Transforming care at the end-of-life
Dying well matters
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**The Deloitte Centre for Health Solutions**

The Deloitte Centre for Health Solutions, part of Deloitte UK, generates insights and thought leadership based on the key trends, challenges and opportunities within the healthcare and life sciences industry. Working closely with other centres in the Deloitte network, including the US centre in Washington, our team of researchers develop ideas, innovations and insights that encourage collaboration across the health value chain, connecting the public and private sectors, health providers and purchasers, and consumers and suppliers.
Welcome to the Deloitte UK Centre for Health Solutions report *Transforming care at the end-of-life: Dying well matters*. The report presents the Centre’s analysis and views on caring more effectively for people in the last days, weeks and months of life.

Death is an inevitable part of life that no one can avoid. Yet, for too many, it is still a taboo subject. In the words of Dame Cicely Saunders, founder of the modern hospice movement, "How people die remains in the memory of those who live on so we should strive to make a good death the expectation rather than the exception in all settings."

International research suggests the UK is leading the way in terms of its hospice care network and statutory involvement in end-of-life care. However, care of the dying remains a lottery in many cases. There is wide variation in quality and frequent failure to meet people’s preferences for place of death. The breakdown of the extended family and impact of an expanding, ageing population are placing end-of-life care under constant pressure, leading to increasing media and political scrutiny.

Many people fear dying, associating it with pain and indignity. While the 2014 House of Lords debate and vote on changing the law on assisted suicide was divided, there is consensus that more effective, compassionate end-of-life care is an imperative and that high quality care in the lead-up to death should be a human right.

This report highlights the core challenges that need to be addressed and some of the more innovative and effective solutions and examples of good practice that are already being deployed. Everyone has a part to play: families, communities, charities, as well as most health and social care staff. There is an important role too, for technology, in ensuring that care and support is available 24 hours a day.

The focus of the report is on England, although the findings should resonate with the wider UK. The report is based on literature reviews and interviews with key stakeholders (commissioners, providers, carers and industry), supplemented by expert views from roundtable discussions. Insights have also been gained through our involvement in the Imperial College London, Institute of Global Health Innovation’s End-of-life Care Forum. Its report: *Dying Healed: Transforming End-of-Life Care Through Innovation*, was presented at the World Innovation Summit for Health in Qatar in December 2013.¹

Karen Taylor
Director, Centre for Health Solutions
Number of people dying and cost of caring for these people

500,000 people die in England every year. Predicted to reach 590,000 by 2030.

Caring for people at the end of their lives costs at least £4.5 billion a year.

Nature of care is increasingly complex

2/3 of people dying are aged 75 or over. This age is increasing as is complexity of their care needs.

In 2012, the leading cause of death for males was heart disease (15.6%) and for females was dementia (11.5%).

National survey of bereaved people

Of the 79% who prefer to die at home, only 50% actually died there.

35% who wanted to die at home, died in hospital.

Place of death

In 2013 over 50% of people died in a hospital (ranging from 38 to 70% depending on location).

Number of people who died in their home/care home – increased from 38% in 2008 to 44% in 2012.
Hospices

Hospices provided ‘gold standard’ care for 360,000 patients and family members in 2013-14.

Public funding covers only a third of hospice activity. Voluntary sector funding covers the rest – at £900 million per year.

125,000 hospice volunteers are an important resource with an economic value of £112 million.

Palliative care

Commissioners spent £410 million on palliative care in 2010-11 (ranging from £186 – £6,206 per death).

In 2011 around 355,500 people had palliative care needs but for 92,000 people per year, these needs go unmet.

Cancer accounts for only 29% of deaths, but cancer patients receive majority of palliative care services across all care settings.

Solutions

In Somerset, patients with access to community based nursing or palliative care services are 67% less likely to die in hospital.

In 2013, 30% of commissioners had operational Electronic Palliative Care Co-ordination Systems in place with 56% planning to implement one.

In London, 77% of patients with an electronic Coordinate My Care plan in place, died in the setting of their choice.
Every year around 500,000 people die in England, two thirds of them aged over 75. Around 75 per cent of these deaths follow a long-term illness, requiring access to end-of-life care. End-of-life can mean any period between the last year of life for a person with a chronic and progressive disease, to the last hours or days of life. End-of-life care encompasses palliative care, which focuses on managing pain and other symptoms, providing psychological, social and spiritual support to patients, and supporting those close to the patient.

End-of-life care seeks to support individuals with advanced, progressive, incurable illness to live as well as possible until they die. People in the last year of life often require a mix of health and social care services in hospitals, hospices and, for many, ideally their own home or care home. Care is delivered by a wide range of people, creating a complex picture of care provision. This includes families and friends, specialist palliative care experts and more generalist staff such as doctors, nurses and social workers. National and local charities and the voluntary sector also play a significant role (Figure 1).

Figure 1. Dying well involves different levels and intensity of care across a continuum of people and support structures

Source: Dying Healed – Transforming End-of-life Care Through Innovation, Institute of Global Health Innovation, Imperial College London, December 2013
Supporting people to live well until they die is challenging

Most attention on dying concerns where and when people die. Equally important is how people die, a consideration that is often ignored. Furthermore, there is wide variation in access to quality end-of-life care. The subject of death and dying also remains somewhat taboo, especially in discussing preference and choice. In a multicultural society, these discussions need to recognise factors such as culture, religion and personal values. For many, a ‘good death’ involves being without pain, in a familiar place with family or friends, and being treated with dignity, compassion and respect.

End-of-life care is a difficult but necessary subject to broach, with the potential to prevent unnecessary suffering if delivered appropriately. Meeting people’s preferences for good quality end-of-life care can also save costs, but requires all parties to work together for the benefit of those approaching end-of-life, their carers and families. It is an area with the potential to unite rather than divide and, done well, could be an exemplar of cost-effective, co-ordinated and integrated care.

In England, in 2008, the Department of Health published a ground breaking ten year End of Life Care Strategy which set out to support all adults nearing their end-of-life, regardless of diagnosis, to live as well as possible until they die. Similar strategies were launched in Scotland, Wales and Northern Ireland. Since then, there have been numerous initiatives aimed at improving the delivery of care in all settings. Data from opinion polls consistently show that 70-75 per cent of people would prefer to die at home. Yet in 2013, over 50 per cent still died in hospital (over 70 per cent in some parts of the country). Place of death varies by condition, with cancer patients more likely than others to die at home or in a hospice.

The state of end-of-life care in 2014

While there have been measurable improvements in end-of-life care, there are still inequalities in access to good quality care and support. For example, although the number of home deaths has risen, the increase has been relatively slow (from 18 per cent in 2005 to 22 per cent in 2012).

There is limited information on the cost of end-of-life care and challenges in understanding the full financial cost of services, including the costs met by the voluntary sector, patients and families. However, existing data suggest an annual spend of at least £4.5 billion, the largest burden of which is incurred in the last months of life. Various reports demonstrate that high spend does not equate to a good death. Community provision of care offers potential to reduce expenditures while at the same time accommodating the expressed wishes of people to die at home or in a hospice.
The 2013 National Survey of Bereaved People – *Views of Informal Carers Evaluation of Services* – found that 43 per cent of respondents thought care for their loved one during the last three months of life was excellent or outstanding. However, 24 per cent said it was only fair or poor, suggesting too many people are still not receiving high quality end-of-life care. Only a third had actually expressed a preference on place of death and, of these, around 80 per cent preferred to die at home but only 35 per cent actually did so. Quality of care was rated significantly lower for people who died in a hospital. Comparing responses from the past three years of survey responses, however, suggests that the overall quality of care has remained relatively static.

Since 2008, various recommendations have been made to improve the confidence, knowledge and ability of clinical and nursing staff to deliver effective end-of-life care. Yet this is still far from the case, as demonstrated by the 2013 review of the Liverpool Care Pathway, *More Care Less Pathway*, which identified inadequacies in care provision. Shortcomings and concerns about significant variations in quality of care were also identified in the 2013-14 National Care of the Dying Audit for Hospitals and the 2014 House of Lords debate on assisted dying. All of which point to the need for a revised approach to end-of-life care.

