

Institute for Public Policy Research



# END OF LIFE CARE IN ENGLAND

A BRIEFING PAPER

11

**Jack Hunter** with  
**Martina Orlovic**

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IPPR  
14 Buckingham Street  
London  
WC2N 6DF  
T: +44 (0)20 7470 6100  
E: [info@ippr.org](mailto:info@ippr.org)  
[www.ippr.org](http://www.ippr.org)  
Registered charity no: 800065 (England and Wales),  
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## ABOUT THE AUTHORS

**Jack Hunter** is a research fellow at IPPR North.

**Martina Orlovic** is a PhD candidate in the Department of Surgery and Cancer, Faculty of Medicine, Institute of Global Health Innovation, Imperial College London.

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# 1. INTRODUCTION

Death is an inevitable part of life. We will all die and almost all of us will experience the death of someone close to them. Dying is an incredibly important life stage, but for too many people the end of life can often be an unnecessarily difficult experience.

Every year in England and Wales over 500,000 people die (ONS 2017). For three-quarters of these people, death does not come suddenly. Instead, dying is a process that may take days, weeks or even years, involving a progressive decline in functioning and frequent interactions with health professionals. During this time, many receive some form of end of life care, designed to ease any pain or distress caused by their symptoms, and to maximise their quality of life until the moment of their death (Hughes-Hallett et al 2011).

The value of this care cannot be understated, not just for those people who are reaching the end of their lives but also for their families and carers.

The need for end of life care is growing. This is partly because the population as a whole, and the older population in particular, is increasing: the number of annual deaths is expected to rise by almost 10 per cent by 2030, to 574,000 (ONS 2016a).

In addition, the increase in the number of those with long-term health conditions means that people are more likely to require complex care for an extended period of time before their death. For example, the Department of Health estimated in 2012 that there were 15 million people in England with a long-term health condition, expected to rise to 18 million by 2025. The number with two or more long-term conditions is projected to increase from 5 million to about 6.5 million (Department of Health 2012b).

Partly in response to these projections, end of life care has been a policy priority for successive governments in the UK,<sup>1</sup> as it is for many others in countries around the world.<sup>2</sup> Specifically, there is considerable interest in a) improving the *quality* of care provided at the end of life, and b) reducing the overall cost of end of life care.

A key element of this has been a focus on the *location* of end of life care. In particular, it is thought that reducing the proportion of people who spend their final days and weeks in a hospital setting is highly desirable from the perspective of *quality* and *cost* of end of life care. Survey data on public preferences also suggest that, given the choice, a majority of people would prefer to die at home,<sup>3</sup> although drawing hard conclusions from this type of data is difficult.

Long-term care systems involve multiple different stakeholders, including not only health bodies such as hospitals, specialist palliative care teams, GPs and community nurses (as well as Clinical Commissioning Groups and Hospital Trusts) but also social care providers (which are commissioned by the local authority) and voluntary sector partners who run hospices and care homes, as well as patients themselves, their families and carers. Any efforts to change how end of life care is designed and delivered in England must ensure that resources and funds available to the system as a whole are allocated efficiently, in order to eliminate

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1 Department of Health and Social Care (2008); Department of Health (2012a)

2 See Robinson et al (2016) for examples

3 For example Natcen Social Research (2017)

unnecessary suffering on the part of individuals, while improving the overall cost-effectiveness of care at the end of life.

This issue (of allocative efficiency in end of life care) will be the focus of a collaborative programme of work between the Centre for Health Policy, Imperial College London, the University of Lausanne in Switzerland, the University of Edinburgh and IPPR, supported by the Health Foundation. The aim of this programme is to determine whether improvements in the efficiency of health and social care delivery at the end of life could enable access to higher-quality and more personalised care for patients.<sup>4</sup>

The programme will use large administrative datasets from England and Scotland with patient-level data to better understand trajectories of patients at the end of life and will assess variation in health care use, costs and care quality between and within countries. This data-driven approach will be complemented by interviews with patients and policymakers to elicit barriers and facilitators of improving care delivery at the end of life, with further outputs expected in 2019.

The purpose of this short briefing paper is to lay some of the foundations for this programme of work. To this end it will:

- provide a brief summary of issues around end of life care, including an overview of evidence regarding the impact of location on the quality and cost of care
- analyse data on the current location and cost of end of life care in England, how this compares at an international and sub-national level
- appraise the current policy agenda of the UK government and NHS England with regard to end of life care, and suggest key areas where improvements should be made.

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<sup>4</sup> For further details see <https://www.health.org.uk/programmes/efficiency-research-programme/projects/allocative-efficiency-end-life-care>

## 2. ISSUES IN END OF LIFE CARE

This chapter will provide an overview of the existing evidence behind the role of different care settings in determining both the **quality** and **cost** of end of life care. It also considers evidence on public attitudes to dying and the end of life.

### DEFINING 'END OF LIFE' CARE

End of life care encompasses the care for patients that are considered to be in the last stage of their lives. It includes care provided to “all those with [an] advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support” (Department of Health and Social Care 2008).

