



Current and future needs for hospice care: an evidence-based report

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The Commission into the Future of Hospice Care has been established by Help the Hospices to help providers of hospice care prepare to meet the needs, challenges and opportunities that will present themselves in 10-15 years' time. It will offer practical help and advice to hospices to guide their work in the next three years as they prepare to respond to the changing context they face in the future. Its conception follows the publication of the report 'Dying for Change' by Demos in 2010 which proposed radical change to care available to people who face the end of life, their families and carers. The Commission will consider what role hospices could play in such transformation of services in the future, in order that providers of hospice care retain a significant role in shaping and delivering care for the dying and the bereaved. To find out more about the Commission, please visit: www.helpthehospices.org.uk/our-services/commission

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Cicely Saunders International was established in 2002 in the name of Dame Cicely Saunders, a founder trustee and its President. Dame Cicely is widely acknowledged as the founder of the modern hospice movement and is credited with "mentoring some of the great world leaders in this field" (Professor Eduardo Bruera). The mission of Cicely Saunders International is to promote research to improve the care and treatment of all patients with progressive illness and to make high-quality palliative care available to everyone who needs it. There is no other charity specifically concerned with carrying out work to identify and promote best practice in palliative care. To find out more about Cicely Saunders International please visit: www.cicelysaundersinternational.org

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Foreword

Six months ago, The Commission into the Future of Hospice Care commissioned Cicely Saunders International to produce an evidence-based report on the future level of need for hospice care towards the end of life. Our question: what are the demographics that will drive future demand for hospice care? Our intention: to bring together what is known and identify what still needs to be known, so that we can help hospices plan for the future.

I am delighted to welcome this working paper; it provides a comprehensive and thought provoking review of the evidence. It also delivers some stark messages and we hope that you will share your reaction to the work with us, so that we might refine our thinking about how hospices can adapt and change. The Commission aims to seek ways to help hospices understand future challenges and plan to meet future needs.

That hospices will need to change is beyond doubt. The scale of the challenge ahead is dramatic and will require hospices to significantly increase the extent and scope of end of life services. The opportunity and the test for hospices will be whether they can develop the greater reach, accessibility and complexity of service required to meet these needs. The report makes clear that the number of people dying each year is set to rise from 2016 and that this rise is a steep curve. In England alone, the number will increase by over 4,000 a year between 2021 and 2025 and by over 8,000 a year between 2031 and 2035.

Our society is also aging and the consequences are hugely significant. In 2010, 1.4 million people were aged 85 or older and deaths in this group represented 36% of all deaths. By 2035, this figure will be 3.5 million and deaths in the over 85s will represent half of all deaths in the UK. As we live longer we are more likely to die as a consequence of chronic disease with a greater number of us living with cancer and dementia. Indeed, in ten years time the number of deaths caused by cancer is expected to increase by 30% for men and 12% for women

and in just eight years the number of people living with dementia will rise to over a million.

In short, the demand for care at the end of life will rise and the nature of that care will become more complex. Hospices will need to take inevitable changes in the future shape of our population into account as they plan future service development. However, these are not the only challenging messages in this report. The authors take us under the demographic headlines in order to identify the future users of hospice care and rightly urge hospices to better understand their needs, preferences and wishes both now and in the future.

First amongst those whose future needs and preferences hospices need to understand are the oldest old. Currently, older members of our society express a preference to die in a hospice but are more likely than other groups to die in a hospital or a care home. This data does not allow for a more subtle interpretation of this preference or the actuality of who may have been involved in end of life care whatever the physical setting. However, it will be important for hospices to consider alternative and innovative ways in which their care might be brought to the individual and consider if a 'hospice-enabled' death achieved in a range of settings from home, care home or hospital could meet their needs and preferences.

The report also highlights the evidence that tells us that older people and people with non-malignant conditions are less likely to receive timely referrals to palliative care. It suggests that hospices need to continue work to establish the partnerships necessary to support new models of care that reach out to people in their communities, earlier in their illness, and connect with their existing specialist care. Crucially, the report emphasises the need for such innovation to be rigorously evaluated for effectiveness and cost-effectiveness as well as being speedily spread and adopted. Hospices have much to do to meet this challenge.

“The scale of the challenge ahead is dramatic and will require hospices to significantly increase the extent and scope of end of life services.”

The evidence suggests that hospices have developed as the gold standard providers of high quality care to people with complex medical and psychosocial needs, both patients and their families. In expanding the range of services offered to meet the widespread and substantial needs of those who will need care in the future they must ensure that the skills needed to provide such care are preserved, enhanced and made available to all who may need them.

As well as bringing existing evidence into focus the report also demonstrates where there are clear gaps in our understanding. These gaps hinder the ability of hospices and all palliative care services to rationally develop the right range of effective services to match future need. The requirement for hospices to do better at collecting and critically examining the data is urgent and imperative. Given our commitment to the development of hospice services that reach out across all those settings where people may need care, it is telling that the hospice sector as a whole has no agreed process for collecting data that would accurately record the number of people

in receipt of hospice care in any one year, particularly beyond the inpatient hospice setting.

Hospices must meet a range of challenges: collecting better data, developing a better understanding of those who needs will dominate future decades, and establishing a robust evidence base for new services. They must also collaborate even more closely with all other providers of support and care to people at the end of their lives. Progress will require commitment and leadership as well as the astute use of resources not only by individual hospices but also those organisations that represent hospices nationally. This report makes it clear that as hospices face the future, they will need to address difficult questions about how to demonstrate the best use of their expertise, experience and public support to meet increasing and wider ranging needs.

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“The authors take us under the demographic headlines in order to identify the future users of hospice care and rightly urge hospices to better understand their needs, preferences and wishes both now and in the future.”

“The increasing number of older people will not be the only driver of future hospice care. People are also more often living alone, often with limited support from friends and relatives. An increasing number of people are employed outside the home, making them unable to provide full time care.”

Executive summary

This report provides evidence on what is known and still needs to be known about patients' and families' needs for hospice care towards the end of life. We focus on crucial factors for hospice care planning for the future in the UK, including the most recent data on actual and projected number of deaths in England, Wales, Scotland and Northern Ireland. This is followed by evidence on people's preferences for place of care and place of death. Finally, we present available evidence on the effectiveness and cost-effectiveness of hospice care and discuss the need for further research. Evidence-based recommendations are provided throughout the report.

How is the size and shape of the UK population likely to change in the future?

UK mortality trends have changed towards people living longer and dying from chronic diseases at an older age. This translates into a different profile of death and dying from when the modern hospice movement started, over 40 years ago. Older people are more likely to suffer from cancer and chronic non-malignant conditions. They are also more likely to have comorbidities and be fragile. Older people can benefit from specialist and generalist hospice care provided in different settings. Some might be able to stay at home with home support; others will need to or prefer to be cared for in an inpatient hospice bed at some point in their illness trajectory, whilst others will need long-term care in institutions such as care homes. Despite differences in diagnosis, controlling symptoms such as pain, breathlessness and depression is a common requirement across different advanced conditions, ages and settings.