**Solutions for transforming end-of-life care for all**

In 2014, the Leadership Alliance for the Care of Dying People, formed to develop a response to the *More Care Less Pathway* report, published Five new Priorities for Care of the Dying Person as part of its final report – *One Chance to Get it Right*. These priorities are an important consensual step in determining a national blueprint for requirements to improve palliative end-of-life care in the last days and hours of life in all settings, but implementation will take time to impact. Meanwhile, there are many models of good practice which, if adopted more widely, would start to transform end-of-life care from the ground up. These include:

- improving the understanding of the needs and wishes of people at end-of-life, by capturing their preferences and sharing this information between all relevant parties involved in caring for the dying person
- education and training in care of the dying should be mandatory for all health and social care staff involved in end-of-life care, including skills in communicating with and supporting families, carers and their advocates
- access to advice and support from specialist palliative care services should be available seven days a week, including making effective use of technology such as telehealth
- research into the key issues raised by the National Care of the Dying Audit and National Survey of Bereaved People should be undertaken, and guidance developed to address the findings
• evidence on the economic costs of different care settings should be developed including on the potential savings from greater use of community care

• as commissioners focus more on quality and integration of care, new incentives that encourage closer partnership working between care providers should be developed, including alternative funding models

• commissioners should ensure all care providers audit end-of-life care, incorporating the views of bereaved relatives, at least annually as part of any contracts or other funding arrangements

• participation in future national clinical audits should be encouraged, including extending these audits to general practice and care homes.

Conclusion

Some individuals, particularly those accessing hospice or specialist community and hospital palliative services, receive high standards of care at end-of-life. However, many others do not. The challenge is to transform care for all at end-of-life so everyone receives the right care based on their needs and wishes. With an ageing population and over-stretched health and social care services, immediate action is essential.

Good end-of-life care should mean people are treated with dignity and respect and, where possible, in their preferred place of care. Organisations responsible for caring for people approaching end-of-life need to embrace, as a matter of urgency, the Five Priorities for Care and improve planning and delivery of services. Emphasis should be on transforming support in the community to reduce unwarranted and unwanted hospital admissions. The reallocation of end-of-life care resources should lead to better care that is cost-neutral if not cost-saving.

43 per cent of respondents thought care for their loved one during the last three months of life was excellent or outstanding. However, 24 per cent said it was only fair or poor.
Part 1. Improving understanding of end-of-life care needs

“How we care for dying people is a litmus test of a good health system and a responsible society – to be judged by the dignity and respect given to all people of all ages in all settings at the end of their lives.”

Foreword to the report Dying healed: Transforming End-of-Life Care Through Innovation – December 2013

Deloitte’s March 2014 report Better care for frail older people: Working differently to improve care highlighted the scale and extent of the challenges facing health and social care in the UK given a growing and ageing population.2 Extending that discussion, this report focuses on:

• understanding how and where people are dying and the extent to which their preferences are being met

• challenges in providing good quality end-of-life care

• potential solutions to support the delivery of and more equal access to high quality care at the end-of-life.

In 2008, the Department of Health (Department) published its national End of Life Care Strategy (Strategy). This took a “whole systems” approach to driving improvement, with additional funding in the first two years reflecting the government’s commitment “to double the investment” in specialist palliative care. The Strategy acknowledged end-of-life care provision was not consistent enough and would certainly be inadequate given growing demographic pressures, particularly:

• an anticipated rise in the number of deaths (which had been falling steadily year on year for decades), from almost 500,000 in 2008 to about 590,000 by 2030

• a need to redress the long-term decline in the proportion of people dying at home, with opinion surveys showing that most people (on average about 70 per cent) stating a preference to die at home, albeit some change their mind as death becomes more imminent, expressing a wish to be taken to a hospice or a hospital.3
Scotland, Wales and Northern Ireland launched their own end-of-life care strategies shortly after and there have been numerous local and national initiatives since, resulting in heightened awareness and prioritisation of end-of-life services. All four UK countries expressed common objectives to:

- improve provision of community services through the development of rapid response community nursing services and better co-ordination of care
- equip health and social care staff at all levels with the skills to communicate with, and deliver care to, people approaching end-of-life and their carers
- develop specialist palliative care outreach support services for all, regardless of their condition
- reduce inappropriate hospital admissions and enable more people approaching end-of-life to live and die in their preferred setting.

One of the main barriers to achieving these goals has been lack of robust, comprehensive information on the extent of end-of-life care needs and on the cost and quality of care provision. This is echoed in reports by the National Audit Office (NAO) and Audit Scotland in 2008.4,5 The independent Palliative Care Funding review in 2011 was an attempt to address this and gain a better understanding of the cost, including a comprehensive review of the research evidence available at that time.6

The NAO review provided a comprehensive baseline on end-of-life care provision in England derived from: censuses of all National Health Service (NHS) commissioners, independent and NHS hospices and a survey of care homes; an in-depth case study of the potential for people to die in their preferred setting; and an economic evaluation of potential cost savings from greater use of home and hospice based end-of-life care. It confirmed that:

- most people would prefer not to die in hospital but lack of NHS and social care support services means that many do when, for around 40 per cent, there is no clinical reason for them to be there
- there is scope for more people to die at home, in a care home or hospice by improving training of all NHS and social care staff in end-of-life care needs, and extending specialist palliative care services for all who need them
- improved delivery of services will require more effective commissioning and partnership working between the NHS, social services and the voluntary sector, including longer contracts
- skills in end-of-life care, developed in hospices primarily with cancer patients, could be extended to other terminal conditions and to the care home sector through outreach services and training.7
The NAO report was subsequently the subject of a Public Accounts Committee (PAC) enquiry. In the response to the PAC’s report and recommendations, the Department:

- agreed the need for commissioners to seek hospital assurance that staff are sufficiently educated and trained in end-of-life care
- stated that tools like the Liverpool Care Pathway (LCP) and Gold Standard Framework (GSF) should be used to support provision of good end-of-life care
- introduced the piloting of end-of-life care registers to capture information about patient preferences and care
- announced development of training in assessment, communication skills, advance care planning and symptom management
- published a patient information guide to help with planning future care
- acknowledged that commissioners had limited understanding about the cost of, and demand for, end-of-life care services, and should account for their spending on end-of-life care and benchmark the resultant information.

**Changes in the place of death**

Supporting people to live at home as they become frail and more dependent remains challenging. Helping them die well is even more daunting. Consequently, the majority of deaths still occur in an acute hospital following a chronic illness. At the time of the Strategy, most deaths (58 per cent) occurred in NHS hospitals, with around 18 per cent occurring at home and 17 per cent in care homes, four per cent in hospices and three per cent elsewhere. The number of people supported to die at home has increased but relatively slowly (from 18 per cent home deaths in 2008 to 22 per cent in 2012). The number of deaths in care homes improved from 17 per cent in 2008 to 21 per cent in 2012, although there remains wide variation by age, geography and health condition.

Since the Strategy was published, performance has been measured predominantly on place of death. On this measure, there has been demonstrable progress; in 2012, for the first time in years, the proportion of people in England and Wales dying in hospital dropped just below 50 per cent. Given around 500,000 people die in England each year, every percentage point improvement means 5,000 people cared for and dying in a different setting. Despite the overall improvement in place of death, there is still some way to go to improve end-of-life care for all.
Improving understanding on where and how people die

A number of external factors influence place of death. These include deprivation levels, population density and age profile, proportion of deaths due to cancer, proportion of people who are single and living alone with no family support, and ethnicity. Understanding of these demographics is crucial to addressing need. Likewise, better understanding of the capacity of care providers within each local area is important to ensuring availability of support for care delivered. However, this level of information is still not readily available.