In recent years, end of life care has become a policy priority in many countries (Hall et al 2011). In England, there have been successive government-led reviews of end of life care,<sup>5</sup> in addition to considerable activity led by and including NHS bodies, regulators and the voluntary sector.

A recurring feature of policy discussions on end of life care has been towards reducing the proportion of people who receive end of life care in hospital. The arguments often put forward for moving more end of life care out of hospitals and into the community are threefold.

1. **Quality** of care is understood to be **higher** outside of hospital settings, at least in part because it allows for a more joined-up and holistic approach.
2. The overall **cost** of care is understood to be **lower** outside of hospital settings.
3. It is thought that, given a choice, **most people would prefer to die at home**.

The weight of evidence behind each of these is explored briefly below.

### QUALITY OF CARE

Compared to the rest of the world, and across the population as a whole, England is a good place to die. A 2015 report by the Economist Intelligence Unit, for example, rated the UK the best place to die out of 80 countries (EIU 2015). And the most recent National Survey of Bereaved People - which reported responses from more than 21,000 people – found that 75 per cent rated their loved one’s care as ‘outstanding’, ‘excellent’ or ‘good’ (ONS 2016b).

End of life care is a vital part of this. There is evidence that that end of life care can have significant benefits in terms of quality of life for patients<sup>6</sup> with advanced stages of cancer,<sup>7</sup> and other diseases.<sup>8</sup>

5 For example, Department for Health and Social Care (2008); Department of Health (2012a); Department of Health (2017); NHS England (2014); The Choice in End of Life Care Programme Board (2015); NHS 5 year forward

6 Zimmerman et al (2008)

7 For example Hui et al (2014); Bakitas et al (2015); Smith et al (2012) Zeigler et al (2018)

8 Detering et al (2010) Salisbury et al (1999); Gade at al (2008)

But there is also considerable evidence that, despite this, the experience of end of life care can be poor for too many people in England today. Specifically:

- a government-commissioned review into choice in end of life care found that, although many experienced good quality care provision, there were “too many examples of poor care” that mean that for many people their choices and preferences are not heard or delivered (The Choice in End of Life Care Programme Board 2015)
- the House of Commons Health Committee (2015) found “great variation in quality and practice across both acute and community settings”
- a report by the Parliamentary and Health Service Ombudsman (2015) suggested that complaints around end of life care were a “recurring and consistent theme” in their casework. In particular, there were issues around:
  - not recognising that people are dying, and not responding to their needs
  - poor management of symptoms
  - poor communication
  - inadequate out-of-hours care
  - poor care planning
  - delays in referrals and care transfers
- the National Palliative and End of Life Care Partnership (2015) concluded in a review of evidence that considerable inequalities exist in the quality of end of life care that mean, for example, that poorer quality of end of life care is more likely for:
  - people from black and minority ethnic communities and deprived areas
  - people who live in very rural or other isolated areas
  - those with learning disabilities, dementia and non-malignant long-term conditions
  - people who are homeless.

The weight of evidence strongly suggests that quality in care varies considerably. Within this, location of care is an important factor.

End of life care can be delivered across different institutional settings. These include clinical settings such as **hospitals**, dedicated palliative care institutions such as **hospices**, or at **home**.

Of these, there is considerable, albeit not yet comprehensive, evidence that a proportion of those who currently receive care in a hospital setting would be better off elsewhere. While hospitals will often be the first point of contact for many people at the end of life, they are not necessarily the best place for symptom management.

Specifically this is because:

- **People are less likely to experience good quality of care in hospitals.** In the National Survey of Bereaved People in England, family members of people cared for in hospitals are consistently less likely to express satisfaction with the quality of end of life care their loved one receives. Likewise, the National Palliative and End of Life Care Partnership (2015) identified “unacceptable variations in aspects of palliative and end of life care such as access to pain control, related to different care settings”, and the Health Service Ombudsman found that the “reasonable expectation that an older person or their family may have of dignified, pain-free end of life care, in clean surroundings in hospital, is not being fulfilled”.



- **People in hospital are at higher risk of unnecessary medical treatment.** There is evidence that people receiving treatment in hospitals at the end of life are more likely to be encouraged towards additional medical treatments. This is the case particularly among cancer patients.<sup>9</sup>

Many such treatments do not improve quality of care. For example, patients receiving chemotherapy near the end of life do not live longer than patients not receiving such therapy (Nappa et al 2011; Saito et al 2011), and some forms of treatment may even negatively affect life expectancy (Greer et al 2011).

On the other hand, however, such treatment is associated with poorer quality of life, including increased physical and psychological distress.<sup>10</sup>

- **People who receive care in hospital are at disproportionate risk of further harm, which can impact upon the quality of end of life care.** There is considerable evidence<sup>11</sup> that hospitalisation can have a significant negative impact on patients' health, in particular that of older patients, through loss of muscle mass, risk of falls, pressure damage, acquired infection, and for those with dementia or cognitive impairment, in particular confusion and delirium.