In the past five years (2007-2011) the annual number of deaths has decreased in all the UK countries (from 0.7% average annual decrease in Ireland to 1.4% in Wales). In 2011, at least half of the population in England and Wales died in hospitals, 21.8% died at home and less than 6.0% died in an inpatient hospice bed. In these countries, people with non-malignant conditions and

those aged 85+ are less likely to die at home and in an inpatient hospice bed (compared to those with cancer and younger people). Women and those aged 85+ are more likely to die in care homes.

Although the number of deaths has been reducing, current projections by the Office for National Statistics predict a dramatic increase in the number of older people in the UK, with the number of deaths also increasing from around 2015. This is slightly later than what previous projections showed (3 years later) because earlier projections were based on more pessimistic assumptions regarding life expectancy. Nevertheless, it is a rise which will inevitably happen as a result of fertility trends and baby-booms right after the Second World War and in the 1960s.

By 2035, people aged 85 years or older are projected to account for almost half (49.5%) of all deaths in the UK (328,469 deaths in this year). The number of deaths caused by cancer is expected to increase (30% for men and 12% for women by 2023); it is also predicted that over a million people will have dementia in the UK in 2021. This will inevitably translate into an escalating demand for hospice care. Planning requires robust evidence on current hospice care capacity (inpatient, community and outpatient), but this information is not readily available.

Main recommendations: Due to an increasing and diverse population demand for hospice care, it is essential to increase the availability of hospice beds and/or investigate optimal ways to use the number of existing inpatient hospice beds. However, it is also paramount to diversify hospice care provision into other models of care and care settings, collaborating with different service providers and care specialties such as geriatrics and disease specific specialties. There are encouraging local practices suggesting that this can be done well. More robust information about hospice care usage and provision is needed.

Where do people wish to be cared for and die? Are their preferences being met?

Evidence from the UK shows that home is the most frequently chosen place to die, despite variations across conditions and age groups. Cancer patients are more likely to choose home than patients with non-malignant conditions, for example. Inpatient hospice is usually the second most frequently chosen place to die. Older people are more likely to choose inpatient hospice than their younger counterparts (although currently they are the group least likely to die there). With an ageing population, it is therefore likely that the number of people choosing to die in an inpatient hospice bed will increase. It will be challenging to expand inpatient hospice bed capacity to the extent of meeting everybody's preferences. Nevertheless, ensuring such additional capacity, while understanding people's preferences and priorities for care, will be crucial to providing adequate levels of hospice care in the future.

Main recommendations: We need to better understand why those aged 85+ and non-cancer patients die less often at home and in hospices. In order to reach them better and verify which hospice care plans meet their needs it is necessary to listen to their preferences and priorities for care. The use of standardised tools to assess these is recommended for all patient groups; these tools are also paramount for documenting advance care plans. Reasons underlying preferences and changes also need to be further investigated.

Is there evidence that hospice care makes a difference to patients and family caregivers?

Hospice care is beneficial to patients regardless of the care setting, particularly in terms of symptom control (especially pain) and patient satisfaction with care. Unfortunately, it is still not known which models of hospice care work better and are more cost-effective. There is also lack of evidence on the effectiveness of hospice care for family caregivers, especially regarding bereavement care. And while home is the preferred place of care/death for the majority of the population, we still do not know if those who die at home experience better outcomes than those who die elsewhere. Finally, although inpatient hospice care seems to be the "gold standard" in terms of perceived quality of care, more evidence is needed to confirm this.

Main recommendations: Hospice care providers need to assess which aspects of their care are more effective/cost-effective in order to optimise the care they provide and to allow the transfer of best practices across settings. Partnerships with research groups may be helpful to design robust evaluations. Future research into hospice care should identify aspects of care in need of improvement and generate evidence on the effectiveness of hospice care on bereavement outcomes for family caregivers.

1. Introduction

Hospice care has developed remarkably in the past four decades. Having begun in the voluntary sector, it has received increased attention from the UK National Health Service (NHS). Over the last five years, with the implementation of the National End of Life Care Strategy¹, focus on providing better care at the end of life has intensified – it has become a health priority across sectors.

Independent hospices are major players in the provision of hospice care. In the UK, they provide about 80% of all adult inpatient care beds, in addition to day care services and home care². Less than a third of adult hospice funding is covered by the Government and the remaining is derived from donations, legacies and trading². There have been calls for greater governmental funding, but at the moment there is still no concrete answer to how this will be done.

Current challenges for hospice care involve funding, new government bodies and regulations at times of major restructuring of the NHS. Contents of the Health and Social Care Act 2012³ such as the creation of another regulatory body (Monitor) have raised concerns about an increased burden of regulatory systems for inpatient hospices⁴. The new Act also does not give a clear description of how hospice care will be funded in the future. The Draft Care and Support Bill (published in July 2012) refers to the creation of a funding system for palliative care in the future (2015). The feasibility of providing health and social care at the end of life for free at the point of delivery will be assessed in the near future³. The next few years will, therefore, be a period of uncertainty and adaptation for independent hospice providers and, consequently, for those in need of hospice care. The impact current reforms will have on funding, planning, provision and receipt of hospice care is still unknown.

Funding and policy issues are not the only challenges in hospice care provision. Access to hospice care is still neither sufficient nor equal for people with different illnesses, ages or ethnicity, even though improvements have happened. Current estimates published in the Palliative Care Funding Review suggest that hospice care needs are being unmet for 92,000 people each year⁵. Age UK estimates that around 800,000 older people per year would benefit from some type of elderly care but do not receive it from the government or from the voluntary sector⁶. These figures are concerning, especially because UK demographics have been changing towards a greater proportion of older people and this is predicted to continue in the future. People's expectations of care are also greater than before⁷.

In light of these challenges, Help the Hospices believes that hospices should be equipped with knowledge to help them provide appropriate and timely care in the future. In 2011, a Commission was created to bring together this knowledge. This evidence-based report is one of a series of publications currently being commissioned. We report data on UK mortality, one of the core indicators of the need for hospice care at a population level⁸. We also report other UK demographic and epidemiological data – showing past trends, present statistics and the most up-to-date projections. The report also provides evidence on people's expectations, preferences and realities in hospice care provision. We show that these factors have important implications for future care planning and need to be well understood and considered in order to plan adequate hospice care. We hope that this publication, along with the other reports in this series help the Commission to meet its aim of providing strategic direction for hospices for the next 10 to 15 years.

2. Methodological notes

Definition of hospice care

The definition of hospice care can vary across countries. For the purposes of this report, the following definition is used: “Hospice care seeks to improve the lives of people living with a progressive and life-threatening condition. By offering high-quality, specialist palliative care it helps them to live as actively as they can to the end of their lives, however long that may be. It not only takes care of people’s physical needs, but looks after their emotional, spiritual and social needs as well. Hospice care also supports carers, family members and close friends, both during a person’s illness and during bereavement”⁹.

When reporting individual studies, all effort was made to focus on studies within the UK population, except when the evidence was too scarce. Literature and systematic reviews have a wider scope and in general include studies from different countries. When reporting data from reviews it was not possible to verify which definition was adopted by each individual study.