As a commitment of the Strategy, the National End of Life Care Intelligence Network, compiling information from a wide range of sources, was established in 2010 (now part of Public Health England (PHE)). According to its 2013 annual report, two thirds of people die aged 75 or over, with the age at death increasing as people live longer. A systematic review of existing population-based research estimated that in high-income countries, 69 to 82 per cent of the dying need palliative care. Likewise, the 2011 Palliative Care Funding Review in England calculated that around 75 per cent of people who die each year, (some 355,000) have some form of palliative care needs and for around 92,000 per year these needs are unmet.

Over the last decade the leading causes of death have changed as the population ages, with multi-morbidity and dementia, senility, pneumonia and stroke becoming more common. In 2012, cancers accounted for 29 per cent of all deaths, while circulatory diseases (which includes deaths from ischaemic heart disease and strokes) and respiratory diseases (including deaths from pneumonia) accounted for 28 per cent and 14 per cent of all deaths respectively. During 2012, the leading cause of death for males was heart diseases (15.6 per cent). The leading cause of death for females was dementia and Alzheimer’s disease (11.5 per cent). Indeed, deaths from dementia and Alzheimer’s disease are increasing as people live longer, with women living longer than men. Some of the rise may also be attributable to a better understanding of dementia meaning that doctors may be more likely to record dementia as the underlying cause of death. Place of death alters, too, with a higher proportion of frail older people, more likely to be women, dying in nursing or old people’s homes. Apart from those who die suddenly (around 20 per cent of all deaths), everyone would benefit from some form of end-of-life care as they approach death.

Around 75 per cent of people who die each year, (some 355,000) have some form of palliative care needs and for around 92,000 per year these needs are unmet.
Research shows that there is a stark variation in place of death between deprived and more affluent areas. A number of factors influence where someone dies – including cause of death and the pace of disease progression – suggesting equity of access issues. Some of these patterns are already well established, for example:

- higher rates of smoking related deaths or higher proportions of deaths in hospital amongst the most deprived (61 per cent of people in the most deprived quintile die in hospital compared to 54-58 per cent in the other quintiles)
- for each underlying cause of death (cancer, cardiovascular disease, respiratory disease and ‘other causes’) people living in the most deprived quintile were most likely to die in hospital
- there were twice as many deaths of people aged under 65 in the most deprived quintile as in the least deprived quintile.¹⁹

Death and dying remains a taboo subject for many people
The subject of death and dying is still ‘off limits’ for many people. In 2009, to help change knowledge, attitudes and behaviours towards dying, death and bereavement, and make ‘living and dying well’ the norm, the National Council for Palliative Care (NCPC) established the Dying Matters Coalition. Its research on attitudes to dying in 2013 found that:

- 70 per cent of people said they were comfortable talking about death, but most had not discussed their end-of-life wishes or put plans in place
- only 35 per cent of respondents said they had a will
- fewer than a third (28 per cent) had registered as an organ donor or had a donor card
- only 11 per cent had written their funeral wishes or made a funeral plan
- only five per cent had set out their preferences for end-of-life care should they be unable to make decisions themselves
- 67 per cent said they would prefer to die at home, with only seven per cent preferring to die in hospital.²⁰

Cultural factors strongly influence patients’ reactions to serious illness and decisions about end-of-life care. The three basic dimensions in end-of-life treatment that vary culturally are communication of ‘bad news’; locus of decision making; and attitudes toward advance directives and end-of-life care.

Pain control is still a leading concern and key to good end-of-life care
Personal concerns about death and dying have changed little over the past 20 years, with concern about: being in pain; leaving families behind; fear of the unknown; being alone; needing to know about the prognosis, care options and likely symptoms; wanting to be involved in decisions about care; not wanting to be kept alive at all costs; and the importance of quality of life over length of life where there was no hope of recovery from a serious illness.²¹
The process of dying can accentuate cultural differences between patients, carers and providers. Patients are often shielded from knowledge of a terminal prognosis even when they suspect they are dying. Families, carers and health professionals can find the subject of death difficult to raise. Acknowledging the possibility is seen by some health professionals as admitting defeat resulting in heroic attempts to prolong life, often at great cost, and failure to discuss and plan for death so the patient’s wishes can be respected.

Pain control is central to all palliative care, with availability of opioids fundamental to quality end-of-life care. A lack of access to pain control can lead to inexplicable suffering, not just for those about to die but also their carers and families who can feel helpless on their behalf.

Although difficult to predict, end-of-life care costs at least £4.5 billion a year

End-of-life care comprises specialist palliative care (such as specialist inpatient facilities); core palliative care (such as community nursing teams) and universal palliative care delivered by generalists (such as GPs and social workers). Given the involvement of both generalist and specialist staff, robust information on the full costs of end-of-life care is limited and difficult to extract from existing sources. Data on costs met by the voluntary sector, patients and families (which are considerable) is even more limited. The challenge in understanding costs is compounded by difficulties in identifying the point at which end-of-life care begins.

The prevailing view is that end-of-life care costs would be reduced if a greater proportion of care was delivered in people’s own homes or care homes rather than hospitals where inpatient costs can be very high. The economics, however, are far more complex; some people at end-of-life require 24/7 care that actually may be cheaper if provided in hospital than in the community.

Data on commissioners’ spend on specialist palliative care collected by the Department in 2010-11 showed a reported spend of around £410 million. While the average per-person spend was £840 per death (costs ranged £186 – £6,206 per death), there was no statistical correlation between higher-spending commissioners and lower hospital death rates. Furthermore, the extreme variation in the data suggested problems with the accuracy of its quality.

By combining Office of National Statistics mortality data and Hospital Episode Statistics data, the Department identified that the total cost of hospital admissions in the last year of life, for adults admitted with a primary diagnosis indicating a palliative care need, was around £1.3 billion. In addition, research underpinning the Palliative Care Funding Review suggested that:

- the estimated average annual cost of Local Authority-funded social care during the last year of life was £1.5 billion
- spend by primary and community providers is between £208 million and £518 million annually on universal palliative care
- ‘fast track’ continuing healthcare funding for 2010-11 indicated that approximately £136 million was spent, with only a minority of recipients living for more than three months.
In addition independent charitable funding of hospices is around £900 million per year.\textsuperscript{24}

The total estimated direct annual spend on patients receiving some palliative end-of-life care is therefore at least £4.5 billion (Figure 2). This excludes self-funders for which no data are available, and care provided by families and carers.

There are also numerous volunteers providing support, the number of which constantly shifts. Estimates from Help the Hospice suggest that some 100,000 hospice volunteers provide day care, bereavement services and home-based care, saving hospices around £112 million a year.\textsuperscript{25}

Figure 2. The estimated annual cost of palliative and end-of-life care (£ million)

Source: Deloitte UK Centre for Health Solutions analysis, September 2014
Calls to end separate funding of health and social care at end-of-life

For those wishing to die at home, it can be difficult to distinguish between the support they receive to dress their bed sores and the support they receive to help them dress. With social care means-tested, many people at end-of-life often have to self- or family-fund care. Trying to understand and navigate this complex funding and support system creates unnecessary stress for families and wastes precious time. It also increases the likelihood that those who do not receive help with their social care will be admitted into an even more expensive hospital bed. Various research projects demonstrate the benefits of social care support:

- the Nuffield Trust tracked the use of publicly-funded health and social care services by 73,000 people during the last months of life, and found wide local variation. They also found that individuals with the highest social care costs had relatively low average hospital costs irrespective of age, suggesting use of social care may prevent hospital admissions.²⁶

- a Nuffield Trust study linking the separate health and social care records of more than 133,055 people aged 75 and over, found that Local Authority-funded care home residents had fewer hospital admissions than those receiving high-intensity social care support at home. They also had fewer outpatient attendances, even relative to people who received no social care at all. This suggests reducing social care budgets and restricting access to care homes is likely to put significant pressure on hospitals.²⁷

The Palliative Care Funding review recommended removing social care means-testing for patients on an end-of-life locality register. Further, in seeking to develop per patient funding, it recommended adding £180 million to the £460 million NHS spend on specialist palliative care. Through cutting hospital deaths by up to 60,000 a year by 2021 at an estimated cost of £3,000 per death, this would be cost neutral (a potential reduction in hospital costs of £180 million per annum).²⁸

Subsequently, in its Care and Support White Paper, the government acknowledged “much merit” in the principle of free social care at end-of-life. A 2013 survey of Members of Parliament (MPs) found that 84 per cent of MPs believed the government should do more to prevent people from dying in hospital if this was against their wishes, and 70 per cent felt social care should be free of charge at end-of-life to enable people to die at home if that was their preference.²⁹

In September 2014 the Barker Commission on the Future of Health and Social Care in England published its final report, A New Settlement for Health and Social Care. In recommending a move towards a combined health and social care system, singly commissioned, with a ring-fenced budget and entitlements that are equitable and fair, it concluded that there is a strong case for all end-of-life care to be free.³⁰

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Part 2. The challenges in providing good quality end-of-life care

In 2010 the Economist Intelligence Unit published the Quality of Death Index, ranking end-of-life care provision across 40 countries. The UK was identified as leading the way in terms of its hospice care network and statutory involvement in end-of-life care. Despite being considered to have a far-from-perfect healthcare system, the UK came top in the ‘quality of end-of-life care’ sub-category, which included indicators such as public awareness, training availability, access to pain control and doctor/patient transparency.