## FINANCIAL COST OF CARE

Given the care implications of an ageing population, and the associated and increasingly pressing need for a sustainable funding arrangement for health and social care for the 21st century,<sup>12</sup> managing the financial cost of end of life care is of increasing importance, not least because the end of life is strongly associated with higher healthcare costs (Hazra et al 2017; Howdon and Rice 2018).

There is evidence that access to specialist end of life care can reduce costs that accrue through unnecessary primary care use. For example, specialist palliative care has been shown to reduce hospital admissions (Henson et al 2015; Seow et al 2014), with further benefits (including a reduction in the likelihood of costly and often aggressive treatments such as chemotherapy in the last days of life) accruing where patients can access palliative care at an early stage (Zeigler et al 2018).

A comprehensive review on the cost-effectiveness in end of life care (i.e. including both generalist and specialist care) was published last year by Public Health England (PHE 2017b). It considered evidence from 44 studies from both the UK and overseas. It concluded that the weight of evidence suggested that palliative care interventions were cost-effective – primarily because they involved in shifting care away from acute hospitals. It's worth noting that an academic review of international evidence reached similar conclusions (Smith et al 2012).

Notable studies included:

- A large review of evidence (Dixon et al 2015) concluded that it was “promising” that end of life care interventions are cost-effective such that that investment in good quality palliative care is likely to be offset by reductions in acute care costs.
- A Nuffield Trust report (Georghiou and Bardsley 2014) modelled the costs of greater take up of a community-based Marie Curie nursing service. They estimated a potential net saving of £487 per person during the last three months of life by shifting care from the hospital to the community. Daily costs in a hospital setting were observed to rise “very rapidly” in the final week of life, with the increase primarily driven by a rise in unplanned and emergency inpatient activity.

9 For example, see evidence cited in Davis (2015)

10 For example, see evidence cited in Davis (2015)

11 Monitor (2015); NAO (2016); Andrews et al (2017); Collier (2012)

12 See: <https://www.ippr.org/blog/the-nhs-desperately-needs-a-new-vision-for-the-21st-century>

- A 2008 report from RAND Europe and NAO, which modelled the different costs associated with different care settings at the end of life. The estimated that the total cost of providing care in the last year of life to the nearly 127,000 patients who died from cancer every year. is approximately £1.8 billion, corresponding to £14,236 per patient. For the nearly 30,000 organ failure (heart and respiratory diseases combined) patients that are in their last year of life the cost of providing care is £553 million, or £18,771 per patient.

However, despite the large number of studies considered, the PHE review found that none constituted a comprehensive and robust analysis of all economic costs. Many were flawed in their study design and in the robustness of data collected, which hampered the degree to which firm conclusions could be drawn. In addition, few studies consider the additional community costs and informal cost to carers involved in shifting the location of care.

Because of these limitations, although the weight of evidence points to a reduction in costs to the taxpayer when end of life care is shifted out of hospitals, the exact extent of the cost-savings cannot be determined with confidence. In addition, there is little clear indication of the extent and nature of those costs that accrue to families and carers when care is shifted into the community. This gap in the evidence base will be addressed in the wider programme of work.

## **PUBLIC ATTITUDES TO END OF LIFE CARE**

That most people would prefer to die at home is a common assertion made in policy documents regarding end of life care.<sup>13</sup>

This is often based upon analysis of survey data, such as the international PRISMA telephone survey for example, which suggested that at least two-thirds of people prefer to die at home, or the VOICES survey of recently bereaved relatives.

This evidence is often used to suggest a clear desire on the part of the general public for shifting end of life care into the community. In fact, there are limitations in the data which make it hard to draw strong conclusions.

Firstly, in many surveys, a large proportion of patients do not have a preference, or change their preferences away from home to hospital as they age or their illness progresses (Wood and Salter 2013; Murtagh et al 2012).

Secondly, the concept of ‘home’ differs between individuals and in many cases signifies something more than just a physical location. Instead, the concept of ‘home’ in the context of end of life care is usually understood as representing familiarity, comfort and the presence of loved ones (Collier et al 2015; Gott et al 2004). This implies an important role for well-resourced and trained palliative care professionals, who the evidence suggests can help to improve patients’ feelings of security when facing life-limiting illnesses at home (Sarmiento et al 2016).

Finally, some surveys don’t ask people to weigh up the importance of location against other pertinent issues, such as access to clinical support or minimising any burden, real or perceived, on family members. This is important because for many people control of symptoms, especially pain, and being accompanied by loved ones can be more important issues than physical location (Pollock 2015).

In fact, when people are asked more generally about their preferences in dying and at the end of life, it is clear that the location of care is one factor among many. For example, the government-commissioned Review of Choice in End of Life Care (The Choice in End of Life Care Programme Board 2015) set out a ‘national choice

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<sup>13</sup> See for example Department of Health and Social Care (2008); Department of Health (2012a)

offer' comprising seven elements of end of life care that people might desire control over.