Definition of the population

We focus on the adult population due to their importance in terms of future demand for hospice care. Most of the available evidence on preferences and outcomes also refers to this group. Furthermore, mortality trends and projections are different for children (as we will see in section 3 of this report). Paediatric hospice care also has different profiles in many ways (e.g. inclusion of non-malignant conditions from the outset and greater collaboration with the health care teams already caring for the patient)¹⁰. We acknowledge that there are at least 43 UK inpatient hospices dedicated to children⁹, but we feel that due to the scope of the report paediatric hospice care should be analysed separately.

Actual and projected number of deaths

We carried out an analysis of 5-year mortality trends (2007-2011) to understand changes in the numbers

and profile of death in the UK. We show data for all ages, but focused the analysis on the adult population since this group is the most relevant for future hospice care planning. Because of the way age categories are reported by the ONS (0-4, 5-14, 15-44, 45-64, 65-74, 75-84 and 85+ years) we considered those over 15 years as adults.

Mortality statistics are published every year by the ONS (England and Wales), the Northern Ireland Statistics and Research Agency Data (NISRA) (Northern Ireland), the General Register Office for Scotland (GRO), and the Scottish Neighbourhood Statistics (SNS) (Scotland). Deaths are shown by age, gender and underlying cause of death (according to ICD-10 codes) for all the UK countries. The ONS shows cause of death for England and Wales together; hence it was not possible to check for differences between the two countries. Mortality by underlying cause of death does not cover contributory causes of death (i.e. someone who died due to cancer might have also had advanced dementia). We report numbers and proportions of deaths for eight illnesses relevant to hospice care which were available for all countries: cancer (C00-D48), dementia (F00-F03), ischaemic heart disease (I20-I25), cerebrovascular diseases (I60-I69), chronic lower respiratory diseases (J40-J47), Parkinson’s disease (G20) and Alzheimer’s disease (G30).

Place of death categories are the same in England and Wales, but different in Scotland and Northern Ireland (Table 1). Since place of death categories changed for England and Wales in 2010, we report only 3-year trends in place of death (2007-2009) and a snapshot of 2010/2011 deaths. Although we do not report the numbers and percentages of deaths taking place in “other communal establishments” and “elsewhere”, we took all into account when calculating the proportions of deaths in the examined settings. We also report place of death by geographical regions within England: North (comprising the North East, the North West and Yorkshire

and the Humber), Midlands and East of England (East Midlands, West Midlands and East of England), London and South of England (South East and South West). In Scotland place of death information is only available for cancer deaths.

The population projections for England, Wales, Scotland, Northern Ireland and the whole of the UK are from the National Population Projections 2010-based Statistical Bulletin, published by the ONS¹¹. These projections are based on the latest available mid-year population estimates and several demographic estimates on future fertility, mortality and immigration. They refer to the usually resident population in the UK (including long-term international migrants). In Appendix A (reporting projected number of deaths by age and gender), the number of deaths for those aged 0-4 include stillbirths. Due to space limitations we only report the ONS principal projection (nine alternative projections are

freely available from their website: www.ons.gov.uk).

Fertility assumptions are shown in terms of completed family size (the average number of children that women born in particular years will have)¹². Because of the way data are reported, the population is sometimes shown in millions and other times in thousands of people. Due to the natural degree of uncertainty from projections, we only report those up to year 2035, except in Figure 3. In this case, we show further projected years to illustrate when the number of deaths is expected to reach the number of births in the UK countries.

Preferences for place of care and place of death

We used an improved search strategy adapted from Higginson and Sen-Gupta's review¹³ to identify studies assessing preferences for place of care or place of death. Keywords included palliative, hospice, terminal, end of life, death, dying, location, place, setting, home, care,

Table 1 – Place of death categories across the UK countries (2007-2011)

	England and Wales	Scotland	Northern Ireland
2007-2009	<ul style="list-style-type: none"> • Home (usual residence of the deceased according to the informant, where this is not a communal establishment) • Hospitals and communal establishments for the care of the sick (NHS and non-NHS - excludes psychiatric hospitals and hospices) • Hospices (include Sue Ryder Homes, Marie Curie Centres, oncology centres, voluntary hospice units, and palliative care centres) • Psychiatric hospitals (NHS and non-NHS) • Other communal establishments • Other private houses and other places 	Cancer deaths only <ul style="list-style-type: none"> • NHS acute hospital • Home • Hospice • Other institution <hr/> Data not yet available for 2009, 2010 and 2011	<ul style="list-style-type: none"> • 36 individual hospitals (identifiable) • Other hospitals (hospitals with a “very small” number of deaths merged into this group) • Nursing homes • All other places
2010-2011	<ul style="list-style-type: none"> • Home (usual residence of the deceased according to the informant, where this is not a communal establishment) • Hospitals (NHS and non-NHS - acute or community, not psychiatric) • Hospices (NHS and non-NHS - include Sue Ryder Homes, Marie Curie Centres, oncology centres, voluntary hospice units, and palliative care centres) • Care Homes (Local Authority and non-Local Authority) • Other communal establishments • Elsewhere 		

Sources: Place of death in England and Wales reported by the ONS (www.ons.gov.uk), in Scotland by the Scottish Cancer Registry (SCR) (www.isdscotland.org/index.asp), and in Northern Ireland by the NISRA (www.nisra.gov.uk/).

“People are living longer and dying from chronic diseases at an older age”

die, prefer, wish, decision, choice. We searched four databases (MEDLINE, EMBASE, psycINFO and CINAHL), our personal databases and reference lists from published papers. We only included studies that 1) were carried out in the UK; 2) reported overall number of participants who expressed a preference; 3) reported numbers/proportions of study participants who preferred to die/be cared for in a hospice. Valid cases shown in Appendix B refer to study participants who expressed preferences. We considered preferences for place of care and place of death to be equivalent. Although a few studies have found that these can differ^{14,15}, the evidence is not yet conclusive. Many UK studies also consider these to be equivalent¹⁶⁻¹⁸. This influenced our decision to include preferences in both scenarios. When calculating preferences we excluded from the denominator those who did not have any preference or did not know where they would prefer to die.

We used data from the PRISMA survey to investigate factors associated with choosing hospice/palliative care unit as the preferred place to die. This was a population-based telephone survey investigating public preferences and priorities for end of life care in seven European countries (including England)¹⁹. The PRISMA questionnaire had 28 questions on preferences, personal values related to end of life care, experience with illness, death and dying and general health and socio-demographic questions. We asked participants: “In a situation of serious illness like cancer with less than one year to live.... Where do you think you would prefer to die if circumstances allowed you to choose?” Participants could choose “own home”, “home of a relative or friend”, “hospice or palliative care unit”, “hospital (but not in a palliative care unit)”, “nursing home”, “residential home” or specify somewhere else. Further information on the survey can be found elsewhere¹⁹.

