's last choices are met, we are too often failing them. It is time that these high aspirations were matched by the reality of what people experience.

***"My father-in-law wished to die at home. Unfortunately his life came to an end over a weekend and the care services available to him were unsatisfactory in that they were unable to provide adequate palliative care to manage his pain. For my father-in-law and his family, choice to die at home worked out badly as he underwent considerable suffering which could possibly have been avoided."*** (Respondent to public engagement)

Situations like these are unacceptable. We need to deliver good experiences and outcomes for all people at the end of their lives, based on honest conversations, clear information and support from knowledgeable, compassionate and well-trained staff and volunteers.

It is vital that we are supported to be ourselves as we near the end of our lives. We need to recognise how and where the attitudes and actions of individuals and society as a whole, as well as the structures of the health and care system, must change. This advice sets out our vision of greater choice through a 'national choice offer' for all people in England at the end of life. We believe everyone should have the chance to benefit from a comprehensive and consistent approach that offers and fulfils individual choices and preferences, and can overcome the fear of lack of control felt by many.

Care and support services need to be focused around what is important to the person and those close to them, whether this is place of care, symptom control or decisions around treatment.

*“My husband passed away four years ago. He asked to be allowed to die at home. Within two days he was brought out of hospital as everything was put in place with great speed and also a phone number was given to me to use if he was ever ill. This was very helpful to me as the people on the end of the phone knew all about his case and I got help within a short time no matter at what hour I had to ring. This was so comforting to have and the care he received from the hospital staff to set up carers and also the help from his local GP and nurses was second to none. I never felt left alone or helpless with the set up. I got some night carers to help me get some sleep. My husband was only at home for a few weeks before he died and even then when I realised he was near the end a phone call to my local doctors was answered with two nurses who came to the house within 15 minutes to see him and he passed away while they were there so I was not alone.”* (Respondent to public engagement)

Many of the problems that we have identified in this advice are not new. While it is important to acknowledge that many positive changes have been made in recent years in the way end of life care services are provided in this country, there is still a great deal to be done to ensure that everybody's needs and preferences are known and met. As a society we all have a role to play; end of life care is everyone's business and needs to be recognised as such.

This report provides a blueprint for Government and the health and care system, as well as wider society. People have told us what they want. Now is the time for action.

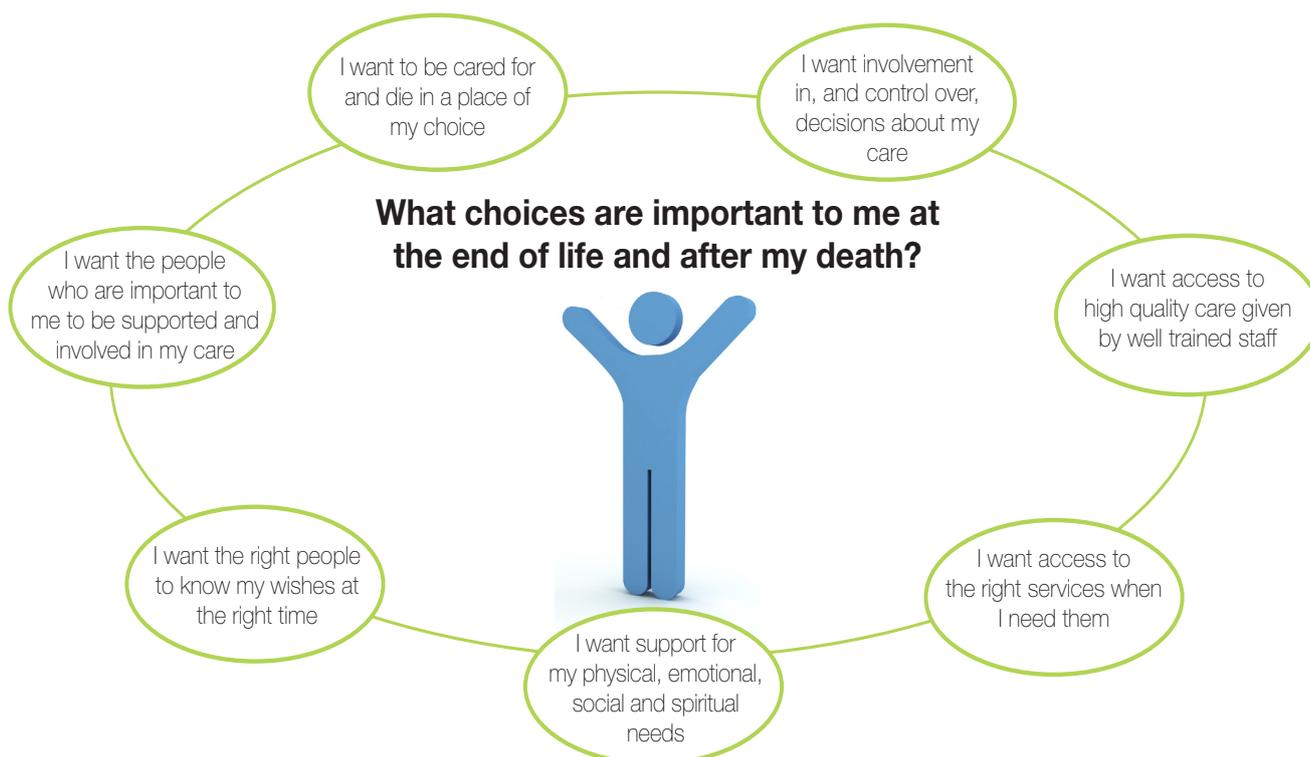
## Executive summary

End of life care<sup>2</sup> has made great strides forward in recent years, in particular following the publication of the End of Life Care Strategy in 2008.<sup>3</sup> However, we know that too many people still do not receive good quality care which meets their individual needs and wishes. For example, only just over half of respondents to the National Survey of Bereaved People (VOICES-SF) felt that their relative had died in a place of their choice.<sup>4</sup> At the same time the challenge of delivering consistently good experiences and outcomes for people at the end of their lives is growing. Each year, around 480,000 people die in England. This is predicted to increase to 550,000 by 2035.<sup>5</sup>

We were asked by the Government to consider how the quality and experience of care for adults at the end of life and those close to them could be improved by expanding choice.

This report identifies the issues people approaching the end of life are currently facing and offers a blueprint for how greater choice in end of life care can be achieved. Our advice is focused around a 'national choice offer' – a simple expression of what should be offered to each individual who needs end of life care.

In forming this advice to Government, we have engaged widely with the public, to ensure that individual experience is at the heart of our work and we are immensely grateful to everyone who came to us with their views and experiences. A number of key themes emerged from this engagement exercise. Many people told us that they wanted choice over their place of care and death; others told us that they wanted choices over other aspects of their care, such as pain control and involvement of family and those close to them.



We know that while many people are offered these choices now, many are not. We believe that asking everyone who is approaching the end of their lives a single question “what’s important to you?” can open the gateway to conversations that ensure people have choices and care that are focused around their needs.

Everyone who says they want to have these conversations should have them, regardless of where they live, their individual circumstances or their clinical condition. These conversations need to take place at the right time, as part of an honest and informed dialogue, throughout the individual’s care. To make this happen, we advise that there is a national choice offer for end of life care as follows:

**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. This offer should be:**

- **made as soon as is practicable after it is recognised that the person may die in the foreseeable future;**
- **based on honest conversations with health and care staff, which supports the person to make informed choices; and**
- **consistently reviewed through conversations with health and care staff.**

However, in our public engagement, many people said that as well as choices about their care, they wanted things like support for physical and emotional needs and access to the right care from well trained staff. We heard how many people did not receive good quality end of life care. This fits in with wider evidence that end of life care services are not consistently good across the country.

People told us that good end of life care needs to be provided to all people as a platform for a national choice offer. We know what good care is. It means that people get the right services, at the right time, in the right place. It means people’s preferences are heard, recorded, shared and acted upon. It means staff who can deliver care with expertise and compassion. It means people being informed about the treatment and care available to them, their condition, and how this might affect them over time. Only through consistent and comprehensive good care can choice be delivered and a national choice offer be meaningful.

To enable a national choice offer, we advise that a number of steps are taken to ensure good quality end of life care for all. Our advice provides a framework to enable both the better commissioning of high quality care and better delivery of these services by health and care organisations and their staff.

We need to support individuals in making their voices heard, and choices and preferences known, so we advise 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; and**
- **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.**

We know that for many people approaching the end of their lives, support from family, carers and those important to them is vital in ensuring that they receive high quality care focused on their needs. We advise 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; and**
- **family members, carers and/or those important to the individual should be involved, where possible, in discussions about care preferences where the dying person has said they should be.**

The services available for people approaching the end of life need to change to enable choices and preferences to be delivered. To achieve this, we advise that:

- **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;**
- **EPaCCS or equivalent system coverage is increased to 100% of localities to enable the recording and sharing of people's choices and preferences;**
- **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;**
- **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; and**
- **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.**

To ensure that health and care services meet individuals' needs fully, health and care staff need to have the knowledge, support and skills to provide high quality care. To achieve this, we advise 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; and**
- **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.**

Many places already have many of these types of services and already offer and deliver good quality care and choice. However, we are also aware that ensuring that this happens everywhere will have financial implications, both spending more money and spending money in different parts of the health and social care system, at a time when funding is under significant pressure.

We have used a wide range of evidence to create a model of care which shows us what we spend on end of life care, and what it might cost if the system were changed to provide good quality personalised end of life care for all which delivers the choices that people would like to make.

This work has produced a number of costed scenarios for improvements in end of life care to deliver a national choice offer. The outcomes from that show that the only way to guarantee a level of care in line with all of the statements in the NICE Quality Standard for End of Life Care, for all locations, with everyone's choices and preferences met, would involve substantial investment - over £800million annually. We accept that in the current financial climate, at a time of great demands on NHS and social care services, this level of additional investment on an annual basis is unlikely.

However, our modelling suggests that a realistic, meaningful level of service improvement can be achieved through relatively modest investment which would make a significant difference to people's quality and experience of care at the end of life. We believe these improvements would make essential progress towards the implementation of a full national choice offer in end of life care. Therefore, we advise that:

- **an additional £130million is identified in the next spending review and invested in social care and NHS commissioned services to deliver a national choice offer in end of life care.**

It has been suggested that the NHS will require £8billion of extra funding, and that further

efficiency savings can also be found. We believe that the £130million that we recommend is spent on end of life care should be seen as a critical part of that £8billion and that this should be viewed in a wider context of decades of neglect of end of life care.

This is, however, only achievable if the people and organisations who deliver this care, in particular the NHS, change the way they work. It requires more care in community settings, with investment in these services coming from the savings flowing from reduced hospital-based care; it requires providers of hospital services to plan care proactively, beyond hospital, to avoid unnecessary admissions; it requires a change in attitudes and behaviour from all involved in the commissioning and delivery of care to make care truly person-centred; and it requires a skilled, capable and flexible workforce.

We know that, in some places, good quality care, focused around the individual's choices and preferences, already happens. At the same time, we recognise that not all NHS, social care and other services are ready to provide the sort of choice offer that we are recommending, and some of the changes that need to happen will take time.