1. I want involvement in, and control over, decisions about my care.
2. I want access to high quality care given by well trained staff.
3. I want access to the right services when I need them.
4. I want support for my physical, emotional, social and spiritual needs.
5. I want the right people to know my wishes at the right time.
6. I want to be cared for and die in a place of my choice.
7. I want the people who are important to me to be supported and involved in my care.

However, it is also clear that location plays a role in determining the likelihood that people are consulted about their wishes for end of life care - with the care needs of many people in hospital not identified. For example, a national audit of English hospitals found that discussions with patients about their wishes for end of life care are recorded in less than half of cases (Royal College of Physicians and Marie Curie Palliative Care Institute 2014).

Overall, then, the evidence regarding public preferences suggests that people are generally supportive of policy efforts to move a greater proportion of end of life care into the community, *but only if* they can rely upon a comprehensive and high quality system of care that gives them control over other elements of care that they also consider important.

## SUMMARY

The evidence generally supports a shift to community, away from hospitals, on the grounds of:

- improved quality
- lower cost
- public choice.

For many people hospital is the right place for them to die. But for others it may not be – the question for policymakers is what proportion of those people who end their lives in hospital might have been better cared for, at lower financial cost, in non-clinical settings.

The next chapter will analyse data, including comparisons between the UK and other countries, to examine:

- the degree of variation in the proportion of people dying in hospital (and therefore the extent to which the number of hospital deaths can be reasonably expected to be reduced)
- the reasons that underpin such variation.

# 3. LOCATION OF END OF LIFE CARE - ANALYSIS

This chapter will consider analysis of the current settings where end of life care is available in England compared with other European nations, and how this breaks down below a national level. The intention is to use this analysis to understand the degree to which there is scope for the proportion of people who receive care in hospital could be reduced.

Given the evidence explored in chapter 2 that broadly supports increasing the proportion of people who die outside of hospital, it will also consider the obstacles to further reducing the proportion of people who receive end of life care in hospital.

### A NOTE ON DATA ANALYSIS OF END OF LIFE CARE

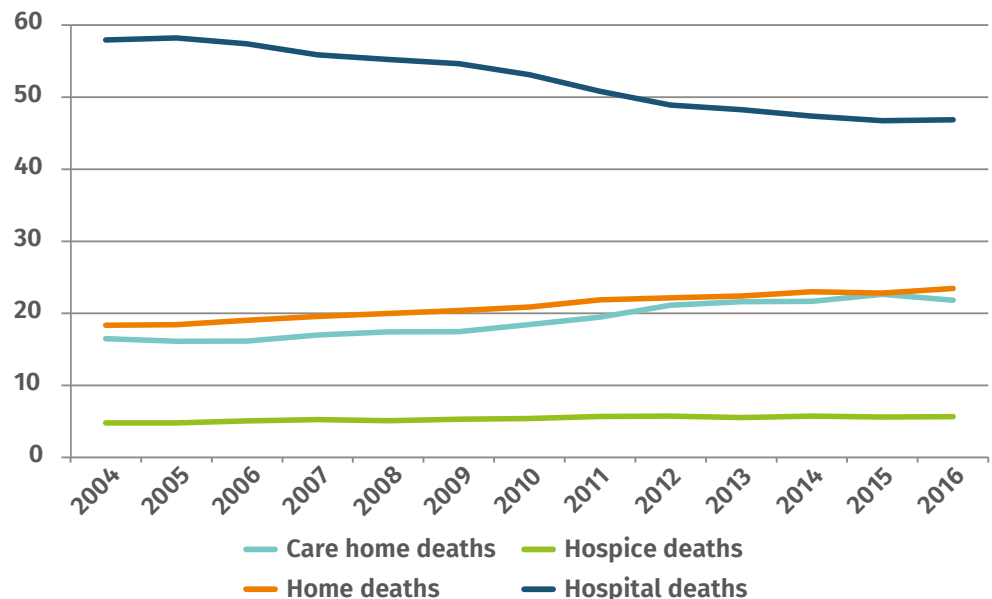
In this section, we use data on location of death to explore the issues associated with the location of end of life care. This is a feature of many other reviews, however it should be noted that for ease of analysis we assume place of death and place of care to be the same – which ultimately limits the strength of any conclusions drawn.

According to the most recent data, just under half of all deaths in England occur in hospital. This number has been steadily decreasing over the past decade, from 58.2 per cent in 2005 to 46.7 per cent in 2015 (see figure 3.1 below).

**FIGURE 3.1**

**The proportion of hospital deaths in England is steadily decreasing**

*Location of deaths in England (%), 2017*



Source: PHE 2017a

But compared to some other countries in Europe, England still has a relatively high proportion of hospital deaths (see table 3.1).