Notwithstanding this international ranking, end-of-life care in the UK has been under intense media and political scrutiny over the past year. This part of the report focuses on the challenges revealed during 2013 and 2014. Specifically the:

- 2013 report on the rationale for the demise of the Liverpool Care Pathway (LCP)
- Results from the National Care of the Dying Audit for Hospitals (NCDAH) 2013-14
- Findings from the 2013 National Survey of Bereaved People – Views of Informal Carers Evaluation of Services – (VOICES)
- Analysis of patient activity data for specialist palliative care services Minimum National Dataset 2012-13
- Help the Hospices survey – Commissioning of Hospice Care in England in 2014-15
- 2014 House of Lords dying with dignity debate and proposed change of the law on assisted suicide.

2013 review of the Liverpool Care Pathway – More Care Less Pathway

In the late 1990s, following concerns that care for the dying in the acute sector was deficient, the LCP was developed by the Royal Liverpool University Hospital and Marie Curie Palliative Care Institute as a way of transferring the ‘model of excellence’ in hospices to other healthcare settings. The LCP was a generic approach intended to ensure that everyone thought to be within hours or days of dying receives uniformly good care, whatever the setting.

Recommended as a model of best practice by the Strategy and in numerous academic research studies and policy guidance, the LCP included direction on: comfort measures; anticipatory prescribing of medicines; discontinuation of interventions that were no longer necessary or in the patient’s best interests; psychological and spiritual care; and care of the family. It was supported by template documents, training for health and care staff, and arrangements for audit and evaluation of the programme.

Various reviews and audits of care for the dying have found improvements in the quality of care and confidence of care givers in all settings from the LCP. However, they have also revealed inconsistencies, poor interpretation and application of the guidance, and a poor death for many people. Among the most high-profile was the February 2013 Francis Report on the findings of public inquiry into failings at the Mid Staffordshire NHS Foundation Trust.
An independent review of the LCP in England, commissioned in 2013, identified serious concerns but also many supporters, including clinicians and relatives of people treated on it. Its report, More Care Less Pathway, concluded that when operated by well-trained, well-resourced and sensitive clinical teams, the LCP worked well. However, there were repeated instances of patients receiving poor care, particularly in busy hospitals at night and weekends. Furthermore, there was evidence of its use as a tick-box exercise, with families suspecting death had been hastened by the premature or over-prescription of opioids or sedatives and unnecessary withholding or prohibition of oral fluids, often without discussion or consultation.\textsuperscript{13}

One underlying problem was terminology, especially as end-of-life can mean any period between the last year of life to the last days or hours, and concern that someone might be placed on the LCP too early. The term ‘pathway’ was also misconstrued, with some doctors and nurses using the LCP as a set of instructions and prescriptions. Furthermore, ‘pathway’ suggested a destination or decision on the part of some clinicians to end the life of dying patients. The review concluded that the term ‘LCP’ was unhelpful and should be replaced with an ‘end-of-life care plan’.

National Care of the Dying Audit for Hospitals 2013-14

The 2013-14 NCDAH, led by the Royal College of Physicians, evaluated the ongoing implementation of the Strategy, incorporating recent national standards and policy guidance including National Institute of Health and Care Excellence (NICE) quality standard for end-of-life care for adults. In contrast to previous years, the 2013-14 audit sampled care of dying people in hospital regardless of whether they were supported by the LCP or other care pathways or frameworks. It also included more hospitals, and questions that reflected recommendations of the independent LCP review. In total, some 6,580 case notes of people who died in 149 hospitals in England in May 2013 were reviewed. For the first time, the views of 800 bereaved carers were also included.\textsuperscript{34}

The main shortcomings identified were that only:

- 21 per cent of sites had access to face-to-face palliative care services seven days a week; 73 per cent provided these on weekdays only.
- 19 per cent of hospitals required mandatory training in care of the dying for doctors and 28 per cent for nurses; 18 per cent of hospitals had provided no form of training in care of the dying in the previous year.
- 53 per cent of hospitals had a named Board member with responsibility for care of the dying; in 42 per cent, care of the dying had not been discussed formally by the Board in the previous year; and only 56 per cent had conducted a formal audit of care of the dying.
- 47 per cent of hospitals had a formal structured process to capture the views of bereaved relatives or friends.\textsuperscript{35}
The case note reviews highlighted wide discrepancies in documentation. The report recommended appropriate mandatory training for all staff caring for patients at end-of-life and availability of face-to-face specialist palliative care teams seven days a week. It also highlighted the need for better communication with patients and relatives; improved decision making and documentation; and Board-level accountability for the quality of end-of-life care.

**National Survey of Bereaved People (VOICES) 2013**

VOICES collects information from the bereaved on the quality of care provided to a friend or relative in the last three months of life. In the 2013 survey, commissioned by NHS England, 21 per cent of the people whose relative responded died at home, 50 per cent died in an NHS or private hospital, 23 per cent in a care home (including residential home) and five per cent in a hospice. The age range of those who had died was 18 to 110 with the majority (88 per cent) being aged 65 or over.

As discussed, a quality marker for end-of-life care is being able to die in the place of choice. However, only 32 per cent of family members said their relative had expressed a preference for where they would like to die. Of those who expressed a preference:

- 79 per cent preferred to die at home but only 50 per cent actually died there
- only three per cent preferred to die in hospital
- 35 per cent who wanted to die at home died in hospital.

The quality of care for people who died from cancer received the highest rating (51 per cent rated care as outstanding or excellent). Overall, care was rated significantly lower for those who died in hospital (33 per cent rating care as outstanding or excellent) than for any other location. For those dying at home, quality of care co-ordination was rated significantly lower in 2013 compared to 2012. However, overall quality of care had not changed significantly between 2011, 2012 and 2013. Figures 3 and 4 detail other key findings.36
Figure 3. Coordination of end-of-life care

In last three months of life, did all services work well together?

3a. Responses according to cause of death

3b. Responses according to place of death

Did the hospital services work well together with GP and other services outside of the hospital?

3c. Responses according to cause of death

3d. Responses according to place of death

Source: National Survey of Bereaved People – VOICES 2013 (July 2014)

Figure 4. Quality of care

4a. Ratings of overall quality of care across all services in the last three months of life

4b. How well pain was relieved during the last three months of life by care setting

Source: National Survey of Bereaved People – VOICES 2013 (July 2014)
National Survey of Patient Activity Data for Specialist Palliative Care Services for the year 2012-13

Some two-thirds of specialist palliative care providers responded to the National Survey of Patient Activity Data for Specialist Palliative Care (SPC) Services, Minimum Data Set (MDS) 2012-13. MDS was launched in 1995 and has been commended by the Department since 1996. It was reviewed in 2008, since then around 23 per cent of the organisations surveyed have submitted no data. All respondents receive feedback enabling them to benchmark their performance.