However, we believe it is essential to set a specific date for the delivery of a national choice offer in end of life care and specific timescales for key service improvements, so that all people in all areas are able to benefit from this. We also believe the offer should be supported by inclusion in documents which outline people's rights in relation to NHS. We therefore advise that:

- **the national choice offer for end of life care be made by April 2020;**
- **this offer should be supported by a 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 reflected in the NHS Choice Framework, which provides information about rights to choice in the NHS, and publicised through the NHS Choices website; and**
- **our advice on 100% coverage for EPaCCS or equivalent systems be implemented by April 2018, and our advice on 24/7 care for people in community settings be implemented by the end of 2019.**

To support staff and organisations delivering care to build the services to ensure good quality care and enable choices by this date, the Government and other statutory organisations, including commissioners of health and social care services, need to create the right conditions. We advise that:

- **NHS England's new guidance for Clinical Commissioning Groups should make explicit reference to enabling preferences at the end of life;**

- **NHS England should also consider preferences at the end of life in its ongoing work on the NHS Standard Contract, new palliative care currencies, the service specification for specialist palliative care and updated toolkit for end of life care;**
- **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;**
- **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;**
- **the existing incentives relating to end of life care in the Quality and Outcomes Framework should be reviewed to take into account people's preferences at the end of life, potentially with regard to the use of EPaCCS or equivalent systems;**
- **Health Education England, in planning for future workforce numbers, should:**
  - **work with commissioners and providers to agree both specialist and non-specialist palliative care workforce requirements, in acute and community settings, to deliver improvements in end of life care; and**
  - **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.**
- **the Government implement a clear policy to make access to social care for people at the end of life fast and free;**
- **health and social care commissioners include initiatives aimed at increasing community resilience and involvement in end of life care in their plans;**
- **the Dying Matters Coalition plays a key role in widening public understanding and supporting the 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;**
- **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; and**
- **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.**

We need to ensure through effective measurement that choice is being offered consistently and people are receiving the care that they have said they want. Therefore we advise 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 been met. These measures should also provide meaningful data to monitor the impact of a national choice offer on health inequalities;**

- **indicators be developed for the NHS and Adult Social Care Outcomes Frameworks to hold the health and social care system to account for delivering choice and improving experience for all at the end of life; and**
- **the Care Quality Commission (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 care as signifiers of quality.**

Our work for this Review has been built on the wealth of evidence now available on end of life care, from academic research and specialist clinical advice, to work done by charities and statutory organisations. We believe that the insights provided by our engagement exercise have enriched this work and added valuable perspective and real-life experience. We do however recognise that there are some limitations in relation to our work, in particular on the costings of specific elements of good end of life care, such as staff training, named responsible clinicians and care coordinators. We advise that:

- **further work be done relating to these costs to support the implementation of the choice offer; and**
- **there be further research into palliative and end of life care, focusing on the priorities identified by the James Lind Alliance, which should provide a richer evidence base for key parts of this advice.**

We believe that a commitment to deliver choice in end of life care by April 2020 is essential. If we want to deliver high quality, personalised end of life care for all, we must ensure that everyone has the choice and access they need. People have very clear ideas about what is important to them at the end of life and what they need to support their care and their choices. We believe the advice we have set out here is a clear, sensible and straightforward way to make this happen.

# Choice in end of life care - the Review, the context and the challenge

## *The Review*

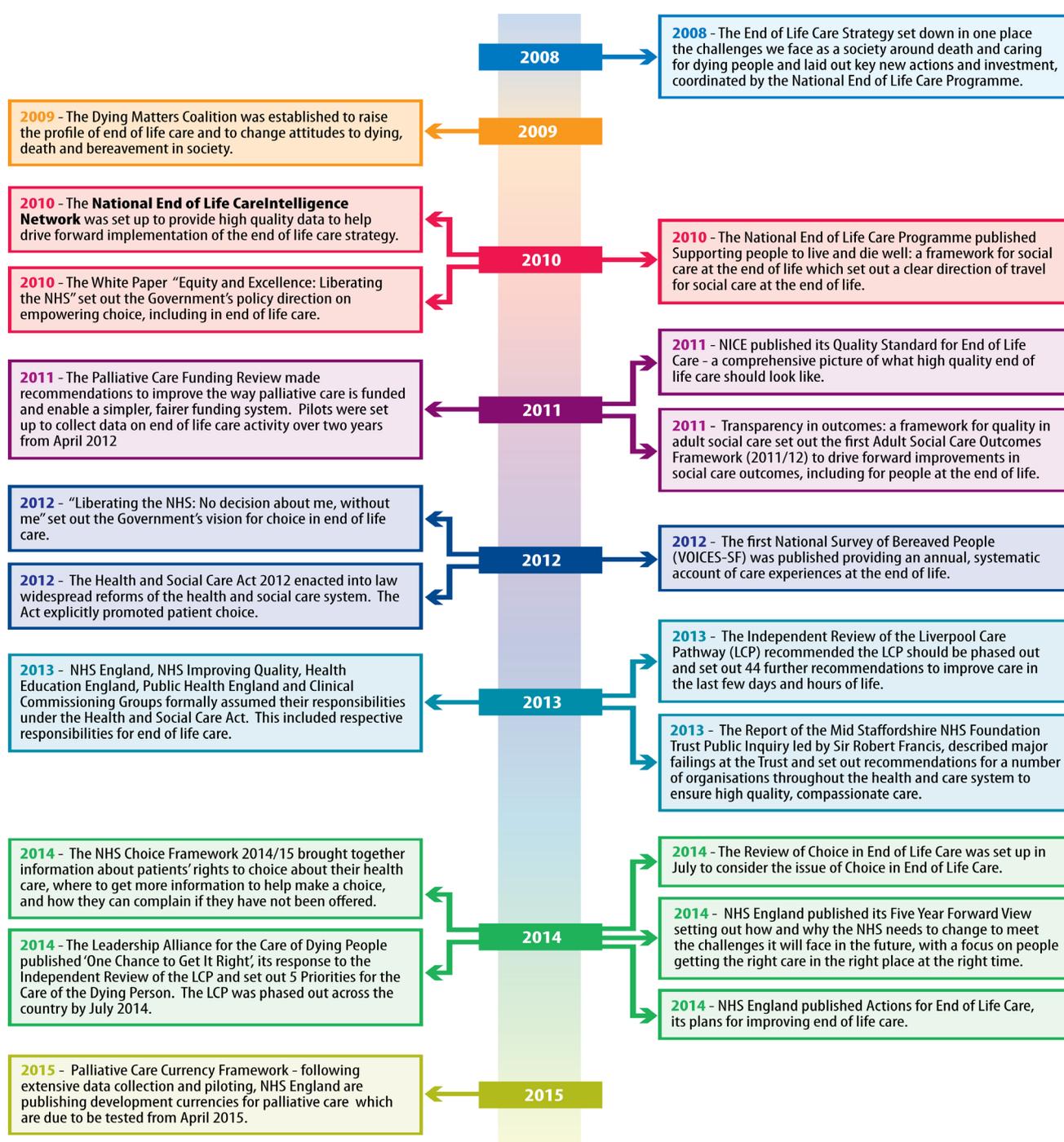
1. In 2010 the Government set out its aim to establish a 'national choice offer' for end of life care.<sup>6</sup> At the same time, it was clear that making choice in end of life care a reality would have implications for changing and improving the way that end of life care services are organised and delivered.
2. The Government established this Review to take this work forward with the following remit:
  - provide independent advice on what a national choice offer for end of life care should include, within the current legal framework, for individuals over the age of 16;
  - identify the enablers and barriers associated with these choices; and
  - consider what services would be needed to support them.
3. Our intention throughout has been to ensure that any recommendations on a national choice offer are achievable, responsive to changing circumstances and accessible to all. But we have also aimed to be person-focused, so that any offer meets the needs of people who are at the end of life.
4. To achieve this, we believe enabling choice in end of life care should mean:
  - practical help at an individual level that will help every dying person express their preferences, should they wish to do so;
  - a commitment to involve those important to the individual in discussions about the dying person's care and preferences, to the extent that the dying person has agreed;
  - support for staff and organisations whose responsibility it is to deliver high quality, compassionate care and implement the preferences and decisions people have articulated;
  - action, from Government and statutory agencies, in response to the specific recommendations in this report, to create an environment where people are informed and empowered to express their preferences and these preferences can be met as far as possible; and
  - recognition that good end of life care is not delivered in isolation – it depends on support and awareness in communities and in wider society.

## The Context

5. This Review took place in the context of an unprecedented focus on end of life care in England. There has been a growing debate in recent years about the direction of service improvement, potential models of care and the role and importance of choice, personalisation and control.

6. Beginning with the End of Life Care Strategy in 2008, a series of key developments and initiatives have driven forward the debate on what good end of life care means for each of us. The timeline in table 1 maps out the key elements and milestones of this activity:

**Table 1: Timeline of end of life care activity**



## The Challenge

7. We are still not providing high level end of life care to everyone in need or who would wish to benefit from it. Neither are we providing care that delivers people's preferences about key aspects of their care. For example, in a recent National Survey of Bereaved People (VOICES-SF) only half of respondents said that their family member had died in a place of their choice.<sup>7</sup>

8. We are poised on the brink of significant demographic change. In 2013, there were around 480,000 deaths in England. Looking ahead to 2035, this figure is predicted to rise by 15% to over 550,000.<sup>8</sup> With each year that passes we expect people to die at an older age, with more complex conditions. The number of people nationally with one long term condition, many of whom will need end of life care, is due to rise by 3 million by 2025; the number with two or three long term conditions is projected to rise by 1.5 million.<sup>9</sup> End of life care services will need to be responsive to these pressures and adequately resourced to reflect the extra demand. The numbers mean that with every 1% change in place of care and place of death, about 5,000 people in England will need to be cared for and die in care settings different from those they experience today.

9. At the same time, by 2020, it has previously been predicted there will be a £20billion gap between what the NHS receives in funding and what it needs to pay for, alongside a predicted shortfall in funding for adult social care – £4.3billion by 2020 according to the Local Government Association and the Association of Directors of Adult Social Services.<sup>10</sup> This unprecedented financial challenge needs to be met with new ways of funding and delivering services so that they can keep on improving and innovating, especially in the context of the need for an extra £8billion of funding suggested in NHS England's *Five Year Forward View*.<sup>11</sup>

10. Although there is a growing need for palliative and end of life care, even with numbers as they are now, many people are still not having their needs met. Despite the progress made since the 2008 End of Life Care Strategy on improving early identification of palliative care needs, it is clear that services have some way to go to understanding and addressing unmet need. Poor identification of needs and consequent levels of unmet need are particularly strongly associated with conditions other than cancer.

11. Finally, we know that people increasingly associate good care at the end of life with personalisation, preference and control. Some (but not all) people are increasingly well informed about what they want from care and have higher expectations about the care they should receive. For many people, high quality, compassionate care at the end of life means care that actively involves the dying person, allowing them the space and time to express their needs, wishes and preferences and for these to be met wherever possible.

12. To achieve these outcomes for people, services will need to make time for staff to have

honest conversations about people's needs and preferences and will require the resources, innovation and commitment to ensure that this happens even with the other demands and pressures they face.

13. Even though progress has been made in recent years, if we are to continue to improve people's care and experiences at the end of life we must recognise that the most potent of challenges have not gone away and are growing with each year that passes. Left unaddressed, they will continue to threaten delivery of high quality care and are likely to perpetuate the disparities in care quality that we know exist today, and which we believe are wholly unacceptable.

14. We believe therefore that this Review comes at a pivotal moment. Only by making plain the link, now, between high quality end of life care and people's care choices can we ensure that services are prepared and resourced to respond.

## What the evidence tells us – the engagement on choice

15. The purpose of this Review is to make evidence-based recommendations on a national choice offer for end of life care so that people are supported in expressing their preferences and making decisions about the care they receive. This section sets out what the available evidence has told us.