**TABLE 3.1**

**Compared to other European countries, England has a high proportion of hospital deaths**  
*Location of deaths in European countries (%)*

Country	Home	Hospital	Care home
Netherlands	37%	31%	28%
Sweden	22%	38%	36%
Greece	49%	40%	1%
Switzerland	24%	40%	31%
Denmark	25%	40%	31%
Italy	49%	43%	4%
Belgium	31%	46%	19%
Germany	33%	47%	15%
<b>England</b>	<b>23%</b>	<b>47%</b>	<b>28%</b>
Estonia	38%	47%	8%
Austria	35%	47%	10%
Poland	43%	51%	3%
Ireland	35%	51%	11%
France	26%	52%	13%
Spain	38%	53%	6%
Israel	29%	59%	6%
Czech Republic	22%	63%	10%
Slovenia	27%	63%	4%

Sources: analysis of data from the Survey of Health, Ageing and Retirement in Europe; PHE 2017a

The picture at a national level obscures considerable variation in the likelihood of dying in hospital by region. In particular, there is a considerably higher proportion of hospital deaths in London (53.2 per cent), and in the West Midlands (49.5 per cent), North West (48.7 per cent) and North East (48.1 per cent).

**TABLE 3.2**

**There is considerable variation in location of death by region in England**  
*Proportion of deaths that occur in hospital by region (%)*

Region	% hospital deaths	Region	% hospital deaths
South West	42%	North East	48%
South East	43%	North West	49%
East of England	45%	West Midlands	49%
Yorkshire and the Humber	46%	London	53%
East Midlands	48%	<b>England</b>	<b>47%</b>

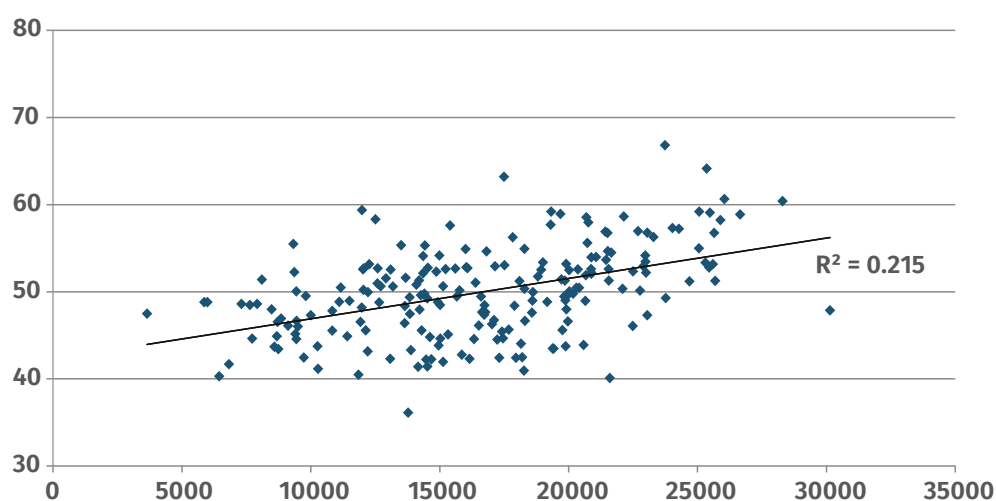
Source: PHE 2017a

In addition, there is a correlation between deprivation and likelihood of dying in hospital, with a higher proportion of people living in more deprived areas who die in hospital. This is perhaps to be expected: deprivation is linked to household finance, quality of housing, family situation, as well as health indicators, all of which are likely to affect people’s ability and/or desire to spend their final days outside of hospital. This reflects the findings of the Marmot review, which demonstrated more generally that health inequalities flow from social inequalities (Marmot et al 2010).

**FIGURE 3.2**

**There is a correlation between deprivation and the likelihood of dying in hospital at the level of the Clinical Commissioning Group (CCG)**

*Proportion of deaths that occur in hospital by CCG (%) and IMD average rank of CCG*



Sources: PHE 2017a, ONS (2015) IMD - Average rank

Taken together, the variation in hospital deaths that occurs both between different European countries and within England itself suggests that there is significant scope for policy to reduce the proportion of people who spend their final days in hospital – and in doing so potentially develop a model for end of life care that is of higher quality and lower in terms of net cost to the taxpayer.

This makes it important to understand the reasons behind this variation - which may lead us to identify those factors that may be within the scope of policy to influence.

### **WHAT INFLUENCES THE LOCATION OF END OF LIFE CARE?**

Our analysis of the literature leads us to the conclusion that there are three primary policy levers that explain the current location of death in England.

1. **Workforce training on end of life care.**
2. **Integration of services.**
3. **Funding for social care.**

We explore each of these briefly below.

#### **WORKFORCE TRAINING ON END OF LIFE CARE**

Of all the people that health professionals work with on a day-to-day basis, a significant proportion will be (knowingly or otherwise) in their last year of life.

One study of inpatient data to a single London hospital, for example, suggested that over one in five people over 70 years old who are admitted into hospital will die within a year (Bielinska et al 2016).

This implies that doctors, nurses and other health practitioners can play a key role in identifying people who may be entering end of life who would benefit from advance care planning. Advance care planning has been shown to improve end of life care by helping the person to live and die in the place and the manner of their choosing (Brinkman-Stoppelenburg 2014). Effective communication by health professionals helps to ensure high quality end of life care (Parry et al 2013) and staff training and development has been identified as a necessary first step to increasing the number of people offered end of life care (Hughes-Hallett et al 2011).