Participants in the PRISMA survey were randomly selected individuals aged ≥ 16 residing in a private household. For this report we used English data only (1,351 participants) to investigate factors associated with choosing hospice as the preferred place of death. We recoded all possible answers on preferences as two answers: hospice versus non-hospice (merging all other possible answer options). We did bivariate statistical tests to identify which factors (socio-demographic, experiences of serious illness, death and dying and preferences and priorities for end of life care – all assessed in the questionnaire) were significantly associated with choosing hospices ($p < 0.05$). All significant factors were included in a logistic regression model to identify those independently associated with choosing hospices (versus elsewhere) as the preferred place of death ($p < 0.05$). As a note of caution, results from regression do not imply causality, only associations between factors. All cases with missing data were excluded.

Experiences and outcomes for patients and families

We identified crucial evidence on patient’s preferences and experiences of hospice care; we prioritised findings from literature reviews (systematic and not systematic) and randomised controlled trials (RCTs) to provide more robust data. In RCTs, patients are randomly assigned either to a group receiving the intervention or to a group that does not receive it (known as the control group). By randomly assigning participants, it is much more likely that the results from the intervention are due to the intervention itself instead of uncontrolled factors. However, since RCTs in hospice care are scarce we also report some results from individual studies using different methodologies.

3. Likely changes in the size and shape of the UK population

3.1 What do we know about mortality trends until now?

Historical mortality trends

The latest mortality trends in the UK and many other developed countries show that people are living longer, but often with a life-limiting condition that would benefit, at some point, from hospice care.

During the 20th century, especially after 1945, medical developments, improvements in nutrition and sanitation and governmental policies reduced mortality due to infectious diseases. As a consequence, more children survived into adulthood²⁰. This was accompanied by an increasing number of births after the Second World War (this population group is one of the most well discussed baby-boom generations).

Throughout the years people were living longer; life expectancy at birth increased from 67.95 years in 1945 to 82.41 years in 2010²¹. The pattern of mortality, therefore, changed from high childhood mortality to high older adult mortality. Instead of a high incidence of infectious diseases, the new generations have chronic and degenerative diseases as the most common causes of death²¹. Due to advances in medicine, mortality from ischaemic heart disease and stroke has more recently declined in the UK and other developed countries^{22, 23}. This is partly due to new available medication to control blood pressure; raised blood pressure is estimated to cause 51% of stroke deaths and 45% of coronary heart disease deaths²⁴.

While the proportion of deaths from ischaemic heart disease and stroke decreased, the proportion of deaths due to cancer and other non-malignant chronic conditions increased. Older age is closely linked with the development of cancer, dementia and cognitive impairment. The longer people live, the more likely they are to suffer from these conditions²⁵⁻²⁸. Cancer Research UK reports that 320,500 people were diagnosed with

cancer in the UK in 2009²⁵. Although cancer can develop at any age, it is most common in older people. Latest cancer incidence figures for 2008 (published in 2010) report that three quarters of cancer cases were diagnosed in people aged 60 and over²⁵.

Age is the strongest risk factor for dementia²⁷; it is estimated that two thirds (68%) of all people with dementia are over 80 years old, 17% are over 90²⁹. Furthermore, one in five people over 80 and one in 20 people over 65 has a form of dementia²⁸. The Alzheimer's Research Trust estimates that 821,884 people lived with dementia in the UK in 2010³⁰. A report from the National End of Life Care Intelligence Network shows that between 2001 and 2009, there were 631,078 deaths for which one or more of the conditions Alzheimer's disease, dementia or senility were mentioned on death certificates (either as the main cause or contributory cause of death)²⁶.

Treatment and care in older age need to be planned taking into account pre-existing health problems and illnesses (referred to as comorbidities); older patients are also usually frail³¹ and many have painful conditions such as arthritis and osteoporosis³². Furthermore, different illnesses present different trajectories. While people with cancer generally present a classic terminal phase with an abrupt onset of disability in the last few months of life³³, patients with dementia have a less defined trajectory, with a longer period of progressive disability³⁴. In the case of dementia and other chronic conditions, it is difficult to define when "really sick becomes dying"³², and this has strong implications for treatment. As a consequence, while some patients can benefit from hospice care, other types of multiprofessional support may be needed too (e.g. geriatric medicine, rehabilitation, mental health)³², especially if people are on their own and very frail.

Despite the existence of different illness trajectories, a high prevalence of certain symptoms seems to cut across different conditions. Solano et al³⁵ found that 11 symptoms were spread across advanced stages

of five diseases: cancer, AIDS, heart disease, chronic obstructive pulmonary disease, and renal disease. Pain, breathlessness and fatigue were found amongst more than half of all patients. Depression was also common amongst all patients (from 36% to 82% across illnesses). This suggests that there is an unmet need for symptom control across a range of advanced illnesses. The existence of an increasing number of older people with different needs is challenging, and demands flexibility to develop comprehensive hospice care. However, it should be possible to develop care packages and services based on symptoms and problems that can help people with a variety of different conditions³⁶. Integration of hospice care with chronic disease management can help to meet care needs common to different groups, while also addressing specific individual needs^{32, 35, 37}.

What about UK mortality trends in the past five years?

From 2007 to 2011, the annual number of deaths

in England decreased from 470,721 deaths in 2007 to 452,862 deaths in 2011 (average decrease of 4,465 of deaths per year or 0.9% average annual decrease), although the reduction was not consistent throughout the years (Table 2). This decrease in the number of deaths happened in all the UK countries. In Wales, there was an annual average decrease of 431 deaths (or 1.4% annual average decrease) from 2007 to 2011³⁸⁻⁴². In Scotland there was an annual average decrease of 581 deaths (1.0% average annual decrease) across the five years⁴³⁻⁴⁷, while in Northern Ireland there was an annual average decrease of 11 deaths (0.7% annual decrease)⁴⁸⁻⁵². Similarly to England, reductions in the number of deaths in Scotland and Northern Ireland were not consistent throughout the years (Table 2)⁴⁷. The age group over 65 accounts for at least 79% of all deaths in each of the UK countries in the five years studied, these are highlighted in Table 2³⁸⁻⁴².

Table 2- Mortality in England, Wales, Scotland and Northern Ireland (2007-2011)