Despite the disappointing response rate, the survey provides an important overview of the changes in scale and outcome of SPC services. It found that community palliative care is helping more people meet their preference to die at home (46 per cent of people receiving services died at home compared with 22 per cent nationally) and that 45 per cent of people referred to a SPC inpatient service are actually discharged, the majority to their own home, dispelling the myth that people only go into a hospice to die (Figure 5).

Figure 5. Outcome of patients treated by specialist palliative care teams in 2012-13

Break down of location after end of stay in inpatients

- Just over half (55 per cent) of those people no longer being cared for by the inpatients service (including day cases) had died.
- The remaining 45 per cent had been discharged, the majority of whom (85 per cent) were discharged to home.

Source: National Survey of Patient Activity Data for Specialist Palliative Care (SPC) Services, Minimum Data Set (MDS), 2012-13, June 2014
Progress in opening up SPC services to non-cancer patients has continued, with an increased proportion of new patients in SPC inpatient units having a diagnosis other than cancer. However, rates are still low and there is still a long way to go, with cancer patients receiving the majority of SPC services (Figure 6).

**Commissioning of Hospice Care in 2014-15 – Help the Hospice annual survey**
Hospices are a small but unique part of the palliative and end-of-life care landscape with a significant role in delivery, providing ‘gold standard’ care for some 360,000 patients and family members. Hospices for adults receive on average a third of their funding from the government. UK hospices raise around £900 million annually from charitable funding with further support provided by some 100,000 volunteers with an economic value of £112 million.\(^{38}\)

Despite the Department’s agreement that funding should be for a minimum of three years, the latest Help the Hospice annual survey found that only a third of hospices had NHS contracts running for more than one year; less than half of all types of statutory funding agreements involved funding for more than one year.\(^{39}\) Furthermore, half of hospices have seen their funding cut or frozen for 2014-15, meaning reductions in some services and suspension of service expansion and innovation. Almost a quarter of respondents felt palliative and end-of-life care was a low priority or not on the agenda of their Clinical Commissioning Group (CCG) and over a third felt that it was a low priority or not on the agenda of the Health and Wellbeing Board. Most hospices were finding it increasingly difficult to be recognised as partners with the statutory sector in addressing local health needs.\(^{40}\)

Figure 6. Percentage of people with cancer and conditions other than cancer treated by specialist palliative care teams, 2012-13

- More needs to be done to ensure that people with diagnoses other than cancer have access to specialist services when needed.

Source: National Survey of Patient Activity Data for Specialist Palliative Care Services, MDS Full Report for the year, 2011-12
The Right to Die Well – House of Lords dying with dignity debate

Euthanasia is an emotive issue that divides most cultures. Since the mid-1970s, surveys in the UK have found public support for euthanasia and physician-assisted suicide hovers between 60 and 80 per cent. The British Social Attitude Survey shows people make clear distinctions between the acceptability of assisted dying in different circumstances: 80 per cent of respondents agree with the legality of voluntary euthanasia by a doctor for someone with a painful, incurable and terminal condition, but less than 50 per cent where the illness is painful but not terminal.

However, some 90 per cent of palliative care doctors in the UK are opposed to assisted suicide, viewing their role as quite distinct from assisted suicide or euthanasia. Whereas for most people the greatest fear about death is dying in severe, untreated pain, a fear perpetuated by media stories and campaigns to allow euthanasia and assisted suicide.

Euthanasia is currently permitted in three European countries: the Netherlands, Belgium and Luxembourg. In Switzerland, assisted suicide has been legal since 1941, provided assistance is given for altruistic motives. The Netherlands and Luxembourg also permit assisted suicide, although Belgium does not. The number of people who have chosen this option remains a very small percentage of those who have died during this period.

In the UK, euthanasia is currently regarded as either manslaughter or murder, while assisted suicide is illegal under the Suicide Act (1961). However, grey areas have emerged. In 2010, the Director of Public Prosecutions indicated that anyone acting with compassion on the will of a dying person was unlikely to face charges. In July 2014, the House of Lords again debated a change in the law to allow assisted suicide, with politicians given a free vote. Following an emotionally-charged ten-hour debate, culminating in a split vote, the bill was granted its second reading and goes forward to a committee of the whole House for further debate.41

Since the mid-1970s, surveys in the UK have found public support for euthanasia and physician-assisted suicide hovers between 60 and 80 per cent.
Part 3. Transforming end-of-life care delivery for all

This part of the report reviews examples of solutions for transforming end-of-life care at both national and local level. In particular it considers:

• what next, following the demise of the LCP

• alternative commissioning approaches to help transform service delivery

• improving access to specialist palliative care in the community

• new approaches to education and training

• use of technology in supporting providers to work differently

• the role of GPs and primary care team in improving end-of-life care.

One Chance to Get it Right: Priorities for Care of the Dying Person

In July 2014, the recommended demise of the LCP was followed by a “new approach” based on five Priorities for Care (PfC) to improve consistency of care for everyone in the last few days and hours of life, irrespective of setting. Developed by the Leadership Alliance for the Care of Dying People (Alliance), a coalition of 21 organisations, One Chance to Get it Right reinforces the principle that the focus of end-of-life care should be on the person who is dying. It recognises that in many cases planning for death should start well before a person reaches the last days of life as an integral part of personalised, proactive care. The five PfC are:

• recognising and clearly communicating that death is a possibility, with decisions made and actions taken in accordance with the patient’s needs and wishes, regularly reviewed and revised accordingly

• ensuring sensitive communication between staff and the dying person and those important to them

• involving the dying person and those important to them in treatment and care decisions as desired

• exploring, respecting and meeting (as far as possible) the needs of families and others important to the dying person

• agreeing, co-ordinating and delivering with compassion an individual care plan that includes food and drink, symptom control, and psychological, social and spiritual support.

NICE is expected to reflect the PfC in developing its new clinical guidelines on Care of the dying adult in the last few days of life (due October 2015). Likewise, the PfC accompanying duties and responsibilities of health and care staff, and implementation guidance for service providers and commissioners, are expected to inform the Care Quality Commission’s (CQC) approach to hospital inspections under which end-of-life care is one of eight core service areas being inspected. The new inspection approach is due to be introduced in October 2014. The CQC is also undertaking a themed review of inequalities in end-of-life care across all providers, the results of which are due in Spring 2015.

Alternative approaches to commissioning end-of-life care services

Commissioning is an important lever in transforming end-of-life care. The NHS standard contract for 2014-15 onwards, while not setting arbitrary limits, confirms that three-year contracts should be the norm. However, as shown in Part 2, this is still far from the case.
There is immense pressure on commissioning budgets to meet the increasingly complex care needs of an ageing population. Commissioners and providers of end-of-life care need to operate more intelligently and efficiently to ensure that the increasing care requirements of a growing number of patients nearing end-of-life can be met with the same or fewer resources.

The King’s Fund advocates the need to commission for outcomes rather than activity. A key requirement for commissioners, therefore, is the ability to specify expected outcomes and empower providers to develop innovative solutions within the framework. Traditional outcome measures, such as morbidity and mortality, are inappropriate for end-of-life care given the importance of the qualitative experience of care, particularly in meeting patient needs and preferences. Commissioning for outcomes can help promote service integration but information technology systems and shared data sources are needed to achieve this.

Following an extensive evaluation of available literature and interviews with commissioners, managers, and clinicians, the King’s Fund identified opportunities for use of commissioning to meet the financial and quality challenges facing the NHS. Factors found critical for promoting a more integrated, personalised approach included a shared vision, contractual levers, clinical involvement and the commissioner or GP acting as broker for care co-ordination. Its evaluation of the commissioning models being explored by the NHS and social care were:

- **lead-contractor model** – although used effectively in some clinical areas, it has not shown success in end-of-life care cases examined, likely due to difficult economic conditions coupled with the start-up costs involved

- **pooled budgets** – while complex to develop and sustain, it is seen as offering the most concrete approach for encouraging integration across providers

- **care pathway approach** – can help promote service integration and personalisation in response to the changing needs of individuals, their carers and their families. This is likely to encourage new entrants to the market, for example from the voluntary sectors

- **personal health budgets** – can stimulate greater patient choice for end-of-life care and overcome some of the difficulties defining whether individual needs are health or social. However, given patchy evidence on their success in this area, introducing them for the first time at end-of-life is not recommended

- **direct payments** – allow individuals to employ the same carers whether they have health or social care needs, and help ensure care continuity and personalisation.