But few health professionals receive proper training on caring for the dying (NCPC 2016). A 2014 survey of nurses suggested that just over one in 10 (10.5 per cent) felt equipped to deliver the appropriate care at the end of life. And only a minority of health trusts provide mandatory training for doctors and nurses on caring for people at the end of life (NCPC 2016).<sup>14</sup>

Training programmes for doctors, nurses and other NHS staff have historically favoured – and continue to promote – a highly medicalised view of the world. Some (such as Gawande 2014) have argued that those in the medical profession tend to pursue the – often misplaced – hope of extending life when they should instead be recognising the reality of approaching death and discussing how to maximise the quality of the time left to patients.

Having trained non-specialists can help to identify patients who are in the final year of life, in order to develop a care plan for them that may reduce the likelihood that they experience an unplanned admission to hospital. A recent Care Quality Commission (CQC) report found that people who might benefit from end of life care are not being identified early enough, and that poor communication is preventing others from receiving a good standard of care (CQC 2016).

## **INTEGRATION OF HEALTH AND CARE SYSTEMS**

The integration of health and care systems is considered an important foundation to higher quality and more cost-effective models of care that form part of a modern health and care system. In particular, integrated systems help to reduce the time spent in hospital settings, both in terms of decreased hospital admissions and easier transfers from acute care (Purdy 2010; Bickerstaffe 2013).

This is particularly the case for end of life care, where a large proportion of people are likely to have multiple health conditions that often necessitates interaction with a complex network of different services and providers. The integration of health and care systems is seen as an important step towards enhancing the quality, efficiency, and patient satisfaction of end of life care.<sup>15</sup>

Commissioning is a key element to this. The creation of pooled and place-based budgets and commissioning functions across public services is seen as a crucial step towards achieving integrated services on the ground (Alderwick et al 2015).

However legislation introduced through the 2012 Health and Social Care Act has fragmented the commissioning landscape, making integration significantly harder (Timmins 2012). The introduction of Sustainability and Transformation Plans can to some extent mitigate the impact of the 2012 Act, and have led to the development

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<sup>14</sup> In 2016 training on caring for the dying was only mandatory in 22 per cent of trusts for doctors and 29 per cent of trusts for nurses

<sup>15</sup> See for example Bardsley et al (2013), Wolfe et al (2016), RAND (2012)

of many ambitious and promising solutions for reforming health and care, although local partners face a number of challenges to putting these into practice (Quilter-Pinner 2017b).

### FUNDING FOR LONG-TERM AND COMMUNITY-BASED CARE

A more community-based system for end of life care depends upon financial investment in social care, as well as changes to funding in the NHS to address the historic underfunding of primary and community care compared to hospitals (NAO 2018b).

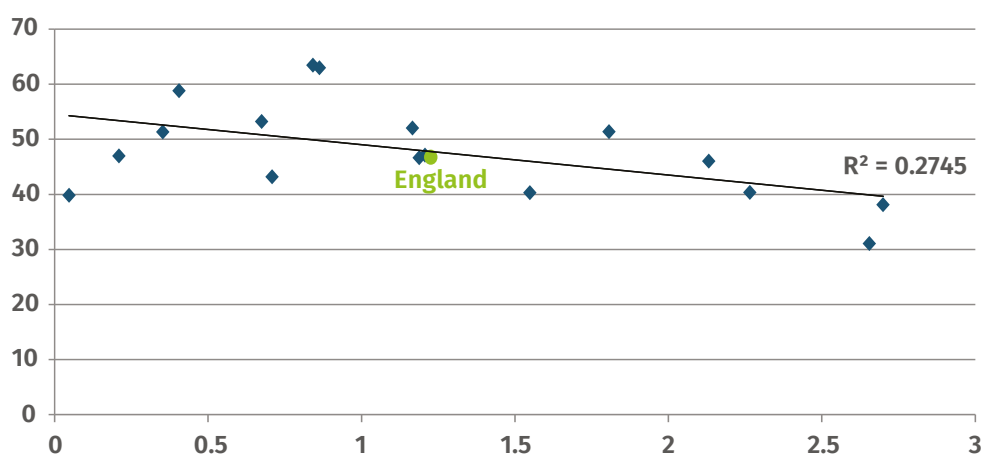
Analysis undertaken for this project indicates that countries that have higher levels of public investment in long-term care<sup>16</sup> as a proportion of national GDP directed towards public spending on long-term care, the lower the proportion of people dying in hospital (see figure 3.3)<sup>17</sup>

As can be seen below, the data for England matches the overall trend. Although significant differences exist in the organisation of long-term care systems between different countries, this suggests that increasing public investment in long-term care in England to a commensurate level to countries with more developed infrastructure for long-term care could result in a significant decrease in the proportion of people who die in acute care settings. If the proportion of deaths that occur in hospital in England was as low as it is those countries (notably the Netherlands but also Sweden and Switzerland), it could mean that as many as one in three of those who currently spend their final days in a hospital might be treated at home or in the community.