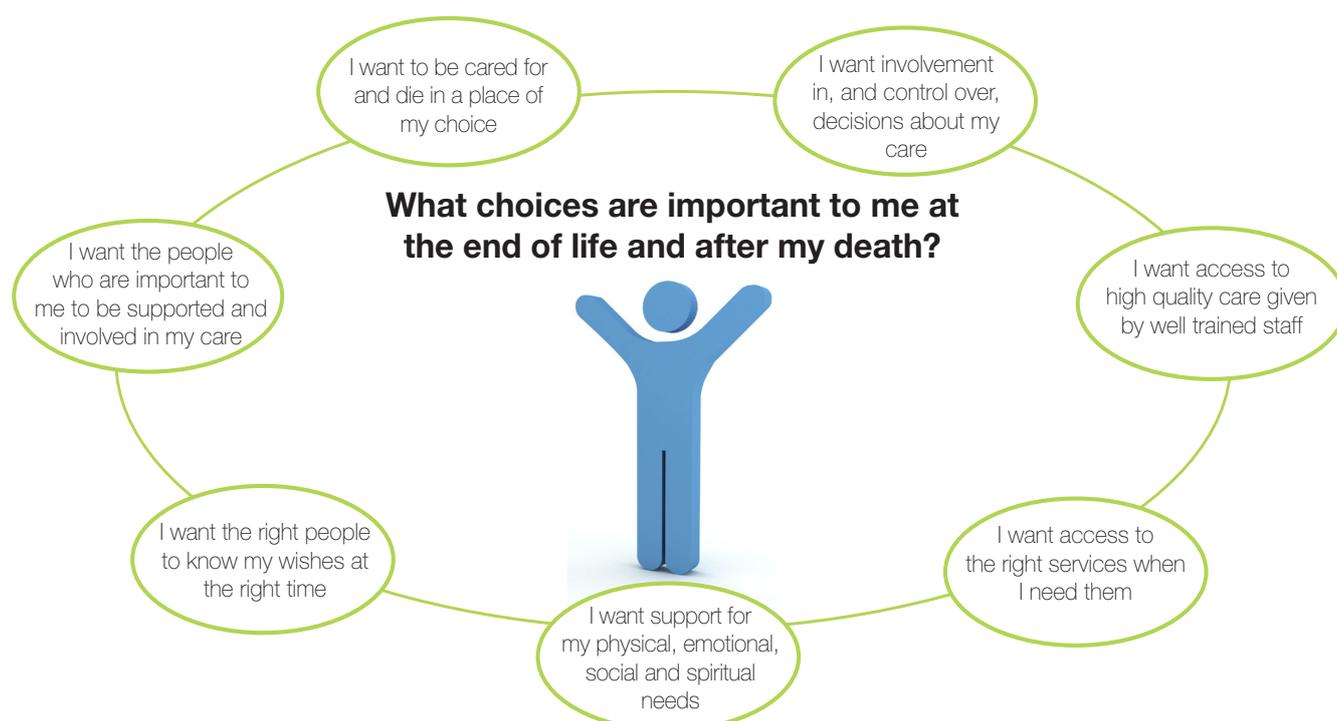
16. Central to this is what people have told us is important to them through the public engagement exercise we undertook as part of the review process. Those results are combined here with data on end of life care and expert and stakeholder views. We have also included findings from academic studies where these were relevant. Together these sources build an overall sense of the key messages emerging from the available evidence on what people want at the end of life.

### Our public engagement

17. We ran an extensive two-month public engagement exercise to gather people's views on choice in end of life care.<sup>12</sup> In this, we asked:

- what kinds of choices should people be able to make about their end of life care?
- what needs to be in place for these choices to be achieved?

18. Seven main themes emerged from our engagement exercise on the kinds of choices people would like to make at the end of life, as illustrated in the following diagram:



19. Over half of all engagement responses focused primarily on place of care and death, reinforcing the importance of this issue to people. Wanting to be involved in care, including control over treatment and open communication with professionals was the next most mentioned theme. Pain management accounted for almost all of the responses in the theme of support for physical and emotional needs.

20. Overall, the majority of people said that they wanted choice about their care but that this should be informed by important considerations about their individual needs, their illness and its trajectory, and other considerations such as the involvement of those close to them.

*“People should have choice, as much as possible within the constraints of their illness, about how they spend their time and with whom. Care should be planned with them and around them.....This applies whether the person is receiving care at home, in a care home, hospital or hospice.”*

*“The most important choice for people is to be given the time and opportunity to express their choices, as all too often individuals are not included in the decisions regarding their care.”*

21. However, many respondents said the most important consideration was that they received good quality care. This is reflected in three of the seven themes we identified; people wanting access to high quality care, wanting the right people to know their wishes at the right time and wanting access to the right service when needed. Some of these responses identified “good care” as their choice and regarded other choice suggestions as peripheral and inessential in comparison. A minority of respondents were negative about the concept of choice and felt it was more important to focus on the delivery of good basic care.

## ***Theme: I want to be cared for and die in a place of my choice.***

22. It is clear that many people are still not being cared for and dying in the place they would want to be, despite all the evidence suggesting that this is an issue to which many of us attach great importance.

23. On place of care and death:<sup>13</sup>

- people said that they wanted to be cared for and die in a place that is familiar, comfortable and where they and those close to them can access the support and care needed;

- being able to choose in general where to die was significantly more important to respondents than being able to choose a specific place of death option, e.g. home;
- home was stated as the preferred place of care more than any other location. However, very few described it unreservedly as the best place to be cared for or die: respondents acknowledged that there may be situations where this was not the best place, particularly if support was not in place to create a more positive experience;
- the choice to die in hospital was considered an important option in certain cases but should be avoided if “inappropriate”;
- people valued alternative models/locations of care which combine the treatments and equipment normally available in a hospital with the comforts associated with home, e.g. hospice at home,
- hospices were also highly valued as delivering high quality, personalised care; and
- people also identified care homes (residential and nursing) and specialist housing (such as sensitively designed extra care housing) as important choice options but they were clear that these settings depend on, and too often do not offer, highly trained staff and support from specialists, hospices and community services.

24. Respondents identified some aspects of the dying environment as being more important than physical location. These included the importance of calm and tranquillity, having loved ones and others important to the dying person close by, and the need to feel secure, safe, respected and dignified. People also acknowledged the importance of a flexible approach to place of care and death given the uncertainty around disease progression and prognosis.

25. Finally, respondents highlighted that people change their minds in line with changing needs and asserted the importance of ensuring people have the flexibility to do this and that services should be responsive to changing needs and wishes.

## Research on preferred place of care and death

26. The evidence that most people would prefer to die at home is extensive and consistent. Over 75% of studies from the UK and other countries show the majority of people stating that they would prefer to die at home.<sup>14 15</sup> This preference is often conditional on the right care being available at home; research has shown that around a fifth of people and family caregivers may change their minds if this is not possible.<sup>16</sup>

27. The National Survey of Bereaved People (VOICES-SF) 2013 provides valuable insight into place of death preferences. According to relatives, 79% of people who had expressed

a preference said that they preferred to die at home. Only 3% of people who expressed a preference said they wanted to die in hospital. 85% of bereaved relatives of people who had died in hospital said that their family member had wanted to die at home.<sup>17</sup>

28. However, there is also evidence suggesting that achieving a home death was not as important to some individuals as other factors such as being free from pain, the presence of family and others close to the dying person, not being a burden to their family, having treatment choices followed and resolving conflicts.<sup>18 19 20</sup>

29. Several studies from a range of countries have shown that more people achieve a home death, if they have expressed a wish to do so.<sup>21 22 23</sup> In particular, evidence indicates that when people and informal carers agree on home as the preferred place of death, people are more likely to achieve a home death, suggesting that supporting individual and caregiver choices for service and treatment options can enable home deaths.<sup>24</sup>

## Research on where people actually die<sup>25</sup>

30. Hospital is the most common place of death. In 2013, in England, 48% of deaths occurred in NHS hospitals, 21.5% occurred in a care home, 22% at home and 5.5% in a hospice inpatient bed, although hospices care for many more people in their own homes.<sup>26</sup> There has been a steady downward trend in hospital deaths in England from 2005 onwards which is mirrored by an increasing proportion of deaths in the usual place of residence (DIUPR - deaths in own home or a care home).<sup>27</sup> In 2013, the DIUPR for England was 44.8%, up from 37.9% in 2008.<sup>28</sup> These trends coincide with the launch of the National End of Life Care Programme in November 2004 which led on work to reduce hospital deaths and enable more people to die at a place of their choice, usually their own home or a hospice, through promoting good practice in end of life care. Research has shown that up to a third of people at the end of life who died in district general hospitals could appropriately have been cared for at home.<sup>29</sup>

31. England has one of the highest rates of hospital death for older people in Europe. Despite preferring to die at home, older people are less likely to do so than other age groups.<sup>30</sup> Moreover, although the majority of people with dementia in England die in a care home (55.3%), two in five continue to die in hospital; this is higher than in other European countries.

32. People who live in more deprived areas are more likely to die in hospital and less likely to want to die at home.<sup>31</sup> This may be due to accessibility of 'out-of-hours' care services, limited knowledge of available care options, limited social support, or inability to bear the costs of caring at home.

33. People dying from cancer, people who die at home or in a hospice and younger people (under 80 years at death) were more likely, according to bereaved relatives, to have had sufficient choice of where to die.<sup>32</sup> Only 40% of people whose deaths were not attributable to cancer, including cardiovascular and respiratory diseases, felt they had enough choice over their place of death, as opposed to 65% of people who died from cancer. People with cardiovascular disease are less likely than those with cancer to die in their preferred place. Despite the majority preference to die at home, we know that a large proportion (59%) of deaths from cardiovascular disease between 2004 and 2011 occurred in hospital.<sup>33</sup>

34. Overall the evidence shows that many people are not achieving their preferred place of death, which in the majority of cases is their own home. We also know especially from what people have said in the engagement that making place of death preferences a meaningful reality for most people will mean ensuring the right environment and health and care support are available in the different settings people may choose.

## ***Theme: I want involvement in, and control over, decisions about my care.***

35. A clear message from the engagement exercise was that people wanted to have control and involvement in decisions about their care. The extent of this control and involvement varied but, at the very least, people wanted to choose how involved they would like to be. The following themes, in particular, were identified as relating to greater involvement in care:

- timely access to information, with support;
- involvement in decision-making, feeling in control over treatment choices (including treatment refusal); and
- honest communication and conversations.

36. On information:

- Access: People said that to enable informed choice, they wanted access to good quality information about the services and care that would 'realistically' be available to them, along with details of the support available, guidance on how to access it and details of any costs involved.
- Timeliness: Respondents felt that receiving information as early as possible would enable better planning and avoid crisis situations.

- Support: People were also concerned about getting the right support from health and care staff to understand and process information, especially about choices, to ensure the process of care planning and exploring choices was constructive, meaningful and tailored to the person's needs.

***“You need a person, not just printed information: Someone to talk things through with.”***

***“Professionals need to be ready to have the conversation with patients and carers about end of life care plans and be ready to provide information.”***

37. On control and involvement in decision-making:

- People said they needed to feel empowered to make decisions and to express themselves, and needed to know that they will be listened to, to enable them to make informed, meaningful choices about treatment or intervention at different stages of care.
- People wanted to feel confident and clear about their power to refuse treatment and, in particular to be enabled and empowered to tell medical staff to cease treatment intended to prolong life in favour of improving quality of life.

38. On honest conversations:

- People said that sensitive, appropriate, honest, timely and two-way conversations with a high degree of awareness of people's particular needs and circumstances were central to enabling choices and good care.
- Respondents highlighted that staff should be trained to conduct these conversations effectively, but that this was not always the case.
- Honesty and openness were highly valued, particularly around prognosis and options of service availability.
- People valued the role and importance of advocates, where appropriate, to speak on their behalf and ensure that their wishes are upheld. Depending on circumstances the “advocate” might be a formal or informal advocate identified by the person themselves, a health or social care professional, or an Independent Mental Capacity Advocate.