Current funding mechanisms remain inadequate for meeting end-of-life patient needs. More appropriate approaches include using a tariff for a pathway or package of care, with local commissioners specifying outcome measures. However, there are several fundamental challenges in adopting this approach:

- defining a discrete episode of care

- ascertaining the cost of an episode or pathway

- developing quality markers applicable to, and measurable within, this context of care.
The Palliative Care Funding Review pilots are testing options to address these issues and develop a tariff for use from April 2015. The Cicely Saunders Research Institute is also undertaking various initiatives to evaluate the economics of palliative and end-of-life care services.

Access to specialist palliative care in the community improves outcomes

Evidence as to whether access to SPC in the community provides a good outcome, including whether the patient actually dies at home, is improving, as shown for example by the Marie Curie Delivering Choice Programme (MCDCP). National data shows that people who have access to community-based nursing or specialist palliative care services, or are included in a local care co-ordination system, are more likely to die at home (on average 46 per cent) than the rest of the population. Research quantifying the benefits of home-based care includes:

- Nuffield Trust review of outcomes for 29,538 people who died after receiving Marie Curie Nursing Service (MCNS) care between January 2009 and November 2011, compared to matched controls, found recipients were significantly more likely to die at home than those who received ‘standard’ care. They were also less likely to use all forms of hospital care. Costs of both planned and unplanned hospital care were reduced, with evidence that home-based care can lower hospital use at end-of-life and help more people die at home.

- Evaluation of the Macmillan Midhurst Specialist Palliative Care Service showed that early referral to a specialist palliative care service is associated with fewer nights spent in a hospital setting, fewer accident and emergency (A&E) attendances and fewer deaths in a hospital setting.

- An independent evaluation of the MCDCP found those receiving the service since 2010 were 80 per cent less likely to die in hospital in Somerset (67 per cent in north Somerset) compared to those not receiving care from it. In the last months of life, emergency hospital admissions were 39 per cent lower (50 percent in north Somerset) and A&E attendances 34 per cent lower (59 per cent in north Somerset).

Given concerns over failings in supporting people to die in their preferred setting, and in line with the government’s commitment to increase choice in end-of-life care, a Department review was launched in July 2014 to improve the quality and experience of end-of-life care for adults, their carers and those who are important to them by expanding choice. The report is expected in 2015. At the same time, Lord Warner introduced a Private Members Bill into the House of Lords to give people the right to ask their GP to register in their medical records that they wish to die at home or the place they regard as home. The Bill proposes regulations to achieve this, and to require health and care staff to honour the wishes of patients in accordance with statutory guidance.

People who have access to community-based nursing or specialist palliative care services, or are included in a local care co-ordination system, are more likely to die at home.
New approaches to education and training

In recommending the need to “enhance the recruitment, education, training and support of all the key contributors to the provision of healthcare,” the Francis report recognised the ward manager’s role as critical. The Quality End-of-life Care for All (QELCA©) training programme for senior ward nurses has proven cost-effective in not only changing their practice but empowering them to lead change (Case example 1).

Case example 1
The Quality End-of-Life Care For All (QELCA©) programme is an innovation in end-of-life care education for generalist nurses

QELCA© was designed by St Christopher’s Hospice, London, to enable and empower clinical nurse managers from acute, community settings or care homes to lead on the delivery of high quality end-of-life care. It was piloted between April 2012 and April 2013 across 17 sites and 21 hospices with 137 nurses taking part. The training comprises a five day course at the hospice followed by six months facilitated action learning. It is designed to be delivered by specialist clinicians who have undertaken the QELCA© ‘Train the Trainers’ programme.

Positive outcomes included increased networking; better working relationships; and raised profile of the hospital palliative care team and hospice, leading to more appropriate referrals. A key change was an attitudinal shift, with nurses empowered and more confident to take the initiative on ensuring more sensitive and appropriate care.

For around 15 years, the National Gold Standard Framework (GSF) Centre in End of Life Care has provided generalist frontline staff with nationally recognised training and accreditation programmes, supporting cultural change in care homes, general practice, people’s homes and hospitals in the last years of life. GSF care homes are recognised by CQC as examples of best practice.61

Other good practice examples in end-of-life care education and training include:

• Palliative Care Teaching Team, University of Southampton – a palliative and end-of-life care module for all adult pre-registration students. Novel features include a clinical and research conference and an assignment assessing communication skills and knowledge.

• ABC End-of-Life Care Project (Anglia team) – end-of-life care training for various professionals, including paramedics, social workers, physiotherapists and healthcare assistants, as well as staff who have previously received little training in end-of-life care such as those caring for people with learning disabilities, the homeless and prisoners.

• Supportive and Palliative Care Team, Royal Surrey County Hospital NHS Foundation – various innovations, including a cancer survivorship symptom management clinic, Clinical Nurse Specialist led weekend working and short-stay beds for end-of-life patients, have resulted in the team seeing an increasing number and variety of patients.62
Many hospices work with their local health economies to provide outreach training and support. For example, the St Christopher Hospice’s Care Home Project Team currently works with 31 residential care homes and 84 local nursing homes to develop end-of-life care skills, support staff and ensure that improvements are sustained. An evaluation of its work with care homes in 2013-14 found that:

- 77 per cent of residents died in their care home
- 85 per cent of residents had a resuscitation decision in place
- 76 per cent of residents died with an advance care plan in place.63

**Technology-enhanced care supporting end-of-life care delivery**

Technology-enhanced care (TEC) can help transform palliative care, especially in rural or remote areas, enabling exchange of skills, information, research and evaluation. It encompasses a growing variety of applications and services, including use of two-way video, email, mobile Short Message Service (SMS) and phones, tablets and smart phones. The support provided by technology can reduce crises, and improve the confidence of patients and carers.

A number of mobile phone apps are in use to help patients: understand more about their illness and new treatment and care; link or connect with their care providers; access their medical record; report and manage their symptoms; and identify risk changes. Coordinate My Care (Case example 2), a London-based care plan for patients with life-limiting illnesses, recently launched a mobile app allowing patients to record their end-of-life preferences on a single electronic record.64

**Case example 2**

**Coordinate My Care** is a clinical service sharing people’s information on preference for care between healthcare providers

Coordinate My Care (CMC) is a confidential electronic record that holds a patient’s preferences for treatment and care to allow them to live well in the last stages of life. Launched in 2013 following a two year pilot study, it is available free through the NHS in London and can be updated whenever a patient changes their wishes, including through a mobile phone app. Data shows that 77 per cent of patients who have died with a CMC plan in place died in the setting of their choice.69

**Electronic Palliative Care Co-ordination Systems**

Electronic Palliative Care Co-ordination Systems (EPaCCS) enable the recording and sharing of people’s care preferences and key details about their end-of-life care. In August 2013, a national survey of commissioners found that of the 89 per cent who responded, 64 (30 per cent) had operational EPaCCS and 111 (53 per cent) had started planning for their implementation. The information available to date from those operating an EPaCCS suggests its use has: helped people to die in their preferred place of death; has decreased the percentage of hospital deaths; and increased the percentage of deaths at home and in hospices. The reported benefits included improved communication and information-sharing between healthcare professionals; better support for making appropriate decisions about patient care; shared decision making, individual care planning; and care integration.66

EPaCCS require appropriate configuration of IT systems, services and infrastructure. This has raised challenges for many commissioners including lack of system interoperability, stakeholder engagement, data ownership and funding. Further implementation is dependent on resolving these issues.
There is also a growing number of innovative online resources providing information and support for improving end-of-life care (see below).