	2007 n (%)	2008 n (%)	2009 n (%)	2010 n (%)	2011 n (%)
England					
Total deaths	470,721	475,763	459,241	461,017	452,862
Deaths 65+					
65-74	75,929 (16.1)	75,969 (16.0)	73,852 (16.1)	73,970 (16.0)	73,100 (16.1)
75-84	149,448 (31.7)	147,315 (31.0)	140,175 (30.5)	138,450 (30.0)	134,096 (29.6)
85+	163,894 (34.8)	170,553 (35.8)	165,214 (36.0)	169,743 (36.8)	169,100 (37.3)
Wales					
Total deaths	32,148	32,066	31,006	31,197	30,426
Deaths 65+					
65-74	5,524 (17.2)	5,512 (17.2)	5,389 (17.4)	5,314 (17.0)	5,239 (17.2)
75-84	10,324 (32.1)	10,110 (31.5)	9,558 (30.8)	9,469 (30.4)	9,112 (29.9)
85+	10,686 (33.2)	11,022 (34.4)	10,725 (34.6)	11,241 (36.0)	10,910 (35.9)
Scotland					
Total deaths	55,986	55,700	53,856	53,967	53,661
Deaths 65+					
65-74	10,814 (19.3)	10,612 (19.1)	10,205 (18.9)	10,092 (18.7)	10,019 (18.7)
75-84	17,630 (31.5)	17,589 (31.6)	16,686 (31.0)	16,877 (31.3)	16,475 (30.7)
85+	15,997 (28.6)	16,106 (28.9)	15,941 (29.6)	16,093 (29.8)	16,501 (30.8)
Northern Ireland					
Total deaths	14,649	14,907	14,413	14,457	14,204
Deaths 65+					
65-74	2,476 (16.9)	2,584 (17.3)	2,539 (17.6)	2,606 (18.0)	2,457 (17.3)
75-84	4,696 (32.1)	4,611 (30.9)	4,427 (30.7)	4,268 (29.5)	4,223 (29.7)
85+	4,397 (30.0)	4,681 (31.4)	4,449 (30.9)	4,531 (31.3)	4,668 (32.9)

Sources: ONS. Mortality statistics: Deaths registered in 2007/2008/2009/2010/2011); GRO. Vital Events Reference Tables 2007/2008/2009/2010/2011; NISRA. Registrar General Northern Ireland Annual Report 2007/2008/2009/2010/2011.

3.2 What are people dying from?

Across all the UK countries, there is a similar distribution of deaths by different causes. At least 27% of all deaths in the five years studied were due to cancer, with the number and proportion of cancer deaths slightly increasing from 2007 to 2011, reaching 29.6% of all deaths in England and 29.3% in both Scotland and Northern Ireland (Table 3). Following worldwide trends, the number and proportion of deaths due to ischaemic heart disease have decreased from 2007 to 2011 (average annual decrease of 3,101 deaths in England and Wales, 427 in Scotland, and 132 in Northern Ireland). Likewise, the number and proportion of deaths from cerebrovascular diseases decreased steadily in England and Wales; in Scotland and Northern Ireland this decrease had yearly fluctuations.

There has been an increasing tendency to record dementia and Alzheimer's (a disease than underlies many dementia cases) as cause of death²⁶. The ONS also reports that up to 2010 some cases of vascular dementia were being coded as cerebrovascular disease (this changed in 2011)⁵³. However, the number of deaths from dementia for all countries is still likely to be underestimated. According to the Alzheimer's Society, only 43% of people currently living with dementia have been officially diagnosed⁵⁴. Issues such as diagnostic definitions (broader or more restricted) and calculations of incidence based on small studies also help to explain why dementia is usually underreported^{27, 55}. Nonetheless, the number and proportion of dementia deaths are increasing in all the UK countries, despite a reduction in 2009. From 2007 to 2011, there was an annual average increase of 3,823 dementia deaths in England and Wales, 138 in Scotland and 109 in Northern Ireland.

Table 3 – Numbers and proportions of deaths by selected underlying causes of death and country (2007-2011)

	2007 n (%)	2008 n (%)	2009 n (%)	2010 n (%)	2011 n (%)
England and Wales					
Cancer	140,080 (27.8)	141,143 (27.7)	140,497 (28.6)	141,446 (28.7)	143,181 (29.6)
Ischaemic heart disease	79,910 (15.9)	76,985 (15.1)	72,170 (14.7)	70,196 (14.2)	64,435 (13.3)
Cerebrovascular diseases	46,597 (9.2)	46,446 (9.1)	43,595 (8.9)	43,363 (8.8)	35,977 (7.4)
Chronic lower respiratory diseases	25,668 (5.1)	26,902 (5.3)	25,419 (5.2)	25,985 (5.3)	25,568 (5.3)
Dementia	14,948 (3.0)	16,610 (3.3)	16,424 (3.3)	18,349 (3.7)	30,257 (6.2)
Alzheimer's disease	5,697 (1.1)	6,231 (1.2)	6,194 (1.3)	6,757 (1.4)	7,505 (1.5)
Parkinson's disease	4,371 (0.9)	4,744 (0.9)	4,789 (1.0)	5,021 (1.0)	3,710 (0.8)
Multiple sclerosis	1,002 (0.2)	1,050 (0.2)	1,012 (0.2)	1,004 (0.2)	1,062 (0.2)
Scotland					
Cancer	15,570 (27.8)	15,525 (27.9)	15,484 (28.8)	15,618 (28.9)	15,731 (29.3)
Ischaemic heart disease	9,343 (16.7)	8,841 (15.9)	8,274 (15.4)	8,138 (15.1)	7,636 (14.2)
Cerebrovascular diseases	5,333 (9.5)	5,367 (9.6)	4,906 (9.1)	4,764 (8.8)	4,594 (8.6)
Chronic lower respiratory diseases	3,104 (5.5)	3,037 (5.5)	2,986 (5.5)	2,807 (5.2)	3,062 (5.7)
Dementia	2,446 (4.4)	2,590 (4.6)	2,585 (4.8)	2,745 (5.1)	2,994 (5.6)
Alzheimer's disease	549 (1.0)	624 (1.1)	634 (1.2)	665 (1.2)	917 (1.7)
Parkinson's disease	309 (0.6)	303 (0.5)	315 (0.6)	363 (0.7)	345 (0.6)
Multiple Sclerosis	122 (0.2)	112 (0.2)	120 (0.2)	133 (0.2)	140 (0.3)
Northern Ireland					
Cancer	3,992 (27.3)	4,086 (27.4)	3,992 (27.7)	4,111 (28.4)	4,159 (29.3)
Ischaemic heart disease	2,494 (17.0)	2,410 (16.2)	2,305 (16.0)	2,234 (15.5)	1,966 (13.8)
Cerebrovascular diseases	1,325 (9.0)	1,329 (8.9)	1,175 (8.2)	1,239 (8.6)	1,094 (7.7)
Chronic lower respiratory diseases	693 (4.7)	760 (5.1)	786 (5.5)	737 (5.1)	774 (5.4)
Dementia	405 (2.8)	520 (3.5)	472 (3.3)	504 (3.5)	841 (5.9)
Alzheimer's disease	291 (2.0)	293 (2.0)	241 (1.7)	279 (1.9)	335 (2.4)
Parkinson's disease	118 (0.8)	122 (0.8)	163 (1.1)	116 (0.8)	113 (0.8)
Multiple Sclerosis	27 (0.2)	30 (0.2)	36 (0.2)	27 (0.2)	39 (0.3)

Sources: England and Wales: ONS. Mortality statistics: Deaths registered in 2007/2008/2009/2010/2011). Scotland: GRO. Vital Events Reference Tables 2007/2008/2009/2010/2011. Northern Ireland: NISRA. Registrar General Northern Ireland Annual Report 2007/2008/2009/2010/2011.