***“[I] would welcome the opportunity to receive advice as part of an honest conversation about how to exercise choices to achieve a reasonable level of end of life care that reassures them and their loved ones and carers that everything is in place to make them as comfortable as possible.”***

***“My mother died earlier this year from pancreatic cancer. Although the clinical care was generally good, I really found the clinicians did not want to talk about how her death would be managed.”***

39. Further to these themes, evidence on shared decision-making has shown that most people want to participate in treatment decisions but many do not achieve their preferred levels of involvement because decisions are delayed and alternative treatment options are not discussed.<sup>34</sup> Ways to improve shared decision-making include interventions to improve information exchange, openness and respect for choice. Staff willingness to share information and communication skills have been shown to enable people to participate in decision-making. Higher levels of shared decision-making are associated with greater satisfaction.<sup>35</sup>

*“I’d like to be able to focus treatment on comfort, symptom control, time with family and to avoid unpleasant and intrusive investigations procedures and treatments.”*

## **Theme: I want the right people to know my wishes at the right time**

40. People felt that discussing wishes about end of life care as early as possible and recording them in a format that they, and people involved in their care, could access was an essential enabler of choice. This is in line with recent guidance on the use of advance care planning to establish a person’s wishes about their care and increase the likelihood that those wishes will be met:<sup>36</sup>

- Early discussions: People identified the importance of thinking and planning for the end of life early, while people are still able to consider and express their wishes, but pointed out the difficulties of initiating these sensitive conversations.
- Access to shared records: Respondents expressed the clear desire for people to have access to electronically held information about their care so that they could update their own recorded wishes and preferences. Respondents expressed concerns about poor access to personal information that those involved in their care, including family and friends, should be able to use to enable their wishes to be carried out, especially when they would not be able to do so themselves.
- People expressed the important caveat that it should not be assumed that all individuals wish to engage in decisions about their future care. Everyone should have the opportunity to discuss their future choices with sensitivity and compassion and to decline to do so if that is their wish.

41. Discussions about people’s choices at the end of life, especially the kind of early discussions highlighted in the engagement, often depend on the recognition that a person is at the end of life. Yet recent research has shown that only 20% of people diagnosed with heart, lung, liver or kidney conditions (organ failure) or dementia either requested or were identified for palliative care before dying, compared to 75 per cent of people diagnosed with cancer.<sup>37</sup> This

research also found people were identified too late (on average only eight weeks before dying) to fully benefit from palliative care.

## ***Theme: I want access to high quality care given by well-trained staff***

42. People valued access to high quality care. They identified the essential elements of good end of life care as: co-ordinated care, good communication, good pain relief, access to equipment, accurate care records, to be treated with compassion, dignity and respect, and care personalised to individual's needs – all to be delivered by skilled and well-trained staff.

***“I want to be able to trust that I will be looked after.”***

43. In many ways these views are not about choice – they relate to the provision of good quality care that should be in place regardless of choice. However, it was clear from the engagement that choice and good care do not operate and are not perceived to operate independently of each other. People said that good care necessarily involves choice and that choice is only valuable when there is a foundation of good care. Alongside this strong call for good quality care, people reported and were keenly aware of existing variation in the quality of care that dying people experience, depending on location, available services, condition and a range of other contextual factors. This may account for the strong insistence on quality care that people expressed.

44. The 2013 National Survey of Bereaved People (VOICES-SF) assessed the quality of support and care given to people approaching the end of life in England. This survey highlighted significant differences in quality of care according to the age of the person who died, cause of death and place of death. It also demonstrated that some people do receive high quality care, irrespective of age, cause of death or care setting. The overall quality of care across all settings was highest for people who died from cancer, for people dying in inpatient beds in hospices and for people under the age of 65, although these three groups strongly overlap. The ratings of “outstanding” and “excellent” were lowest for people who died in hospital.<sup>38</sup>

45. Bereaved people were more likely to rate the quality of care as “excellent” in all settings for cases where the person had died from cancer compared to when the person had died from other conditions.<sup>39</sup> Relatives reported that hospital staff were less likely to show dignity and respect for the deceased “all the time” than GPs or hospice staff. For most care settings and services, dignity and respect was shown by staff “all the time” more often for those who died of cancer compared with other causes.<sup>40</sup> Other studies have shown that 90% of the public agree that all healthcare staff should receive compulsory training in how to talk sensitively to people

who are dying and their families.<sup>41</sup>

## **Theme: I want access to the right services when I need them.**

46. The engagement highlighted the value of good access to services including specialist palliative care, community care, hospice provision and 24/7 care. Good co-ordination of care was seen as key to ensuring these services worked together:

- People valued specialist palliative care but said it was not sufficiently accessible everywhere; respondents highlighted rapid access according to need, including 24/7 specialist palliative care advice, as critically important for symptom control and crisis management.
- People said that community care services were not always available or accessible; more services were needed with better trained staff so that people in all areas of the country could access high quality community services.
- People wanted access to low cost or free, easy-to-use equipment, with prompt delivery and collection.
- Co-ordinated care with consistent messages and standards of care, and better access to information was seen as essential but in practice not achieved.
- People called for a universal electronic palliative care record which all relevant agencies can access, as well as more effective use of technological advances to provide care, for example, the use of new media, smart phone apps, telemedicine, telecare, electronic care records, integration and sharing of information on IT systems.

***“The right people should have access to my wishes at the right time.”***

47. There has been a significant growth in the provision of palliative care and a greater understanding of the palliative care needs of people and their families, but access to services on a 24/7 basis has been inconsistent.<sup>42 43</sup>

48. As well as identifying general variation in access dependent on available services and location, research has identified some specific inequalities of access. Older people,<sup>44</sup> people from black and minority ethnic communities,<sup>45 46 47</sup> and poorer people<sup>48</sup> are comparatively less likely to be aware of and access appropriate treatment and care during advanced disease. People with severe mental health problems, people with learning disabilities, gypsies and Irish Travellers, homeless people, drug users, and people in prison or the criminal justice system face similar issues.<sup>49</sup> There have also been concerns around access for young adults in transition between children’s and adult end of life care services.<sup>50</sup>

49. The reasons given in the evidence for disparities in access to palliative care included: i) referral patterns to specialist palliative care; ii) a lack of understanding among healthcare staff about what palliative care is; iii) gate-keeping practices by specialist palliative care services; iv) patient preferences for more aggressive or curative care or a mistrust of end of life care; v) strong religious and familial support systems; and vi) a lack of awareness and knowledge of palliative care and related services among people with advanced disease.<sup>51</sup>

## ***Theme: I want support for my physical, emotional, social and spiritual needs.***

50. Within this theme, people said pain management and symptom control were the aspects of their overall wellbeing that mattered to them most. Respondents also valued holistic support, emotional support and spiritual care.

*“Patients are so often afraid of a ‘bad death’ - pain, nausea, fear and other symptoms - they need reassurance and promises they will receive help with these.”*

*“We need more flexibility with what ‘care’ means for each individual. It is not only physical.”*

*“I may have many needs, please don’t just deal with one!”*

51. Evidence shows the importance that people place on effective pain relief as they approach the end of life.<sup>52</sup> However, only 39% of respondents to the 2013 National Survey of Bereaved People (VOICES-SF) said that pain was relieved “completely all the time” during the final hospital admission. Less than a fifth (18%) reported that people who had died at home had their pain relieved “completely, all the time”. This compares with nearly two-thirds (62%) of those who died in a hospice who experience complete, continuous pain relief. In hospitals and care homes the effectiveness of pain relief was similar across cancer, CVD and other causes.<sup>53</sup>

## ***Theme: I want the people who are important to me to be supported and involved in my care***

52. The engagement exercise showed that when people consider their needs at the end of life, they are also concerned for their relatives and those who care for them, and how they will be affected by their death.

53. People expressed these concerns as: a need for better support for carers, both while they undertake caring responsibilities but also after the person has died; access to bereavement

support for those who want it; the ability to involve families in decisions around treatment and care as far as the dying person wishes; support with practical tasks such as funeral planning and making wills; and the importance of having people around the dying person as they are dying, no matter which environment that happens in.

54. The suggested support for carers took several forms, although respite care featured strongly. This area also often overlapped with other themes, such as the importance of coordinated care and the need for 24/7 care and access to advice, the absence of which both have a detrimental effect on carers as well as people who are dying. There was an emphasis on giving carers information and even training, especially given that people are often taking on caring responsibilities for the first time when someone close to them is dying and may not feel confident in this role. In particular, concerns were expressed that this lack of expertise may result in increased hospital admissions if symptoms worsen and carers are not informed about what to expect or do when this happens.

*“The most important thing for me was that my husband died peacefully and happy at home with me by his side – that might not have been the case had he been in the hospice or hospital. But it is damned hard work and work that is not recognised or acknowledged by the wider health profession.”*

*“My wife wished to die at home and she did. I believe she was pleased but I feel I could have done more for her. At my then age (64), I had no idea what to do to help her and no notion of what to expect as my wife got progressively worse. I could possibly have done more for my wife and done it better if I had been given instruction in what dying entailed and what sort of care would help. Witnessing death is beyond the experience of the vast majority of people in the modern world.”*

## What the public engagement found on how choice can be delivered

55. The second part of our main engagement question asked what needs to be in place for people’s choices to be achieved. The vast majority of the responses we received fell into three broad themes:

- Care where and when it’s needed.
- Coordinated care.
- The right care of the right quality with the right staff.

## **Theme: Care where and when it's needed**

56. People felt that services that provide and support care at the end of life should be available twenty four hours a day, seven days a week. They emphasised that services should be responsive to people's needs and their availability well communicated with a clear point of contact.

***“There needs to be a robust rapid response service so in the event of a crisis, help is available within as short a time as possible, 24 hours a day.”***

57. The engagement also found that:

- access to staff with specialist knowledge of palliative and end of life care and bereavement should be available to complement and support colleagues in all settings;
- community services should be set up to provide holistic support to people who are dying in particular for those who choose to die at home;
- care and support should be available and accessible at all times;
- access to good pain relief, complemented by anticipatory prescribing, was particularly important;<sup>54</sup> and
- there is not enough access to hospice care provision, either inpatient beds or hospice-at-home services.

58. Community services were highlighted as a priority by the National End of Life Care Strategy.<sup>55</sup> Access to services seven days a week is also a significant issue. A joint inquiry by the Royal College of General Practitioners and the Royal Pharmaceutical Society in 2011 found that “access to palliative care medicines during out of hours continues to be difficult in most areas.”<sup>56</sup>

## **Theme: Co-ordinated care**

59. There was an overwhelming appeal from our engagement for better co-ordinated care: joined up services and systems, care planning, shared care records, integrated IT systems, better co-ordination and communication between health and social care professionals, community services, and family involvement. People said that trying to access help and support at such a stressful time can be extremely challenging; how to access support and who to contact was not clear to many. Disagreements over who should fund care and agencies that were not responsive to people's needs and preferences were identified as causing particular problems.

*“Care for people at the end of life will often involve multiple health and social care providers, working across commissioning boundaries and in a variety of care settings. Therefore, good communication and coordination between professionals is critical”*

*“As a doctor working in Palliative Care, I knew my Dad fulfilled the eligibility criteria for NHS Continuing Healthcare (CHC), but when I asked the GP for an assessment I was told they did not have continuing healthcare in his area - only the DS1500 form. Eventually, after seven months and numerous phone calls and emails he was assessed for CHC. This involved several people, most of whom had never met him before, sitting in a room with him asking my Mum and I to explain the difficulty of caring for him because of his disability, dementia and behaviour. At the end of the assessment he turned to us and said “I’m such a burden to you.” His funding was approved. Three months later he died.”*

60. People said that:

- they wanted organisations to have shared access to information, a single number to contact and support staff (care coordinators) to help them “navigate” the system;
- they felt that having a named professional responsible for their care at the end of life would improve coordination and ensure preferences are met; and
- bereaved carers reported in the 2013 VOICES-SF survey that the planning and coordination of care was often extremely poor; less than half (42%) of respondents thought that community services were “definitely” well coordinated and less than a third (31%) thought that hospital services “definitely” worked well together with GP and other services outside hospital.<sup>57</sup>

61. Current initiatives to improve planning, information sharing and coordination include:

- Primary care practices in the UK receive additional payment for maintaining a register of palliative care patients, meeting regularly to discuss patients’ needs, and recording their preferred place of death.
- Electronic Palliative Care Coordination Systems (EPaCCS), which are dynamic records of information about a person’s care and preferences, have helped as many as 80% of those people identified on the system to die in their preferred place, where they have been implemented. However, many areas in England are still not covered by EPaCCS, and in many of these areas it may be difficult for the full range of health and social care providers to access the system. It will also be important for these areas to ensure that once an EPaCCS is in place, it reaches a significant percentage of the overall population who have end of life care needs, and in particular people with conditions other than cancer.