**FIGURE 3.3**

#### Increased public expenditure on long-term care appears to affect the proportion of hospital deaths across European countries and Israel

*Proportion of deaths that occur in hospital (%) and public expenditure on long-term health care as % of GDP*



Note: Health expenditure figure is for UK as a whole

Sources: OECD.stat Dataset: Health expenditure and financing; analysis of data from the Survey of Health, Ageing and Retirement in Europe; PHE 2017

<sup>16</sup> Long-term care refers to care services for people with chronic health problems that affect their ability to perform everyday activities. In contrast to rehabilitative or curative care, long-term care often involves a wide range of services and tends to be designed towards symptom management and preventing further deterioration



The international evidence, therefore, supports an argument for increased spending on long-term care in order to increase the likelihood that end of life is spent outside of hospital setting. In particular, a more comprehensive and accessible care system may reduce the number of admissions to hospital, particularly emergency admissions.

In 2016/17, 24 per cent of emergency admissions to hospital were potentially avoidable (National Audit Office 2018a). Despite this, the number of emergency admissions to hospital is steadily increasing (up nearly 10 per cent from 2013/14 to 2016/17), driven primarily by an increase in the number of people aged 65 and over being admitted to hospital. This increase has corresponded with a sustained reduction in social care.

Although the evidence base is not yet conclusive (Gott et al 2013), various recent studies suggest that hospital admissions could be reduced significantly if patients were offered high quality community support.

For example, a Cochrane review of evidence from the UK, USA, Sweden, Norway, Italy, Spain, Canada and Australia (Gomes et al 2016) concluded that there was robust evidence that palliative care services in the home double the odds of home death when compared to usual care. Hospital admissions appear to be lower in countries such as the Netherlands, where GPs are trained and supported to prevent hospital readmissions at the end of life, combined with a high level of coordination in primary care (Pivodic et al 2015). And Orlovic et al (2017) find a correlation between increased expenditure on long-term care and reduced hospitalisations between the countries studied.

This chapter finds that there is considerable scope to reduce the likelihood that people spend their final days in a hospital setting, both at a national level and below. It explores the three key areas that evidence suggests determine the variation in end of life care. The concluding chapter will briefly explore the current policy context in England and set out some top-level recommendations for change.

## 4. CONCLUSIONS AND KEY AREAS FOR POLICY

This chapter will briefly set out the current policy context with regard to end of life care and highlight key areas for policymakers to consider in order to ensure a greater proportion of care is delivered in the community.

Across central government, the NHS and the voluntary sector, there is a consensus that there is considerable scope to improve the way that care is designed and delivered for those reaching the end of their lives.

In addition, at a time when the NHS is having to deal with the longest period of funding constraint in its history, there is also keen interest in ensuring that care at the end of life, which is disproportionately expensive compared to care at other stages of life, is cost-effective as well as of the highest quality.

The location of care is a key consideration in debates about how to make end of life care more effective, more equitable and more cost-effective.

Most recently, and as part of the wider ‘mandate for NHS England’ (Department of Health 2017), the government has explicitly set an expectation for a significant improvement in patient choice at end of life care by 2020, including “ensuring an increase in the number of people able to die in the place of their choice, including at home”.

Likewise, NHS England is currently working with other national organisations from across the public and voluntary sectors through the National Palliative and End of Life Care Partnership, in order to improve palliative and end of life care through “partnership and collaborative action between organisations at local level”.<sup>17</sup>

This is in line with policy trends across the health service more generally. For example, the Five Year Forward View calls for out-of-hospital care “to become a much larger part of what the NHS does” and acknowledges the importance of people getting the “right care, at the right time, in the right setting, from the right caregiver” (NHS England 2014).

But despite these top-level commitments, there is considerable work to put this into practice. In particular, there has been very little sign that policymakers are taking seriously the need for substantial financial investment in order to rebalance the location of health care away from hospitals and towards primary and community care (Darzi 2018).

There is also a hugely urgent and well-documented need to establish a sustainable and effective funding system for social care in England, not least as a means to ensuring a comprehensive system of care in the community that is able to effectively relieve the current levels of demand upon acute care settings in England today (ibid).

In this report, we argue that investment in community-based end of life care will generate long-term pay-offs for the health and care system as a whole. This is because of the considerable evidence that this type of care is most effective, both in terms of costs to the taxpayer and for the wellbeing of the patient.

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<sup>17</sup> See: <http://endoflifecareambitions.org.uk/>

The purpose of this report is to lay some of the foundations for an in-depth and comprehensive programme of work exploring allocative efficiency in end of life care. More in-depth analysis and substantive policy recommendations regarding how to enable access to higher-quality and more personalised care for patients will be forthcoming as part of this wider piece of work.

Nonetheless, the research carried out for this short paper has identified three key areas for consideration:

**1. The government, NHS organisations and Health Education England should consider ways to encourage the health and care workforce to have meaningful conversations about death and dying with those at the end of life, their families and carers.**

Despite recent improvements, too few people have meaningful conversations with medical professionals, family and other carers regarding the end of life, the options available to them with regard to care, and their personal preferences and those of people close to them. In addition, health and care staff who are not specialised in the provision of end of life care will still work with people who are at this stage in their life.