3.3 Where are people dying?

By analysing England and Wales separately, it can be seen that home deaths increased in both countries, although there was a slight decrease in 2008 in Wales (in both numbers and proportions) and a decrease in numbers in England in 2009 (Table 4). This translated into an average increase of 1,668 home deaths per year in England and 61 in Wales, from 2007 to 2011. Still, in both countries home deaths remain below a quarter of all deaths. It is important to notice that the ONS reports home deaths and care home deaths separately, differently from the approach adopted by the UK End of Life Care Strategy (which merges care homes and own homes as “usual place of residence” and uses the number of deaths in these settings as a key marker of progress for the Strategy)⁵⁶.

Inpatient hospice deaths have increased only marginally in England, whilst in Wales there was an increase in proportions up to 2010 followed by a decrease in both numbers and proportions in 2011. The proportion of deaths taking place in these settings is higher in England but small in both countries (5.6% in England and 2.7% in Wales in 2011). There was an average increase of 266 inpatient hospice deaths per year in England and an average decrease of 29 in Wales, from 2007 to 2011. While the proportion of deaths in hospitals/care homes decreased steadily in England (average 0.9% decrease per year, representing on average 6,467 less deaths per year - driven by increases of deaths in NHS institutions), there was an irregular pattern in Wales across the years.

The proportion of NHS hospital/care home deaths was higher in Wales (69.3%) compared to England (64.2%) in 2009, but the opposite was true for non-NHS institutions (representing 9.5% of all deaths in England and 8.4% in Wales, also in 2009)³⁸⁻⁴².

When analysing England and Wales together, we see that home deaths increased for both genders, but women still die at home less often than men (18.6% compared to 25.1% for men in 2011) (Appendix C). Although home deaths have also increased for those aged 85+ (1,125 annual average increase in the number of deaths), this group still dies at home less often than all other age groups over the age of four. Cancer patients die more frequently at home than non-cancer patients (28.7% versus 18.9% in 2011), although the number of home deaths has increased for both groups. Proportions of home deaths also varied across regions, ranging from 21.0% in London to 22.5% in the East Midlands and East of England⁵³.

In England and Wales, the marginal increase in inpatient hospice deaths happened for both genders, although proportions for men are higher than for women (5.7% for men compared to 5.2% for women in 2011) (Appendix C). The proportion of inpatient hospice deaths also increased marginally in all age groups (except amongst those up to 14 years old), with the highest average annual increase amongst those aged 65-75 (0.2% per year). Throughout the five years analysed, cancer patients died more frequently in inpatient hospices than non-cancer patients (16.9% compared to less than 1% of non-cancer patients in 2011), regardless

Table 4 - Deaths by place of death in England and in Wales (2007-2011)

	2007 n (%)	2008 n (%)	2009 n (%)	2010 n (%)	2011 n (%)
England					
Home	91,974 (19.5)	94,715 (19.9)	93,236 (20.3)	95,831 (20.8)	98,645 (21.8)
Hospice	24,426 (5.2)	23,958 (5.0)	24,096 (5.2)	24,651 (5.3)	25,490 (5.6)
Hospital/care home	308,358 (65.5)	308,915 (64.9)	294,755 (64.2)	N/A	N/A
NHS	263,119 (55.9)	263,023 (55.3)	251,340 (54.7)	N/A	N/A
Non-NHS	45,239 (9.6)	45,892 (9.6)	43,415 (9.5)	N/A	N/A
Wales					
Home	6,463 (20.1)	6,359 (19.8)	6,352 (20.5)	6,583 (21.1)	6,708 (22.0)
Hospice	887 (2.8)	888 (2.8)	873 (2.8)	938 (3.0)	830 (2.7)
Hospital/care home	22,482 (69.9)	22,608 (70.5)	21,502 (69.3)	N/A	N/A
NHS	19,941 (62.0)	20,055 (62.5)	18,894 (60.9)	N/A	N/A
Non-NHS	2,541 (7.9)	2,553 (8.0)	2,608 (8.4)	N/A	N/A

Hospices include Sue Ryder Homes, Marie Curie Centres, oncology centres, voluntary hospice units and palliative care centres. N/A - not available.

Source: ONS. Mortality statistics: Deaths registered in 2007/2008/2009/2010/2011.

of age. Consequently, there was a marked difference in absolute numbers (24,185 cancer patients died in inpatient hospices in 2011 compared to only 2,176 non-cancer patients) (Appendix C). The proportion of cancer deaths in inpatient hospices across the five years studied remained roughly the same (16.9% both in 2007 and 2011). Amongst non-cancer patients, children 5-14 years have the highest proportion of inpatient hospice deaths. There was a small increase in absolute numbers of inpatient hospice deaths for both cancer and non-cancer patients (annual average increase of 124 deaths for cancer and 128 for non-cancer), including for those over 85 years old, who are commonly referred to as the “oldest old” (average increase of 76 deaths per year for cancer

and 55 for non-cancer). We find a similar trend to home deaths, with the oldest old dying in inpatient hospices less often (in both cancer and non-cancer) (Figure 1)³⁸⁻⁴².

When analysing inpatient hospice deaths by English region, it can be seen that London and the South of England had similar proportions of inpatient hospice deaths during the entire five-year period (Figure 2). The South of England is the region with the highest number of inpatient hospice deaths (8,215 in 2011). The Midlands and East is the region with the highest annual average increase of inpatient hospice deaths (n=125), while London is the region with the lowest (annual average increase of two deaths from 2007 to 2011).

Analysing trends for hospitals and care homes is more

Figure 1 – Proportion and absolute number of inpatient hospice deaths by age and cause of death in England and Wales (2007-2011)