### Examples of online resources that provide information and support to promote good quality end-of-life care

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<thead>
<tr>
<th align="left"><strong>Dying Matters, England</strong></th>
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<td align="left"><strong><a href="http://dyingmatters.org/">http://dyingmatters.org/</a></strong></td>
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<tr>
<td align="left"><em>Dying Matters is a coalition established by the National Council for Palliative Care in 2009 to support implementation of the end-of-life care Strategy with the goal of promoting awareness and support, changing knowledge, attitudes and behaviours towards dying, death and bereavement, and through this make a 'good death' the norm. Reported achievements include significant improvements in the confidence of general practitioners (GPs) following participation in the Communication Skills Training Workshop for GPs.</em></td>
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<tr>
<th align="left"><strong>Good Life, Good Death, Good Grief, Scotland</strong></th>
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<td align="left"><strong><a href="http://www.goodlifedeathgrief.org.uk/">http://www.goodlifedeathgrief.org.uk/</a></strong></td>
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<tr>
<td align="left"><em>Good Life, Good Death, Good Grief is an alliance founded by the Scottish Partnership for Palliative Care, to raise awareness of approaches to dealing with death, dying and bereavement and promote openness and community involvement so that death can be dealt with constructively.</em></td>
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End of Life Care for All e-learning project
End of Life Care for All (e-ELCA) is an e-learning project commissioned by the Department to support implementation of the Strategy through enhanced training and education of health and social care staff involved in delivering end-of-life care. Launched in 2010, it provides free online training for the NHS workforce across England to ensure that well-informed, high quality care can be delivered by confident and competent staff and volunteers. It includes more than 150 interactive sessions arranged in four core modules: Advance Care Planning; Assessment; Communications Skills; Symptom Management, Comfort and Wellbeing. There are also modules on Social Care, Bereavement and Spirituality and an Integrating Learning module to help consolidate and apply understanding in different situations.

End-of-life care co-ordination and advance care planning
Advance care planning (voluntary discussion and recording of care and treatment choices) has its origins in palliative cancer care and is widely recommended for all people who are dying. Its routine use has the potential to create a new model based on perceived good practice. Research shows that when a plan is made, patients usually die where and how they would wish. One example operating in Ireland (Case example 3), which progressed from a paper-based tool to an electronic record, is being rolled out in Lancashire, England. Another, demonstrating improved care co-ordination, is the Bedfordshire Partnership for Excellence in Palliative Support (Case example 4).

Case example 3
Development of the Think Ahead online end-of-life care planning tool
Think Ahead is a citizen-led advance planning tool developed by the Forum on End-of-life in Ireland, a project of the Irish Hospice Foundation (IHF), to help people Think, Talk, Tell, and record and review their preferences for future care, as well as associated legal and financial matters, organ donation and funeral arrangements.

Phase One, a printed form, was launched in 2011 with its use by GPs. In 2013, a survey of 100 patients from five participating General Practices found high levels of acceptability: most had no difficulty completing the form, were not upset by it and felt it should be more widely available. It was considered effective in encouraging discussions on end-of-life issues.

Phase Two, which includes a revised form, was launched in May 2014 following agreement between IHF and Patients Know Best, the world’s first patient-controlled, online medical records system, to pilot ‘Think Ahead online’ in Ireland. The updated form is slimmer and more accessible than the original, and includes provision for users to create an Advance Healthcare Directive, reflecting proposed changes in draft legislation.

Case example 4
Partnership for Excellence in Palliative Support (PEPS)
PEPS was piloted across Bedfordshire, UK in December 2011 to co-ordinate previously fragmented palliative care. Led by Sue Ryder and NHS Bedfordshire, it provides access to a single, 24-hour telephone point of access, bringing together 15 organisations in a ‘hub and spoke’ model. With senior nurses as the first point of contact, PEPS enables fast identification of the most appropriate care professional. Use of a shared electronic record ensures ready availability of patients’ records. The records also fulfil the requirement for an EPaCCS register of palliative patients.

An evaluation found 65 per cent of those who died were supported to die at home, with only 11 per cent dying in an acute hospital. There was also a positive impact on emergency admissions (30 per cent fewer), a 30 per cent shorter length of stay and reduction in cost of around £300 per admission. Qualitative results show that PEPS is highly valued; over 87 per cent of GPs felt it had made a difference to co-ordination of palliative care and in supporting people to die in their preferred setting.
The GP and the primary care team’s role in the delivery of end-of-life care in the community

Caring for people nearing the end of their lives is part of the core business of general practice. The GP and the primary care team are in an ideal position to co-ordinate good care and to help reduce some of the worry and stress when someone is at the end of his or her life. In recognition of this, collaboration between the Royal College of General Practitioners and the Royal College of Nursing and others produced a UK-wide web resource with signposts to policy guidance, support and advice. However, there is limited independent evidence on the quality of end-of-life care provided by GPs.

Concerns over the increase in unplanned admissions, including those at the end-of-life, led NHS England to issue guidance for GPs detailing the expectations surrounding the implementation of an enhanced service (ES) payment to help reduce avoidable unplanned admissions. GP practices are expected to use an appropriate risk stratification tool or alternative method to identify vulnerable older people, high-risk patients and patients needing end-of-life care who are at risk of unplanned admission to hospital. A care plan template is included in the guidance. This plan has met with some criticism in relation to questions about anticipatory care, specifically the question about whether to perform cardiopulmonary resuscitation. GP groups have raised concerns about the fact that they do not have sufficient trained staff to handle such questions sensitively. Further concerns have also been raised by GPs that this new ES could be harmful to patients who are dying, unless managers relax stringent deadlines for practices. In the light of these concerns NHS England is reviewing the care plan template.

While there are clearly changes that are needed, as well as some clarification around how this relates to the information collected as part of the requirement for an EPaCCs, if handled sensitively this could be a way to collect more data about end-of-life wishes, and to get more people to talk about the subject. These developments should also help improve understanding of patients’ needs at end-of-life and the extent to which GPs are meeting these needs.

Conclusions and recommendations

End-of-life care is complex and challenging but the principal aim is to support more people to die well in their preferred place of care. Good end-of-life care means treating people with dignity and respect in all care settings. Some people, particularly those who are able to access hospice and specialist palliative care in the community or hospital, receive high standards of care in their final weeks, days and hours, but many others do not. Despite the higher profile now given to the need for good end-of-life care and more robust data and evidence on what works well and what does not, there is still significant fragmentation of services and widely variable quality of care.

The research suggests that there is scope to use existing resources spent on end-of-life care more effectively to provide more care of the right quality in the preferred place of care. Meeting people’s preferences for good quality end-of-life care can also be more cost-effective and has the potential to unite services around the individual. However, it requires commissioners and providers to work together for the benefit of those approaching end-of-life, their carers and families. Done well, it could be an exemplar of cost-effective, co-ordinated and integrated care.
Over the last few years there have been numerous publications presenting evidence and recommendations on improving end-of-life care, but the scale and number of recommendations makes it difficult for relevant organisations to assimilate them effectively. In embedding the five Priorities for Care across health and social care, Alliance members should also consider how to help organisations address relevant recommendations from other national reports, for example, the National Care of the Dying Audit and VOICES survey.