## **Theme: The right care of the right quality with the right staff**

62. People felt that a person's preferences regarding end of life care should be shared, preferably electronically, with all who need access, to ensure the right information is available at the right time.

*“People often have to explain the same thing to different staff, which can not only be frustrating and time consuming but can also make it feel as though no-one is listening.”*

63. Research has shown that advance care planning can be used to establish a person's wishes about their care at the end of life and this increases the likelihood of their wishes being met.<sup>58 59</sup>

64. Staff skills and training were considered paramount. Anyone involved in caring for the dying should have the relevant training and should be valued. Care delivered with compassion, maintaining dignity and respect, is fundamental to high quality care. Respondents felt that training should be focused in the following areas: communication skills, effective information provision, advance care planning, palliative care, how to identify when someone is dying, communicating with people who have visual or hearing impairments, pain management, and needs around specific conditions such as dementia.

65. End of life care for the most part is provided by non-specialist staff; the one million health and one-and-a-half million social care workforces will come into contact with people approaching the end of life and their families at some point.<sup>60</sup> A study of local GPs and community nurses found a high level of knowledge concerning key issues in pain management and syringe driver use that should equip them well for their central role in palliative care.<sup>61</sup> However, we know from other surveys that: nurses say they do not have the time to discuss end of life care and that 25% of GPs have never initiated a conversation with one of their patients.<sup>62</sup> A further survey of Royal College of Physician members in 2012 reported that two thirds of physicians had attended no end of life care training in the previous 5 years.<sup>63</sup> An appraisal of literature reviews on end of life care for minority ethnic groups in the UK found that many studies highlighted the need for training in care that is sensitive to cultural differences.<sup>64</sup>

66. Successful honest conversations depend on staff having received the right training. Discussions about options, between people and clinicians, are essential for individuals to express choices about where and how to spend the end of life. Research by Marie Curie, however, showed that some GPs found it difficult to raise and discuss death and dying, particularly with people diagnosed with conditions other than cancer,<sup>65</sup> including dementia.<sup>66</sup>

67. Further research studies have explored GP communication with people with heart failure approaching the end of life. The studies found that:

- End of life care is rarely discussed, with conversations focusing largely on disease management.
- Clinicians are unsure how to discuss the uncertain prognosis and risk of sudden death, fearing they may cause premature alarm and destroy hope.
- Clinicians wait for cues from people before raising end of life care issues.<sup>67</sup>

68. The National Survey of Bereaved People (VOICES-SF) 2013 found that 31% of people whose loved ones died from cardiovascular disease felt that their relative “definitely” did not know they were likely to die, compared to just 5% for cancer.<sup>68</sup>

## Building a national choice offer

69. We know that in many places, many people have their conditions identified in a timely way, and their preferences and choices are recorded on individual plans of care, which are shared among all healthcare staff and are regularly reviewed in line with the person's changing wishes. However, we know that for many people this is not the case, and their choices and preferences are not heard or delivered.

70. A 'national choice offer', made to everyone regardless of where they live, their individual circumstances or their clinical condition, should be the mechanism for ensuring that good end of life care happens everywhere.

71. Our engagement exercise, taken together with academic studies and wider evidence, has provided us with a clear view on the choices people have said they would like to make to ensure that they have a good experience at the end of their lives.

72. First and foremost amongst these was that many people wanted a choice of location of care and death. In our engagement this was not always expressed as the choice to receive care and die at home; instead people said they wanted a choice in general about the place of care and death. Of course, this necessarily needs to be a place which is appropriate to the level and complexity of care that people need.

73. Many other respondents focused on people wanting choices relating to specific, individual elements of care such as levels of pain relief, involvement of family and loved ones and wider elements of their treatment.

74. We believe that asking everyone who is approaching the end of their lives a single question "what's important to you?" about their end of life care can open the gateway to an honest and informed dialogue that ensures people have choices and care focused around their needs. Therefore we advise that a national choice offer for end of life care be as follows:

**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:**

- **made as soon as is practicable after it is recognised that the person may die in the foreseeable future;**
- **based on honest conversations with health and care staff, which supports the person to make informed choices; and**
- **consistently reviewed through conversations with health and care staff.**

75. In enabling any choices and preferences that the person has made, clinical necessity must always be a major factor. We advise that health and care staff be as open as possible in offering these choices, and fully outline the implications of people's choices and individual care preferences to ensure that the person remains in control of their own care.

76. We also know that, for some people, their choice in relation to end of life care will be to have no discussions about their care. This personal choice must be recognised, noted and respected by those involved in the individual's care. Choice can only be offered; there is no obligation on the individual to take this up.

## **Good end of life care**

77. However, alongside the clear views on choices expressed in our engagement, many people said that they wanted things such as support for physical and emotional needs and access to the right care from well trained staff. Furthermore, many people said choice is not possible without good quality care already being in place.

78. We all agree that person-centred care, delivered with compassion and expertise, is not something that should be subject to choice; it is what all people should have in all instances. We also agree that greater choice can only be offered from a basis of good care for everyone. It is important therefore that we make clear what good quality end of life care is to enable this national choice offer.

79. A great deal of work has already been done to identify what is required to give people good end of life care. Good end of life care enables people to live in as much comfort as possible until they die, and to make choices about their care. It means providing support that meets the needs of both the person who is dying and the people close to them, and includes management of symptoms, as well as provision of psychological, social, spiritual and practical support.

80. The NICE Quality Standard for End of Life Care for adults, published in 2011 and revised in 2014, provides a comprehensive view of the high quality end of life care that should be provided by health and social care to all adults approaching the end of life, regardless of the underlying condition or setting.<sup>69</sup> It sets out an integrated approach to the provision of services as fundamental to the delivery of high-quality care to people approaching the end of life, their families and carers through 16 quality statements, grouped under six overarching themes:

<b>NICE Quality Standard for End of Life Care for Adults</b>	
<b>Theme</b>	<b>Quality Statements</b>
Identification, information and assessment	<ul style="list-style-type: none"> <li>– QS1 Identification</li> <li>– QS2 Communication and information</li> <li>– QS3 Assessment and care planning</li> </ul>
Holistic support	<ul style="list-style-type: none"> <li>– QS4 Physical and psychological</li> <li>– QS5 Social, practical and emotional</li> <li>– QS6 Spiritual and religious</li> <li>– QS7 Families and carers</li> </ul>
Access to services	<ul style="list-style-type: none"> <li>– QS8 Coordinated care</li> <li>– QS9 Urgent care</li> <li>– QS10 Specialist palliative care</li> </ul>
Last days of life	<ul style="list-style-type: none"> <li>– QS11 Last days of life</li> </ul>
Care after death	<ul style="list-style-type: none"> <li>– QS12 Care of the body</li> <li>– QS13 Verification and certification</li> <li>– QS14 Bereavement support</li> </ul>
Workforce	<ul style="list-style-type: none"> <li>– QS15 Training</li> <li>– QS16 Workforce planning</li> </ul>

81. This integrated, person-centred approach is reflected in the 5 Priorities for Care identified by the Leadership Alliance for the Care of Dying People, a coalition of 21 national organisations.<sup>70</sup> These Priorities act as a guide for health and care staff in caring for people in the last days and hours of life:

***The Priorities for Care are that, when it is thought that a person may die within the next few days or hours:***

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

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

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

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

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

82. Together, these two aligned guides provide a clear framework for the delivery of good end of life care, which can be easily recognised by those receiving and giving care.

## ***How can we ensure good end of life care and support choice for everyone?***

83. From an analysis of our engagement, we are confident that many people receive good end of life care. Approximately two thirds of those involved said that their loved one's experience was positive, with negative experience reported by a third of people. This is consistent with other evidence on overall experience in end of life care, such as the National Survey of Bereaved People (VOICES-SF) 2013, in which 76% of respondents rated the end of life care received by their relatives as outstanding, excellent or good.<sup>71</sup>

84. However, too many examples of poor care show us that in some areas, and in some instances, poorly coordinated and delivered services stop choice from happening. To be in a position to make a national choice offer to all people, there first needs to be a universally good service as platform for delivery. This is a key responsibility for decision-makers and commissioners at every level.

85. Some of the barriers to good end of life care are caused by services not being commissioned in line with the NICE Quality Standard. Some are caused by organisations not working in a coordinated way and as a result, hindering efforts to support, enable and deliver people's preferences.

86. We believe that whatever the circumstances or services available, every interaction with a health or care professional can and should support people's preferences. There will always be choices and preferences to be made, and these are best done as part of a consistent, informed and informative dialogue, not least in discussing what choices are achievable or appropriate to each person.

87. However, we also know that where there are high quality, well coordinated services in place, people receive good care and their choices can be met. This should happen for everyone. There are a number of key features that can be brought together to deliver good end of life care for all.

88. The first of these is **early identification** of people who are in the last year(s) of life. There have been improvements in this area, supported by initiatives such as Dying Matters' *'Find your 1%' campaign*<sup>72</sup> and the British Heart Foundation/Marie Curie's Caring Together programme in Glasgow.<sup>73</sup>

89. However, too many people who are dying are still being identified too late. The issue is particularly apparent in the case of people with conditions other than cancer.<sup>74</sup> We know that these people are less likely to have their end of life care choices and preferences discussed and met,<sup>75</sup> and have comparatively less access to specialist palliative care when they need it.

90. In many cases, this is due to uncertainty around prognosis. It is difficult to discuss death and dying when it is likely to happen soon; it is even harder to discuss this when the possibility of dying is less imminent. Many staff and people find themselves in this situation due to the uncertainty that is particularly, but not exclusively, related to chronic conditions other than cancer. This leads to people not getting early access to palliative and end of life care, which restricts their choices. It is important to recognise that it is never too early to express preferences and plan for end of life care. Every encouragement should be given to professionals and the public to initiate these discussions as early as possible and at least at the point when dying becomes a possibility, not to wait until it becomes a certainty.

***Case study: British Heart Foundation 'Caring Together'***

The British Heart Foundation Scotland, Marie Curie Cancer Care and NHS Greater Glasgow and Clyde are working together to provide better end of life care for patients with heart failure. The unpredictable trajectory of heart failure means that many patients are not identified for end of life care at a time far enough in advance for them to fully benefit. Prognostic tools, used in the Caring together pilot, however, have shown that by assessing patients against certain criteria, Heart Failure Specialist Nurses can identify a significant proportion of those entering the end of life phase of their illness. The average time from referral to death for Caring Together patients is 35 weeks. This longer period has allowed clinicians to address holistic end of life care needs.

Everyone referred to Caring Together receives a holistic assessment. A 'one-stop shop' has also been established in hospital, where benefits and social care assessments can be carried out at the same time. Anticipatory care plans are then developed in partnership with the individual, family and carers, on how needs can be met. Care plans are held electronically, forwarded to all involved in a person's care and are accessible to unscheduled care providers. All patients on the Caring Together programme are allocated a care manager to act as the patient's main point of contact for information, advice and support. Caring Together patients are more likely to be cared for and die in their preferred place.

91. One potential way of improving this situation could be greater involvement of palliative care specialists in care led by other specialists focused on the specific condition. Greater joint working (sometimes referred to as parallel planning, in particular in paediatric medicine) could allow for earlier discussions and identification of palliative care needs to take place alongside ongoing treatments. **We advise 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.** This will require co-operation and active leadership within and across organisational boundaries.

92. We know that good, early care planning, tailored to people's needs and preferences at the end of life is one of the things that makes the most difference to people in terms of the care they experience. One of the reasons why early discussions about care planning are so important is because people may lose capacity to make decisions about their care as their condition worsens.