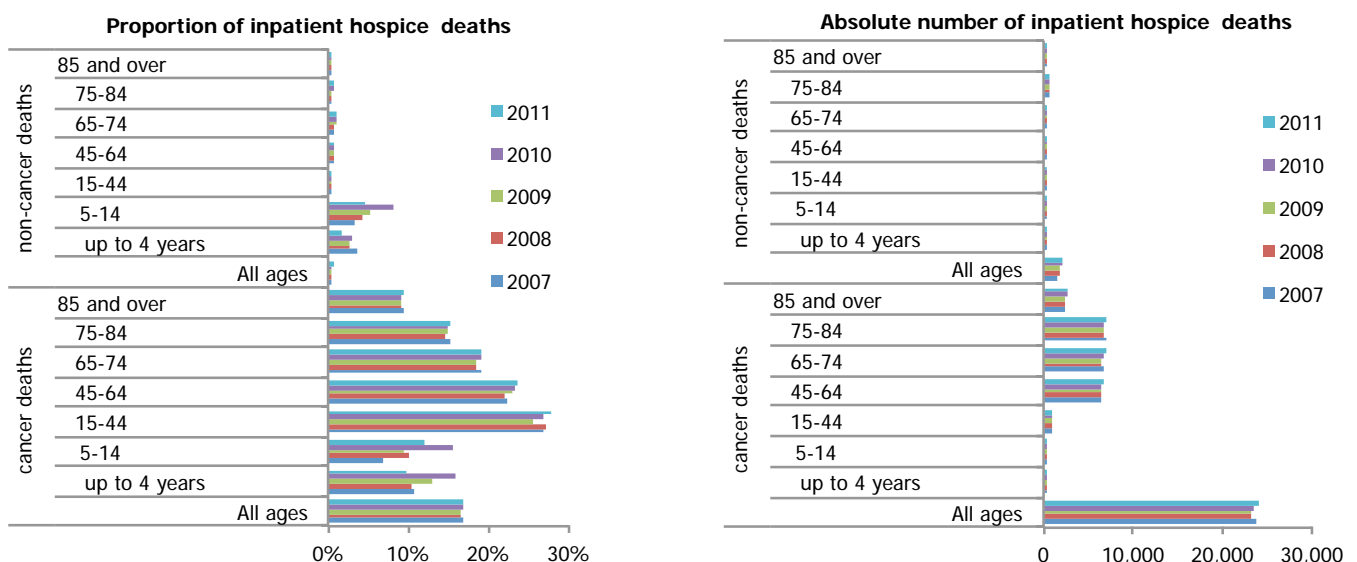
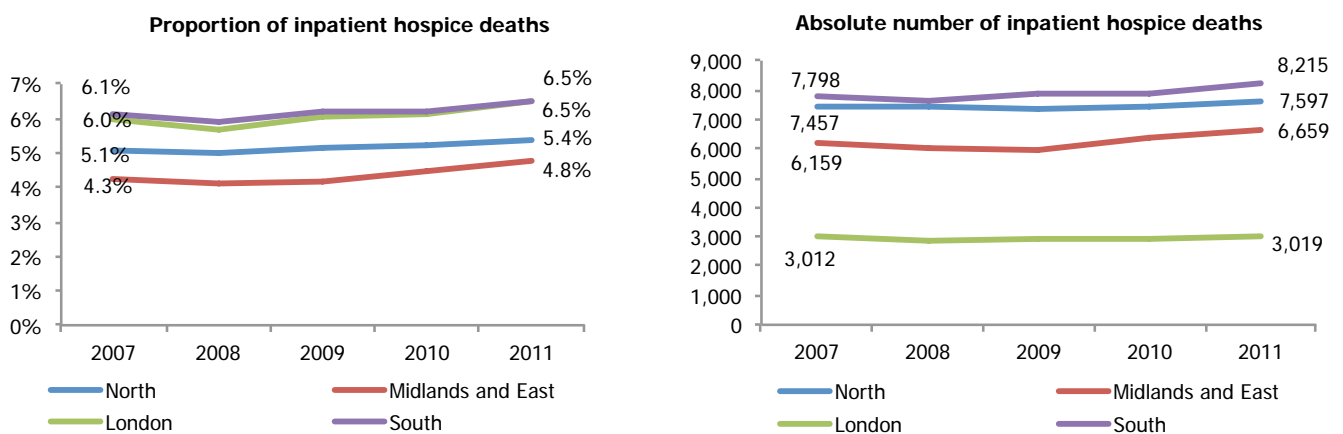


Figure 2 – Proportion and absolute number of inpatient hospice deaths by English region (2007-2011)



Source: ONS. Mortality statistics: Deaths registered in 2007/2008/2009/2010/2011.

difficult since these two places are shown together until 2009. It is known, however, that the overall number and proportion of institutionalised deaths have decreased up to this year⁵⁷. Wales and London have the highest proportion of deaths in these settings (69.3% and 68.0% respectively), while the South of England has the lowest (60.9%). The distribution of cancer/non-cancer deaths in these settings (i.e. hospitals and care homes) is less heterogeneous than in inpatient hospices and at home, since at least half of all deaths occurred in hospital/care homes, regardless of illness (51.2% of cancer patients and 69.9% of non-cancer patients in 2009). The proportion of people dying in these settings increases with age from 15 years onwards regardless of illness (except for non-cancer patients over 85 years old)³⁸⁻⁴².

Mortality data from 2010 and 2011^{42,53} show the current number of deaths in hospitals and care homes separately. The number of hospital deaths has decreased from 264,962 deaths in 2010 to 249,387 in 2011, a 6% decrease (Appendix C), while the number of care home deaths has increased from 89,320 deaths in 2010 to 92,386 in 2011, a 3% increase. The proportion of hospital deaths is slightly higher for men than for women (53.2% for men in 2011 compared to 49.9% for women), while the proportion of women dying in care homes is almost twofold (24.8% for women in 2011 as compared to 13.0% for men). Since women live longer than men, they are less likely to have spouses as caregivers, and more likely to need institutionalised support⁵⁸. This would also explain why women die less often at home when compared to men. The proportion of deaths in care homes is also higher for the oldest old in England and Wales; more than a third (33.9%) of deaths in this age group in 2011 happened in a care home. Perhaps this is not surprising as older people with life-limiting conditions (e.g. dementia) and with less social support than their younger counterparts can potentially be better assisted receiving 24-hour institutionalised health and social care. The extent to which needs are currently met in care homes is, however, uncertain (Box 1).

Data show that the differences in inpatient hospice deaths are very similar to the differences in home deaths for older people, women and patients with non-cancer conditions. These groups are also less likely to die in inpatient hospices. Furthermore, although more people are now dying at home and in inpatient hospices, more than half of the population still die in hospitals. It is important to acknowledge the fact that hospital deaths are very likely to remain a reality for a substantial proportion of the population, and that death and dying in these settings are not always accompanied by negative outcomes for patients and families (see section 5).

Some of these trends are also evident in Scotland and Northern Ireland (Box 2). In these countries most

people still die in hospitals, although the numbers and proportions of home and inpatient hospice deaths have been slowly increasing^{62,63}. In Scotland, cancer patients aged 85+ still die less often at home (17.1% in 2008) and in inpatient hospices (11.0% in 2008) than any other adult age group.

Box 1 - Care homes as places to live and die

Around 376,000 older people live in care homes in the UK⁵⁹. Many have high levels of health and social care needs. The residents are often disabled, requiring assistance in activities of daily living (ADL) such as washing, eating or getting dressed and have some sort of cognitive impairment⁶⁰. Approximately 40% have particular needs as a result of dementia. Other chronic conditions and cancer are also common. These are usually accompanied by other problems such as loss of appetite and dehydration. Currently (2011), 19% of all deaths in England and Wales happen in care homes⁵³.

There are wide variations in access to healthcare services for care home residents across the UK. The Care Quality Commission conducted an online survey with Primary Care Trusts (PCTs) about the services provided to people living in care homes in 2009/2010⁵⁹. This showed that PCTs had very different views on the healthcare needs for people living in care homes; they also did not seem to understand that many older people die shortly after moving into residential care. PCTs also had difficulties in answering the survey questions. The study showed a significant variation in the specialist services available to older people; provision of a geriatrician service to care homes was found in 60% of PCTs. The authors concluded that care for older people was not an active priority for PCTs.

There is current recognition that more needs to be done in this setting and that it will have increasing importance in the future³². Improving collaboration between care homes and hospice care teams is a key component of the Gold Standards Framework in care homes (GSFCH), for example⁶¹.