Figure 7 provides a synthesis of the various actions that should help improve the delivery of good end-of-life care in each care setting. In addition, the research underpinning this report suggests the following recommendations could help improve end-of-life care more generally:

- improving understanding of the care needs and wishes of people at end-of-life, by capturing their preferences and sharing this information between all relevant parties involved in caring for the dying person

- education and training in care of the dying should be mandatory for all health and social care staff involved in end-of-life care, including skills in communicating with and supporting families, carers and other advocates. This should be a priority for Health Education England

- where indicated, specialist palliative care services should be available seven days a week, to support dying patients and their families and carers, including making effective use of technology

- research into the key issues raised by the National Care of the Dying Audit and VOICES survey should be expedited, including developing guidance on the recognition of dying, hydration and nutrition, symptom control, and communication. The National Institute for Health Research should continue to prioritise its support of a better evidence base for these aspects of care (as detailed in Once Chance to Get it Right)

- further evidence is needed on the economic costs of different care settings and potential savings from greater use of community care. Results from the palliative care pilots should be evaluated and shared as soon as possible

- as commissioners focus more on quality and integration of care, new incentives that encourage closer partnership working between care providers should be developed, including the alternative funding models recommended by the King’s Fund, underpinned by the outcome of the Palliative care funding pilots

- commissioners should require all care providers to audit end-of-life care, incorporating the views of bereaved relatives, at least annually, as part of any contracts or other funding arrangements

- participation in future national clinical audits should be encouraged, including extending these audits to general practice and care homes.
## Figure 7. Actions to improve end-of-life care

<table>
<thead>
<tr>
<th>Early identification of patients in last year of life</th>
<th>Needs assessment and care planning</th>
<th>Co-ordination of patient care</th>
<th>Delivering high quality care in different settings</th>
<th>Care in the last days of life</th>
</tr>
</thead>
</table>
| • use risk stratification to identify patients at end-of-life | • single health and social care home assessment | • appoint end-of-life care co-ordinator to co-ordinate high quality care:  
  - clearly apportion responsibility for aspects of care  
  - ensure effective co-ordination of care and case management  
  - single point of contact for patients and carers 24/7  
  - review physical care and equipment needs  
  - ambulance services given access to appropriate information | • ensure all staff providing end-of-life care have appropriate training  
• care provision should reflect the Priorities for Care  
• audit care provided against agreed standards such as the GSF  
• promote spreading of good practice. | • GP/hospital formal identification of the dying phase in all settings  
• support patients to die in the setting of their choice including meeting their physical, practical, psychological and spiritual needs  
• ensure access to appropriate symptom control  
• ensure support for carer(s)  
• recognise and confirm wishes regarding resuscitation and organ donation. |
| • communicate clearly with people identified as at end-of-life and record discussion | • agree and record individual care plans and regular review of needs and preference | • timing of reviews and planned visits escalated based on whether patient is in last year, months, weeks or days of death | • common input e-forms for use by appropriately trained staff to place patients on an end-of-life care register. | • appoint end-of-life care co-ordinator to co-ordinate high quality care:  
  - clearly apportion responsibility for aspects of care  
  - ensure effective co-ordination of care and case management  
  - single point of contact for patients and carers 24/7  
  - review physical care and equipment needs  
  - ambulance services given access to appropriate information | • develop common e-record that can be shared by all staff (EPaCCs or similar) and by patient and whoever the patient agrees should have access. |
| • common input e-forms for use by appropriately trained staff to place patients on an end-of-life care register. | • assess needs of carers. | • ensure all staff providing end-of-life care have appropriate training | • care provision should reflect the Priorities for Care  
• audit care provided against agreed standards such as the GSF  
• promote spreading of good practice. | • ensure access to appropriate symptom control  
• ensure support for carer(s)  
• recognise and confirm wishes regarding resuscitation and organ donation. |

Source: Deloitte UK Centre for Health Solution’s research, 2014
Notes

1. Dying Healed: Transforming End-of-Life Care through Innovation. Report of the End-of-Life Care working group. Sir Thomas Hughes-Hallett, Professor Scott Murray, Dr James Cleary, Dr Liz Grant, Dr Richard Harding, Professor Alex Jadad, Dr Mark Steedman and Karen Taylor OBE, December 2012. See also: http://www.wish-qatar.org/app/media/386


14. Factors influencing death at home in terminally ill patients with cancer: systematic review, Gomes & Higginson, April 2006. See also: http://www.bmj.com/content/332/7540/515


16. How many people need palliative care? A study developing and comparing methods for population-based estimates, Murtagh FEM, Bausewein C, Verne J, Groeneveld EI, Palliative Medicine, May 2013. See also: http://pmj.sagepub.com/content/early/2013/05/20/0269216313489367.abstract

19 Deprivation and Death: Variation in place and cause of death, National End-of-life care intelligence network, February 2012. See also: http://www.endoflifecare-intelligence.org.uk/resources/publications/deprivation_and_death
27 Care home residents least likely to be hospitalised, Nuffield Trust, March 2012. See also: http://www.nuffieldtrust.org.uk/media-centre/press-releases/care-home-residents-least-likely-be-hospitalised
31 The quality of death – Ranking end-of-life care across the world, the Economist Intelligence Unit Commissioned by the Lien Foundation, 2010. See also: www.eiu.com/sponsor/lienfoundation/qualityofdeath
34 National Care of the Dying audit for Hospitals 2013-14, Royal College of Physicians, May 2014. See also: https://www.rcplondon.ac.uk/sites/default/files/ncdah_exec_summary.pdf
37 National Survey of Patient Activity Data for Specialist Palliative Care Services – Minimum Data Set report 2012-13, National Council for Palliative Care, June 2014. See also: http://www.endoflifecare-intelligence.org.uk/resources/publications/mds_report


43 One chance to get it right – improving people’s experience of care in the last few days and hours of life, Leadership Alliance for the Care of Dying People, June 2014. See also: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

44 Ibid


49 Ibid

50 Ibid


52 Complexity and costs, Cicely Saunders Institute – King’s College London. See also: http://www.csi.kcl.ac.uk/studies/study-complexity-and-costs.html

53 Marie Curie Delivering Choice Programme publications and evaluations. See also: http://www.mariecurie.org.uk/en-gb/Commissioners-and-referrers/Resources/publications-and-evaluations/?Tab=2

54 National Survey of Patient Activity Data for Specialist Palliative Care Services – MDS Full Report for the year 2012-2013, National Council for Palliative Care, June 2014. See also: http://www.ncpc.org.uk/sites/default/files/MDS%20Report%202013_1.pdf

55 The impact of the Marie Curie Nursing Service on place of death and hospital use at the end-of-life, Nuffield Trust, November 2012. See also: http://www.nuffieldtrust.org.uk/publications/marie-curie-nursing

56 Midhurst Macmillan Community Specialist Palliative Care Service, King’s Fund, April 2013. See also: http://www.kingsfund.org.uk/publications/midhurst-macmillan-community-specialist-palliative-care-service


59 Last orders – rationale behind his Bill on the right to die at home, Norman Warner, July 2014. See also: http://www.labourlords.org.uk/last-orders


61 The Gold Standard Framework Centre in End of life Care. See also: http://www.goldstandardsframework.org.uk/

62 Journal of Palliative Nursing Awards 2014, in collaboration with Macmillan Cancer Support. See also: http://awards.ijpn.co.uk/

63 St Christopher’s Group Annual Report 2013-14, St Christopher’s Joining up Care. See also: http://www.stchristophers.org.uk/sites/default/files/annualreview/St%20Christopher%27s_Group_Annual_Review_2013-14.pdf

64 Delivering a Digital Death, Cross, M, BMJ 2013;346:f2528, April 2013. See also: http://www.bmj.com/content/346/bmj.f2528

65 Co-ordinate My care. See also: http://www.coordinatemycare.co.uk/index.html


67 End-of-life Care for All – e-learning project, Health Education England. See also: http://www.e-lfh.org.uk/projects/end-of-life-care/

68 Never the right time: advanced care planning with frail older people, Eynon T, Lakhani, MK and Baker R, British Journal of General Practice, October 2013. See also: http://bjgp.org/content/63/615/511.full.pdf

69 Patient Knows Best: Manage Your Health. See also: http://www.patientsknowbest.com/

70 Think ahead and plan for End of Life, July 17th. See also: http://www.thinkahead.ie/taoiseach-launches-think-ahead-phase-2/


72 Matter of life and death – helping people to live well until they die, General practice guidance for implementing the RCGP/RCN End of Life Care Patient Charter, August 2012. See also: http://www.rcgp.org.uk/~/media/CIRC/Matters%20of%20Life%20and%20Death%20FINAL.ashx


74 Unplanned admissions DES could cause harm to dying patients, experts warn, Pulse Today, September 2014. See also: http://www.pulsetoday.co.uk/news/clinical-news/unplanned-admissions-des-could-cause-harm-to-dying-patients-experts-warn/20007515.article#.VBWkqDZwbIV

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