93. The Mental Capacity Act 2005 and its accompanying Code of Practice established a clear framework about how decisions should be taken when it is determined that a person lacks capacity to make a decision for themselves. Where a person lacks capacity to make a decision about their care or treatment, the Act makes clear that the person who makes the decision on their behalf (which could be a health or care worker or relative) must act in the best interests of the person, including making decisions about withholding and withdrawing treatment. In doing so, decision-makers must take account as far as possible of the known wishes of the person, and consult with relatives and colleagues as appropriate to help inform their decision.

94. Advance care planning and good, early care planning in general, play a crucial role in conveying these wishes and ensuring individual care choices and preferences are recorded and delivered. These wishes might take the form of refusing a specific treatment, making an advance statement setting out their wishes and preferences, or appointing people under a Lasting Power of Attorney to make decisions on their behalf.

95. It is, therefore, vitally important that the full range of information on what people want - from location of care and death, to how much involvement they want from relatives and those close to them, to advance care planning and legal documents such as advance decisions or Lasting Power of Attorney - should be recorded and shared between all staff and people involved in the individual's care, if this is what the individual wants.

96. We believe it is vital that everyone with end of life care needs is offered an individual plan of care which sets out what is important to them. As well as acting as the basis for an individual's care in the final year(s) of their life, these plans should allow a dialogue between the individual and health and care staff to be built which enables preferences to be refined and reviewed as circumstances change.

97. However, to ensure that people's choices and preferences are acted upon, all health and care staff must have access to what people have told them they want. A key tool in enabling the sharing of individual care needs and preferences are electronic data sharing systems such as **Electronic Palliative Care Coordination Systems (EPaCCS)**. EPaCCS have expanded since their use was pioneered following the recommendation in the End of Life Care Strategy (2008).<sup>76</sup> A recent evaluation of established EPaCCS demonstrated that they have enabled up to 80% of people who were included in EPaCCS to die in their preferred place of choice, which delivered cost savings to the NHS through reductions in acute hospital admissions and bed use.<sup>77</sup>

98. The Government has demonstrated its commitment to the expansion of the coverage of EPaCCS through work led by NHS Improving Quality, which aims to raise overall EPaCCS coverage to 70% of all Clinical Commissioning Group areas by April 2015.

99. We think that the benefits of EPaCCS or equivalent systems should be available to all people, and all health and social care organisations, and advise **that EPaCCS or equivalent system coverage be raised to 100% of all localities, and that these systems are fully accessible to view and update for all involved in the provision of end of life care services, in particular social care.** The advance care plans that they contain should also be **explicitly linked in with the care plans offered to all people with a long-term condition**, to provide a seamless continuum of care planning through to the end of life for this growing section of our society. Ensuring that an EPaCCS record is offered to everyone approaching the end of life, not solely or mainly people with cancer, is of vital importance.

100. Health and care staff must be ready to meet the challenge of delivering people-centred end of life care. This means that they must be organised in a way that supports choice and good care, and supported and trained so that they have the competence and expertise to deliver.

101. Many people who responded to our engagement highlighted the need for **24/7 community end of life care**. 24/7 care is recognised as a cornerstone of palliative and end of life care best practice and vital to enabling people to die at home if they wish to do so.<sup>78</sup> The NICE quality standard for end of life care includes provision of 24/7 holistic support, co-ordinated care, urgent care and access to specialist palliative care. Academic studies have shown the link between various models of community care and high levels of people being able to achieve a key choice, the location of their care and death.<sup>79 80 81</sup> They have also identified variation in type and level of provision nationally.<sup>82</sup>

102. We advise that **each local area establishes 24/7 community end of life care**. Exact models of provision would have to be locally determined to meet local needs, but as a minimum they should feature increases in both specialist and non-specialist clinical time with people, greater use of social care services and 24/7 access to telephone support. These increases

should be such that people can access assessment, care and support with a level of expertise and within a timescale appropriate to their needs and preferences at any time of the day or night.

103. Increasing community capacity can be challenging, especially in the current financial situation, but new service models are strongly supported within NHS England's *Five Year Forward View*. To achieve this it will be important that health and social care commissioners work jointly with providers to ensure that services are designed to reflect the choices people want to make. We know that if more people are treated in community settings, then the NHS can make savings in the acute sector.

#### **Case study: Sue Ryder Partnership in Excellence for Palliative Support (PEPS)**

Sue Ryder's PEPS service in Bedfordshire is a partnership of 15 organisations which supports the patient and their family to stay in their preferred place of care. It has been in place for three years and evidence shows that nearly half (46%) of patient and carer calls were made 'out-of hours' (after 5pm, before 9am). Of these, 79% of 'out of hours' calls were made by a relative or carer and 21% by the patient. In the year to May 2014, the service avoided 166 hospital admissions. Since January 2014, the local ambulance provider has worked closely with PEPS to change ambulance service patient pathways and ways of working. Under these arrangements, when a call is made to an ambulance, crews are able to see if a person is known to the PEPS service via their computer aided dispatch system and contact PEPS for further information (e.g. on preferred place of care or DNACPR status) once the crew has attended the call as normal and stabilised the patient. PEPS can then coordinate the patient's care in the community according to clinical need and patient preference. A minimum of two admissions a week are being avoided in this way through closer working with the ambulance service.

104. It is now time for concerted effort to achieve this change. We know that this would have major implications, not least in workforce planning. The specialist palliative care workforce surveys carried out by the National Council for Palliative Care and Public Health England, most recently in 2013,<sup>83</sup> raise the possibility of a growing recruitment and succession crisis in specialist palliative care nursing, with higher proportions aged over 50 than in nursing more generally. The RCP has identified a 25% shortfall in consultants in palliative medicine by 2020.<sup>84</sup> We advise that Health Education England (HEE), **in planning for future workforce numbers, should work with commissioners and providers to agree both specialist and non-specialist palliative care workforce requirements, in acute and community settings, to deliver**

**improvements in end of life care.** We further advise that this planning takes into account how **breaking down organisational boundaries can allow staff currently working in acute settings to play a greater role in delivering care in community settings.**

105. Regardless of location, to ensure that services meet individuals' needs fully, health and care staff need to have the knowledge, support and skills to provide high quality care. Respondents to our engagement exercise highlighted this as a key element of the delivery of good care and choice.

106. HEE has a clear duty to ensure an effective system is in place for education and training in the NHS. Skills for Care is responsible for developing the adult social care workforce in England. We advise that HEE, Local Education and Training Boards (LETBs) 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.** These specific skills should enable staff to understand the importance of people's preferences and how to deliver them, and emphasise the importance of good communication in end of life care.

#### ***Case Study: Quality End of Life Care for All (QELCA) Training Programme***

The QELCA programme, originating from St. Christopher's Hospice, is designed to promote the delivery of high quality end of life care in the acute setting. The programme encourages staff to think about their own care choices at life's end, which they can then share with their friends and families. LOROS Hospice and University Hospitals of Leicester NHS Trust have collaborated to provide a 5 day training programme for senior ward nurses from the acute trust. Based at the hospice, this includes 2 days observation of practice followed by 6 action learning sets over 6 months. This has enhanced practice at end of life, with nurses focusing on making changes relevant to their ward area thus enabling patients to make informed choices when advance care planning and improving the scope of the care experience for patients, their relatives and carers.<sup>85</sup>

107. As well as having the skills to deliver good quality care, staff need both the time to deliver and clarity about responsibilities. Recent initiatives from the Government have seen a named senior clinician provided for people with the most complex health and care needs,<sup>86</sup> and for people being cared for in acute settings.<sup>87</sup> We advise that there should be **a named senior clinician with overall responsibility** for each person who is receiving end of life care. There should also be explicit arrangements for cover for this role in times of absence.

108. To further the link between the individual and those delivering their care, respondents to our engagement highlighted the high quality service given by individuals acting as a single point of contact for the person and those important to them regarding issues with the services and treatments required. These ‘care coordinators’ were seen as invaluable in either navigating the health and care system on behalf of people or offering advice on services. We advise that the **option of a ‘care coordinator’ be offered to everyone with end of life care needs.** This role could be fulfilled by either a care or health professional, or a family member, friend or carer, but it should be an individual with authority and expertise who can deliver results for the individual. There should also be explicit arrangements for cover for this role in times of absence.

109. Health and social care services need to work together to ensure the provision of good end of life care, especially in community settings. Many respondents to our engagement told us about the delays in organising care packages for their loved ones caused by the needs and financial assessments required **to access social care support.** This can mean people staying in hospital unnecessarily, when they may want to be at home or in the community.

#### ***Case Study: Northampton Health Care NHS Foundation Trust end of life care practice development team***

The Northampton Health Care NHS Foundation Trust end of life care practice development team work across Northamptonshire. In 2013/14 they provided education and support to over 2000 health and social care staff on topics such as advance care planning, DNACPR, communication skills and practical care skills for novice carers. The aim was to offer real time education and support that would translate directly into practice:

*“I had to call a GP to a 96 year old lady whose health was severely deteriorating due to what was believed as cancer although not diagnosed as the lady did not want any intervention. When the GP arrived he stated that the lady needed to be admitted to hospital as she was in Heart failure. Myself and my team challenged the decision and explained that the lady did not want intervention and her choice was to die at home. The GP was reluctant as he felt we should be treating the condition so I asked him for a second opinion. After taking advice from a Senior Doctor he made the decision to leave the lady here and she was set up with a syringe driver and passed away peacefully a few hours later....if I had not attended the workshops I would not have had the confidence to challenge the GP and I have no doubt the lady would have passed away in hospital. The lady’s family could not be more thankful of the way their Mother was cared for and that her last wishes were upheld.”*

(A care home manager)

110. Delays in organising care, or restrictions on it, when people are at the end of their lives are unacceptable and limit choice. This issue was highlighted by both the Independent Palliative Care Funding Review<sup>88</sup> and the Dilnot Commission on the Funding of Long-Term Care.<sup>89</sup> We advise that the Government implement **a clear policy to make access to social care for people at the end of life fast and free.**

**Case Study: STARS**

The STARS (Support, Talk, Act, Review, Share) Liverpool Care service is commissioned by Liverpool Clinical Commissioning Group and delivered jointly by Crossroads Care Cheshire, Manchester and Merseyside, and Marie Curie. STARS provides high quality personal and social care services delivered by staff trained in end of life care (including registered nurses, Carer Support Workers and Health Care Assistants with a qualifications in End of Life Care). Care is provided in the patient's place of choice (usually their home setting) during the last 12 weeks of life. The service contributes to the social and emotional wellbeing of the individual and their carer. It enables patients to die at home, in a familiar and comfortable environment, and to feel supported in doing so. More people are dying in their place of choice than before STARS was in place.

111. The Care Act 2014 also created a legal obligation for local authorities to meet **a carer's eligible needs for support.** Responses to our engagement exercise show the importance of support for carers in allowing individual choices on location of care and death to be met. An advance care plan, held on EPaCCS or equivalent system, should set out who the carers will be, and their needs should be regularly assessed by healthcare staff responsible for their loved one's care, with support being offered as appropriate through the period of care-giving and the period of bereavement. Staff should seek the consent of the people concerned (the person and their carer) so that information can be shared with local authorities for a formal carers' assessment to take place.

112. Alongside formal carers, we know that family members play a vital role in many people's end of life care. We advise that **family members and carers should be involved in discussions about care preferences** where the dying person has said they should be, and this is appropriate and helpful.

113. We know that the experience of dying, death and bereavement, like all major life events, has an impact not only on individuals but also the communities in which we live. Very often the greater part of the care and support that people receive will come from their family and communities, rather than the health and care sector. As NHS England's *Five Year Forward View* has acknowledged, we need to "harness the renewable energy" of families, communities, employers, schools, faith and community groups and others who have an important contribution to make.

114. This is particularly true at the end of life. We need to rebuild **capacity and confidence in society at large to discuss, plan and provide practical help and support for each other through dying death and bereavement**, if the things that are truly important to people are to happen. Examples of this include employers supporting staff with caring responsibilities and flexible policies for bereavement leave and schools including dying death and bereavement in Personal Social Health & Economic Education (PSHE) and Citizenship classes.