Health and care staff should be given the time, skills and confidence to allow them to engage with people at the end of life in an informed, sensitive and honest way. A cultural shift in both frontline and commissioning attitudes towards informal carers, who play a central role in ensuring good quality end of life care, is also required (Ewing and Grande 2018).

As such, hospital trusts and Sustainability and Transformation Plans (STPs) should ensure regular training on working with people at the end of life for gatekeepers such as GPs, and primary care staff to increase the likelihood that people who are acknowledged to be reaching the end of life, and their family and carers, are fully appraised of their situation and the options available to them

**2. The government should consider how to drive integration of health and care commissioning and provision at the local level and at pace, including through further devolution.**

A more effective system for end of life care should be informed by the needs of, and resources available to, local areas and their population. A more integrated approach to designing and delivering health and care provision is an important element of this.

However, despite much of the high-level policy focus of national government and NHS England has been on encouraging and developing greater collaboration and integrated working between NHS bodies and others to date, there are signs that the rhetoric does not match with reality on the ground. The reforms introduced as part of the 2012 Health and Social Care Act have undermined efforts to join up commissioning, and the continued fiscal constraints placed upon the NHS, and social care in particular, also risk undermining efforts to better align and integrate services.

At a sub-regional level, there is substantial variation in the degree to which the new Sustainability and Transformation Plans (STPs) prioritise end of life care. One analysis last year suggested that 29 out of 44 STPs did not include specific actions to improve end of life care, and two in five (18 in total) failed to mention end of life care at all (Macmillan 2017).

Commissioners and STPs should ensure that end of life care is put at the heart of their strategies, and that all relevant partners (especially non-health bodies) are involved in designing services best suited to the needs of their populations. In particular, they should be working alongside service providers to develop capacity to better support end of life care in the community.

Devolution offers a potentially important mechanism to develop a more integrated and place-based approach to end of life care, as is being demonstrated through the Greater Manchester Health and Social Care Partnership (Quilter-Pinner and Antink 2017). This is because, as well as allowing for health and care to be designed and commissioned together, it also enables much closer engagement with other important stakeholders who can play a significant role in this area, including housing associations and the voluntary sector.

As such, the government and NHS England should make it clear that they are prepared to devolve elements of health care to combined authorities or equivalent strategic local government bodies where appropriate, and where this has been proved successful.

**3. The government should consider how it will incentivise the NHS to shift towards more primary and community care, as well as determining a radical and realistic financial settlement for social care. The forthcoming the Health and Social Care Green paper is an opportunity to do this.**

The evidence presented in this paper suggests that a significant shift in the location of end of life care will require substantial investment to develop and support capacity in the community.

Firstly, if we want to shift care out of hospitals the proportion of NHS funding provided to *community and primary care* will need to increase dramatically. This should include greater resourcing for care models that enable people to spend their final days and weeks at home where possible and where appropriate. It should also include a more sustainable funding system for local hospices, who are major providers and funders of care at the end of life. Transformation funding will be necessary to assist with this (Health Foundation and Kings Fund 2015).

Secondly, significant additional investment in *social care* is necessary, in order to provide a sustainable and effective ecosystem of support that allows people to maximise their quality of life, outside of acute medical settings where appropriate and where desired, and which does not place unnecessary or undue costs on their families and carers.

This would require a significant and radical change. Spending on social care has experienced a significant decline year on year (Quilter-Pinner 2017a) and local authorities, who are responsible for designing and commissioning social care, have seen their budgets dramatically reduced annually since 2010 – forcing many to respond, in the absence of meaningful ability to raise their own funds, by increasing eligibility thresholds for care and reducing unit rates for providers.

This has had the entirely unavoidable effect of increasing unmet need (and thereby costs elsewhere in the system, including increasing the reliance on unpaid carers as well as demand pressures on the NHS), as well as negatively affecting quality and safety, by increasing demands on the workforce and placing greater strain on the provider market (Quilter-Pinner and Snelling 2017).

The government is preparing a green paper on care and support for older people, which it intends to publish by summer 2018,<sup>18</sup> and which it says will address the need for a “long-term, sustainable solution” to providing the care older people need.

This, alongside the autumn budget, represents an opportunity to set out how care will be funded in future. Specifically, it should include a long-term vision for funding primary and community health care and social care.

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<sup>18</sup> See: <https://www.gov.uk/government/news/government-to-set-out-proposals-to-reform-care-and-support>

This should involve powers to local areas where appropriate and should involve a review of local government funding needs and revenue-raising powers for the long term – as well as setting out the role for central government in setting national standards, regulation and redistribution.

However, it is far from clear that the government's vision will include the size and scale of investment for care that would be commensurate with a radical shift in funding, nor whether it will also consider long-term options (including devolved fiscal measures) to ensure the long-term sustainability of local authorities.

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