115. Choice at the end of life is likely to largely remain unattainable without a continued focus on changing society's approach to how we talk – or don't talk – about dying. The Dying Matters Coalition has been leading the way in raising public awareness about the importance of talking more openly about dying, death and bereavement and supporting people to make their choices known – and has been having a growing impact. We are also encouraged that a range of initiatives are either in place or being developed to support health and care professionals in having what can be difficult conversations about end of life care. Both approaches are invaluable alongside each other and must be encouraged, supported and sustained.

116. We therefore advise that **the work of the Dying Matters Coalition should be encouraged, supported and sustained**, as should initiatives aimed at building the confidence of health and care professionals on these issues. Together, these approaches should help ensure a 'proper national conversation about dying', as recommended by the Independent Review into the Liverpool Care Pathway,<sup>90</sup> which will widen public understanding and support the development of choice.

117. We also support **public health approaches to end of life care**, for example the Dying Well Community Charter,<sup>91</sup> published by the National Council of Palliative Care and Public Health England, and the Compassionate Cities approach<sup>92</sup> and advise that **health and social care commissioners include initiatives to support and strengthen community resilience and involvement in end of life care in their plans.**

#### ***Case Study: Future Matters (Islington)***

This project is a community based approach to raising awareness of death and dying and improving end of life care planning. Islington Clinical Commissioning Group commissioned a local community training provider working together with Age UK, to deliver the Future Matters programme in Islington over a 2 year period (2013-2015). The programme has focused on training and supporting volunteers, from a wide range of third sector organisations and community groups, to become Future Matters (End of Life Care Planning) Volunteers. Through the programme, volunteers acquire the knowledge, skills and tools to raise awareness of the importance of end of life care planning, and enable and support communities to put their end of life care plans in place.

## ***How much would a national choice offer cost?***

118. Overall NHS, social care and voluntary sector spending on care in the final months of a person's life is considerable. However due to end of life care being carried out by a range of health and care staff in the statutory and voluntary sector, both specialists and generalists, and in a series of different locations, it is difficult to place an exact figure on the current cost.

119. In 2011, the Independent Palliative Care Funding Review estimated that annual NHS spending on adult specialist palliative care was around £460million.<sup>93</sup> A recent report by the Nuffield Trust suggested that the cost of providing local authority funded social care for people at the end of life was around £1,000 per person, which for an end of life population of 350,000 equates to £368million.<sup>94</sup>

120. This Review's terms of reference stated that our advice should "take the form of costed options, as far as possible within the evidence that is currently available". To establish a clear picture on both the likely level of current spending on people at the end of their lives, and the cost and savings related to improving services and expanding the use of non-hospital services, we have created a model of the cost of end of life care services covering individuals' needs over a three month period. Full details of this work can be found at Annex B of this report.<sup>95</sup>

121. This model covers a range of services including: NHS acute and community costs; specialist palliative care staffing; hospice inpatient costs; and social care costs including care home fees, domiciliary home care, and equipment and adaptation costs. This model is based on "per person" service use, with different levels of need incorporated, ensuring the individual is central to the process.

122. In creating this model, we have been able to build an estimate of current spending on end of life care as a baseline. We know that there is significant variation of services across England, so we have taken an 'average' view to arrive at a baseline figure. We estimate that the current annual spending on care for people in the final year of life in England, covering NHS specialist and non-specialist services and social care, is around £3.9billion. Of this, approximately £2.7billion is on NHS services, £450million is on services provided by the voluntary sector (mainly hospices), £360million is on social care services funded by local authorities. The remaining £430million is spent on social care services by those who fund their own social care costs.

123. The model evaluates the cost of three possible options, which relate to increasing provision of end of life care services to enable the offer and delivery of choice. These three options are:

- **Option 1** – Maintaining what is currently available across the country now (no change).
- **Option 2** – Increased service availability that would enable choice and improve care.
- **Option 3** – Further increased availability and additional services that would enable choice and improve care.

124. Moving from option 1 to option 2 sees an increase in the usage of community services, such as district nursing and allied health professionals (such as occupational therapists/physiotherapists/dieticians), pharmacists, social care services and specialist palliative care teams per person. Hospital unit costs decrease to reflect that improvement in community services and the more widespread provision of specialist care should reduce the number of admissions and A&E visits per person. Option 2 of the model offers the additional workforce capacity to allow community services to be put in place to ensure 24/7 care; exact models of provision would have to be locally determined to meet local needs. Option 2 would also entail increased usage of hospices and increased incremental cost to the voluntary sector.

125. Option 3 is more aspirational and builds on option 2. It incorporates additional, more innovative methods of care such as telecare and telehealth. It also includes a further increase in usage of the previously mentioned services to ensure individuals can have their choices met. Further details on the services included in the three care options and their incremental increases can be found in Annex B.

126. As well as three options covering increasing services, the model also envisages three different scenarios where differing proportions of people die in hospital, hospice, home or care home. These three scenarios are:

- **Scenario A** – There is no change as to where people die currently (based on the latest available death registration data).
- **Scenario B** – More people die in their usual place of residence or in a hospice inpatient bed. In this scenario hospital deaths decrease by 20% and are redistributed to usual place of residence proportionally according to latest ONS death registration data.
- **Scenario C** – As scenario B, but with a greater proportion of people dying in their usual place of residence and hospice inpatient beds. As a result there is a reduction in hospital deaths by 40% compared to scenario A. These deaths are then redistributed to the individual's usual place of residence proportionally according to ONS death registrations.

127. It should be noted that 'place of death' has been used as a proxy for place of care and death in the modelling, because there is more reliable data about where people die than about where they are cared for. However, it should be remembered that any real world change based on these scenarios would, of necessity, involve changes in place of care as well as place of death.

128. From the results of our engagement, we are confident that in offering greater choice in end of life care, many people would see place of care and death as the most important choice to them, with others prioritising other choices such as levels of pain management.

129. More end of life care services would be needed to enable the delivery of these choices. Relating this to the model, this means a movement from option 1 to option 2 and/or option 3. Presuming that the majority of people would prioritise the place of care and death in the event of a choice offer, we would move from scenario a to scenarios b and c.

130. Table 2 shows the incremental costs to the state of each option and scenario when compared with baseline as the situation is believed to be now (option 1 under scenario a).

**Table 2: incremental costs (£m) to NHS and local authority funded social care of different levels of service and location of care**

<b>Incremental Cost (£m*)</b>	<b>Scenario a</b> (no change)	<b>Scenario b</b> (20% reduction in hospital deaths)	<b>Scenario c</b> (40% reduction in hospital deaths)
<b>Option 1 (Baseline services)</b>			
<b>(Total)</b>	<b>–</b>	<b>£40</b>	<b>£100</b>
NHS spend	–	-£30	-£20
Social Care Spend	–	£70	£120
<b>Option 2 (Better service availability enables choice)</b>			
<b>(Total)</b>	<b>£50</b>	<b>£130</b>	<b>£200</b>
NHS Spend	£30	£30	£50
Social Care Spend	£20	£100	£150
<b>Option 3 (Even better service availability &amp; extra services)</b>			
<b>(Total)</b>	<b>£610</b>	<b>£730</b>	<b>£830</b>
NHS Spend	£560	£580	£610
Social Care Spend	£60	£150	£220

\* Totals may not sum due to rounding to the nearest £10m.

131. The costed options presented in table 2 offer a variety of possible service levels and configurations. The incremental cost to the state for NHS and social care services in each option takes into account the cost of enhancing community services, minus the savings in the acute sector from treating people in their own homes and care homes, such as reductions in hospital stays and unplanned admissions.

132. In addition to the costs to the state for NHS and local authority funded social care services, the options we have identified have additional cost implications for the voluntary sector, mainly through the delivery of additional hospice inpatient services, and for individuals who would be required to fund their own social care services. These costs are reflected in table 3 below.

**Table 3: incremental costs (£m) to NHS, voluntary sector and social care (local authority funded and self-funded) of different levels of service and location of care**

Cost (£m*)	Scenario a (no change)	Scenario b (20% reduction in hospital deaths)	Scenario c (40% reduction in hospital deaths)
<b>Option 1 (Baseline services)</b>			
<b>(Total)</b>	<b>£0</b>	<b>£180</b>	<b>£410</b>
NHS spend	£0	-£30	-£20
Charity Spend	£0	£50	£160
Social Care Spend	£0	£70	£120
Self-funding Spend	£0	£80	£150
<b>Option 2 (Better service availability enables choice)</b>			
<b>(Total)</b>	<b>£100</b>	<b>£320</b>	<b>£580</b>
NHS spend	£30	£30	£50
Charity Spend	£0	£50	£170
Social Care Spend	£20	£100	£150
Self-funding Spend	£50	£150	£210
<b>Option 3 (Even better service availability &amp; extra services)</b>			
<b>(Total*)</b>	<b>£710</b>	<b>£970</b>	<b>£1,260</b>
NHS spend	£560	£580	£610
Charity Spend	£0	£50	£170
Social Care Spend	£60	£150	£220
Self-funding Spend	£90	£190	£270

\* Totals may not sum due to rounding to the nearest £10m.

133. The two scenarios under option 1 offer savings to the NHS through more people being treated in community settings. However, there are significant additional social care costs under these scenarios. More importantly, we do not feel that these options would support the improvements in care needed to deliver greater choice in end of life care for everyone, as they do not provide for greater provision of community health services.

134. The scenarios under option 3 would require significant additional investment in both NHS services and social care. We believe that scenario 3a is unworkable, as in the event of greater choice we presume, based on available evidence, that people would choose to be cared for and die in their own home or usual place of residence (normally a care home), and this scenario provides for no additional community health services.

135. We believe that scenarios 3b and in particular 3c provide for the level of care that would guarantee the offer and delivery of a national choice offer in end of life care for all. These scenarios envisage care which is fully in line with all of the statements in the NICE Quality

Standard for End of Life Care, for all locations, with people's choices and preferences met. We believe that this level of service, and substantial investment from Government, is the only guarantee of a comprehensively delivered 'national choice offer' for end of life care.

136. However, we accept that in the current financial climate, at a time of great demands on NHS and social care services, this level of additional investment on an annual basis is unlikely. Therefore, the scenarios under option 2 offer a realistic level of improvement in end of life care which would still support a national choice offer. These scenarios feature a relatively modest overall increase in spending from the NHS, and a sliding scale of increasing spending on social care as more people are treated in community settings. There are additional costs on the voluntary sector in each of these scenarios, plus additional costs for people who fund their own social care.

137. We believe that scenario 2a is unworkable for the same reasons outlined above for scenario 3a. This means that scenarios 2b and 2c remain as the only viable options for improving end of life care to enable greater choice. We know that any offer of choice would see a gradual movement away from the delivery of care in acute settings to community settings (and to a much lesser extent, hospices). Option 2b envisages this to be a 20% reduction in deaths in hospital, which we feel is a realistic level to plan for in the coming years. We believe that the investment identified in this option will give end of life care a long-awaited boost and deliver long term improvements in people's overall care as well as choice at the end of life. **Therefore, we advise that the Government identifies the investment in option 2b in the next spending review to deliver a national choice offer in end of life care.**

## ***Delivering greater choice in end of life care***

138. We fully recognise that to establish a national choice offer in end of life care for everyone requires significant investment, especially in relation to social care services, and significant service reorganisation to deliver the theoretical savings to the NHS achievable from moving services out of hospital to make the necessary investment in community services possible. We also recognise the burden that more people being cared for and dying in a place of their choice is likely to have on the voluntary sector.

139. We need to give the NHS, social care and the voluntary sector the time to build the services; but we must set a deadline to ensure that the services and systems are put in place so that people get the choices that they want and improve their experience at this important time of life.

140. We advise that the Government finds the investment identified in option 2b above and introduces **the national choice offer for all people receiving end of life care by April 2020**, backed by **a 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.**

141. **The offer should be included in the NHS Choice Framework and supporting information for patients should be published on the NHS Choices website.** To ensure that the system is ready to make and deliver this offer, we advise that **100% coverage of EPaCCS (or equivalent system) be achieved by April 2018, and every local area should establish 24/7 end of life care for people being cared for outside of hospital by the end of 2019.**

142. We also recognise that there are areas we have highlighted where further work would be helpful to draw an exact picture of costs. This includes staff training costs, the cost of care coordinators, the cost of a proactive service offered by a named lead clinician for everyone in receipt of end of life care, and bereavement support. As well as these recurring costs, there are also potential one-off, capital costs to enable the delivery of better care, such as home adaptations and new technology.

143. However, we know that many of the savings derived from reductions in unplanned admissions and hospital stays, which have been identified at a national level in our model, can be achieved at a local level, such as the Midhurst Macmillan service where earlier referral avoided around 20% of total costs in the last year of life.<sup>98</sup>

144. Furthermore, many of the key elements which will enable good care and choice need not cost additional money. For example, the benefits to both the quality of care and health costs delivered by establishing an EPaCCS are well documented.<sup>99</sup> These savings are down to the way that EPaCCS and equivalent systems hold and share details of the individual's plan of care, leading to better coordinated care, fewer admissions to hospitals and shorter hospital stays.

145. We know that the majority of areas in England should have an operational EPaCCS by April 2015. Many of these and other areas will already offer the services needed to deliver choice, as evidenced by the majority of respondents to our engagement exercise stating that their care was good.

146. The places which already offer good care and enable choices in end of life care should continue to do this, ideally in line with the national choice offer we have proposed. We want these areas to be seen as beacons of good practice, and advise that their work **should be shared more widely to show others how it is done.** This should prompt action to deliver greater quality and choice from other areas that are close to having the services needed, and also show areas where good care and choice are not always being delivered potential ways forward.

***Case Study: The Midhurst Macmillan Service***

This is a community-based, consultant-led, specialist palliative care service, set up in response to the sudden closure of a Macmillan Cancer Support palliative care unit. It is an innovative model of successful home-based specialist palliative care services with co-operation between the NHS, the voluntary sector and the local community. The service is hosted in Sussex NHS Community Trust and uses the Trust's administrative, human resources and finance systems. The service and its staff are located at Midhurst Community Hospital, which acts as a base for the team; there are no palliative care beds at the hospital, but they have access to a treatment room for outpatient appointments.

The service operates seven days a week with an out of hours answering machine which can be accessed remotely. Key elements of the model include: strong local relationships with a wide range of key partners in care ensuring its ability to 'capture' people nearing the end of life before; referrals from multiple sources to a single-entry point supporting effective decision-making and care co-ordination; a single assessment process for health and social care needs of the patient and their family; dedicated care co-ordination; rapid access to care from a multidisciplinary team and a responsive provider network.

***Case Study: Coordinate My Care***

'Coordinate My Care', developed at the Royal Marsden NHS Foundation Trust, is an electronic system that lets patients with life-limiting illnesses define a personalised urgent care plan which is shared electronically with all agencies and professionals involved in their care, including NHS 111, London Ambulance Service, GPs, social care and accident and emergency. More than three-quarters of the people who have died while on the programme did so in the place of their choosing, at home, in a hospice or care home. Because more people achieved their preferences to die out of hospital, an independent evaluation of 'Coordinate My Care' has calculated that the programme has delivered an average saving of £2,100 per person.

## ***Shaping the health and care system to enable choice in end of life care***

147. A national choice offer focused on what is important to the individual in their end of life care should promote and reinforce the delivery of high quality, coordinated, compassionate, person-centred care.

148. We know that this is in line with the direction in which the NHS has been moving for some time. This has been given new impetus by NHS England's *Five Year Forward View*, the work of the Better Care Fund in promoting greater integration between health and social care and the increasing use of personal budgets for health.

149. Greater integration in commissioning offers a way forward in breaking down the barriers between health and social care systems, and enables the delivery of choice. NHS England's Integrated Personal Commissioning Programme (IPC),<sup>100</sup> announced in July 2014, aims to bring together all of an individual's health and social care funding, giving them more control over how this money is used through person-centred care planning and personal budgets. The per-person funding system for specialist palliative care that is under development by NHS England should, when introduced, support the delivery of greater choice in end of life care. NHS commissioners and providers shaping their services on the basis of this overall direction of travel, with the individual's needs as their central focus, should help enable greater choice and quality for all people, including people approaching the end of their lives.

150. However, we believe that there are specific mechanisms and levers which should be implemented or amended to incentivise health and care organisations to ensure that people are receiving the offer of choice in end of life care, and realising their choices.

151. Currently, primary care practices in the UK receive payments under the Quality and Outcomes Framework (QOF) for maintaining a register of palliative care patients, meeting regularly to discuss individuals' needs, and recording their preferred place of death. We advise 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.

152. NHS England has responsibility for providing leadership and support on commissioning to Clinical Commissioning Groups (CCGs). Their recently published *Actions for End of Life Care 2014-16*<sup>101</sup> sets out a series of actions to improve end of life care in England. To improve commissioning of end of life care services so as to support people's preferences and greater personalisation, we advise that NHS England's **new guidance for Clinical Commissioning Groups makes explicit reference to enabling preferences at the end of life**. We also

advise that consideration be given to enabling preferences in the following ongoing work:

- the development of the **NHS Standard contract**;
- the work on **national development currencies for specialist palliative care**;
- the development of the **new service specification for specialist palliative care**;
- work on an **updated commissioning toolkit for end of life care**; and
- work to develop individual **outcome and experience measures for palliative care**.

153. If more end of life care is to be provided in community settings, it will be increasingly important to ensure there are **strong partnerships between health and social care organisations and staff delivering care across the statutory and voluntary sectors**. There are specific gains to be made from implementing integrated care approaches in terms of enabling people's preferences and providing truly coordinated care across the health, social care and voluntary sectors. There may also be significant gains in quality of care and in efficiency. With the advent of the Better Care Fund, CCGs are well placed to identify these gains and we would advise all CCGs in drawing up plans for integrated services to strongly consider the potential for these improvements to end of life care services.

154. Health and Wellbeing Boards (HWBs) also have a key role to play in improving end of life care services and ensuring health and social care services are integrated. We advise that all **HWBs should consider enabling people's preferences at the end of life**, better coordinated care and integrated models of end of life care in making strategic plans for health services in their local areas.

155. Personal budgets for both health and social care have the potential to provide people with greater choice and control over their care. To date these have not been a particular feature in end of life care. However it is entirely possible that, as people who have been using personal budgets to help manage their care in relation to long-term conditions start to reach the end of life they will want to carry on using these budgets to shape their care. There is also the potential for end of life care providers, particularly in the voluntary sector, to support people to pool their budgets and design bespoke local services built around their individual choices and preferences. We advise 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.

156. We also know that more and more people want to make their views on the care they want at the end of their lives known in advance of needing end of life care. There needs to be a way of capturing these preferences and sharing them with health and care staff to inform open and honest conversations. We know that in the past year NHS England's Patient Online programme has vastly improved individuals' access to their own medical records,<sup>102</sup> and note the positive

direction of travel and emphasis on end of life care in the National Information Board's recent report *Personalised Health and Care 2020*.<sup>103</sup> We advise 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.**

## ***Measuring the delivery of choice and its impact***

157. To measure the impact of the offer of choice on people's experience in end of life care, new metrics should be developed to evaluate its impact and hold health and care organisations to account for delivery.

158. Metrics also need to be developed to monitor progress on implementation, for example the roll out of EPaCCS or equivalent system (by geographic area and by medical condition), so that the Government and the public can be clear about whether we are on track for a choice offer to be available for everyone by April 2020.

159. Metrics created using real time feedback from the individual on whether they had been both offered and achieved their choices, can provide a new source of information which builds on the questions in the National Survey of Bereaved People (VOICES-SF), which ask bereaved relatives whether they felt that their loved ones were both offered and achieved the choices that were important to them. We advise that the work to develop **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 been met. These measures should also provide meaningful data to monitor the impact of a national choice offer on health inequalities.** They should be used by local commissioners as a tool to drive improvements in areas where they are needed.

160. In the longer term, presuming the introduction of EPaCCS or equivalent systems on a nationwide basis, the information stored on these systems could be accessed and used with other metrics to support the development of **indicators for both the NHS and Adult Social Care Outcomes Frameworks** which holds the health and social care system to account for both the offer and delivery of choice in end of life care, directly linking this to improvements in individual experience of care.

161. Aligned to this, we advise 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 care as signifiers of quality.

162. To further ensure that the services commissioned and provided by the NHS, social care and the voluntary sector reflect what people want, we advise that there be **further funding for research into palliative and end of life care**, focusing on the ten priorities identified by the James Lind Alliance's Palliative and End of Life Care Priority Setting Partnership.<sup>104</sup>

163. Taken together, these measures will enable health and care organisations to develop their services and offer people the choice in end of life care and hold them to account for delivery.

# Advice to Government on the steps needed to deliver choice in end of life care

We believe that a commitment to deliver the following national choice in end of life care by April 2020 is essential, as otherwise there will continue to be unacceptable variation in choice and access to high quality end of life care services:

**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:**

- **made as soon as is practicable after it is recognised that the person may die in the foreseeable future.**
- **based on honest conversations with health and care staff, which supports the person to make informed choices.**
- **consistently reviewed through conversations with health and care staff.**

The following advice provides a clear framework to ensure that all people can benefit from services focused on what is important to them through the delivery of the choice offer:

## *For the individual*

**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.**

**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.**

**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.**

**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.**

## ***For family and carers***

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.

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.

## ***For the workforce***

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.

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.

That Health Education England, in planning for future workforce numbers, should:

- work with commissioners and providers to agree both specialist and non-specialist palliative care workforce requirements, in acute and community settings, to deliver improvements in end of life care.
- 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.

## ***For health and social care organisations***

**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.**

**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.**

**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.**

**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.**

**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.**

**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.**

**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.**

**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.**

**That health and social care commissioners include initiatives aimed at increasing community resilience and involvement in end of life care in their plans.**

## ***For the Government and national organisations***

**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.**

**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.**

**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 for specialist palliative care and the updated commissioning toolkit for end of life care.**

**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.**

**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 been met. These measures should also provide meaningful data to monitor the impact of a national choice offer on health inequalities.**

**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.**

**That the Government implement a clear policy to make access to social care for people at the end of life fast and free.**

**That the *Five Year Forward View* 'Models of Care Board' explores the integration of health and social care at the end of life as one of the models of care that has the potential to be transformative in delivering care closer to home.**

**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 care as signifiers of quality.

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 uncoded elements of this advice such as staff training, named responsible senior clinicians and care coordinators.

## ***For society and community***

That the Dying Matters Coalition has a key role to play in widening public understanding and supporting the 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.

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.

# References

<sup>1</sup> Full details of the Review's terms of reference are available online at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/341515/Terms\\_of\\_reference\\_for\\_review.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/341515/Terms_of_reference_for_review.pdf).

<sup>2</sup> Historically there has been some confusion about the definition of the end of life and of palliative care as distinct from end of life care. This report uses those terms as they are defined in Annex G of the *One Chance to Get it Right* report, produced in June 2014 by the Leadership Alliance for the Care of Dying People. For the avoidance of doubt these definitions are as follows:

**End of life** - Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: a) advanced, progressive, incurable conditions; b) general frailty and co-existing conditions that mean they are expected to die within 12 months; c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; d) life-threatening acute conditions caused by sudden catastrophic events. In General Medical Council guidance the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.

**Palliative care** - The World Health Organisation has defined palliative care as follows: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families; enhances quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.

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- <sup>11</sup> NHS England, (2014). *The NHS Five Year Forward View*. [online] London: NHS England. Available at: <http://www.england.nhs.uk/ourwork/futurenhs/>.
- <sup>12</sup> A detailed report of the engagement methodology and findings can be found in Annex A of this report which is published online at gov.uk alongside the main report.
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