Box 2 - Place of death in Northern Ireland and Scotland

Similarly to trends in England and Wales, at least half of deaths in Northern Ireland still happen in hospitals, although there has been a reduction in both the proportion (0.6% annual average reduction) and absolute number of deaths (average reduction of 135 deaths per year) between 2007 and 2011. In 2009, however, there was an increase in the proportion of hospital deaths (not accompanied by an increase in numbers). Proportions and absolute numbers of nursing home deaths have increased.

Place of death in Northern Ireland (2007 – 2011)

	2007 n (%)	2008 n (%)	2009 n (%)	2010 n (%)	2011 n (%)
Hospitals	7,520 (51.3)	7,515 (50.4)	7,355 (51.0)	7,311 (50.6)	6,980 (49.1)
Nursing home	2,259 (15.4)	2,427 (16.3)	2,241 (15.5)	2,309 (16.0)	2,914 (20.5)
All other places	4,870 (33.2)	4,965 (33.3)	4,817 (33.4)	4,837 (33.5)	4,310 (30.3)

In Scotland, at least half of cancer patients die in hospitals, although there was a decrease from 2007 to 2008 in both proportions and absolute numbers (from 51.0% to 50.1%, a reduction of 137 deaths).

Place of death in Scotland for cancer patients (2007 – 2008)

	Home n (%)		NHS acute hospital n (%)		Hospices n (%)		Other institutions n (%)	
	2007	2008	2007	2008	2007	2008	2007	2008
all ages	3,732 (24.5)	3,761 (24.7)	7,760 (51.0)	7,623 (50.1)	2,729 (18.0)	2,839 (18.7)	981 (6.5)	988 (6.5)
0-5	7 (58.3)	0 (0.0)	4 (33.3)	2 (100.0)	1 (8.3)	0 (0.0)	0 (0.0)	0 (0.0)
5-14	8 (57.1)	10 (58.8)	6 (42.9)	6 (35.3)	0 (0.0)	1 (5.9)	0 (0.0)	0 (0.0)
15-44	90 (25.8)	105 (30.3)	151 (43.3)	148 (42.8)	106 (30.4)	92 (26.6)	2 (0.6)	1 (0.3)
45-54	262 (28.9)	235 (26.9)	418 (46.0)	377 (43.1)	218 (24.0)	257 (29.4)	10 (1.1)	6 (0.7)
55-64	689 (28.4)	715 (30.0)	1,146 (47.2)	1,113 (46.7)	559 (23.0)	529 (22.2)	33 (1.4)	28 (1.2)
65-74	1,173 (27.7)	1,165 (27.2)	2,147 (50.7)	2,138 (50.0)	794 (18.8)	872 (20.4)	120 (2.8)	101 (2.4)
75-84	1,112 (22.5)	1,117 (22.9)	2,649 (53.6)	2,577 (52.8)	817 (16.5)	820 (16.8)	361 (7.3)	369 (7.6)
85+	391 (16.9)	414 (17.1)	1,239 (53.4)	1,262 (52.0)	234 (10.1)	268 (11.0)	455 (19.6)	483 (19.9)

Trends of cancer deaths at home and in inpatient hospices are similar to England and Wales. In 2008, 24.7% of cancer patients died at home. Both numbers and proportions of home deaths have increased from 2007 to 2008. Almost a fifth (18.7%) of cancer patients died in inpatient hospices in 2008; there were increases in numbers and proportions from 2007 to 2008. Also in a similar pattern to England and Wales, the oldest old patients are less likely to die at home and in inpatient hospices.

Sources: The Northern Ireland Statistics and Research Agency (2012). Registrar General Annual Report 2011. Scottish Cancer Registry (2010). Deaths from Cancer by Place of Death: Scotland, period 2004-2008

3.4 What do we know about trends in hospice care services?

The study of mortality trends is based on death registration information, which is subject to a series of validation and completeness checks⁶⁴. Despite some limitations (such as some inconsistencies regarding cause of death) mortality data are a reliable source of information to guide policy and future care planning. Trends in hospice care services, on the other hand, are more complicated to assess. Place of death information can help by providing the number of people who die in receipt of hospice care in inpatient hospices and palliative care units, but it does not report on those who might have had a hospice-enabled death at home, hospitals and care homes. Furthermore, each hospice care provider can have a different system in place to register patient activity; and a single patient might be in receipt of hospice care in more than one setting. Compiling information on hospice care usage in a consistent, standardised way is therefore very challenging. As a consequence, there are currently no official statistics available that accurately show UK trends over time in terms of hospice care provision.

Help the Hospices publishes yearly statistics about hospice care in the UK in its Hospice and Palliative Care Directory⁹. The data are shown for inpatient hospice units, palliative care units (and the respective number of beds for both), community and hospital providers of hospice care. Although information is available on the number of providers, there is no data on the number of services each of them offers, or how far reaching services from the same provider can be (e.g. in terms of geographical coverage or number of partnerships with other providers). Although the number of available beds is helpful to estimate service capacity, the data are limited in terms of overall patient activity and hospice care provision.

The Minimum Data Set (MDS) for specialist palliative care reports on UK patient activity in specialist services in the voluntary sector and the NHS (inpatients, day

care, community care, hospital support, bereavement support and outpatients). The MDS is heavily dependent on hospice services completing a survey every year. The overall response rate in 2010 reached 62%, varying widely by service type (from 44% for bereavement and outpatient services to 75% for home care services)⁶⁵. If the services that do not respond to the survey do not have the same patterns as those that do, then national estimates are not an accurate portrait of the UK hospice services. Another limitation of the dataset is the fact that the number of people using each service is estimated based on the number of contacts, and one single patient is likely to have had more than one contact in one year. The National Council for Palliative Care is aware of the limitations (which also affect data comparability across years) and is working towards improvements.

One of the consequences of having limited data on care provision is that we do not accurately know how many people were in receipt of hospice care in a given year, especially in settings other than inpatient hospices and palliative care units. We also do not know if the current services are being used to their full capacity, and this makes it difficult to plan how much expansion is needed to accommodate the increasing demand in the future.

3.5 Is the UK population expected to increase in the future?

According to the most recent ONS projections, the UK population is expected to increase 17.5% from 2010 to 2035 (from an estimated 62.3 million to 73.2 million)¹¹ (Table 5). The biggest increase in numbers will be in England (19%) and the smallest in Scotland (11%). The post Second World War baby-boom generation, now in their 60s, will continue into the oldest ages; this group will represent the over 85s in 2035. Another baby-boom generation was born in the 60s; by 2035 these will be amongst those over 70 years old⁶⁶.

Table 5 – UK estimated and projected population up to 2035 (in millions)

	2010	2015	2020	2025	2030	2035
England	52.2	54.5	56.6	58.6	60.4	62.1
Wales	3.0	3.1	3.2	3.3	3.3	3.4
Scotland	5.2	5.4	5.5	5.6	5.7	5.8
Northern Ireland	1.8	1.9	1.9	2.0	2.0	2.0

Hospices include Sue Ryder Homes, Marie Curie Centres, oncology centres, voluntary hospice units and palliative care centres. N/A - not available.

Source: ONS. Mortality statistics: Deaths registered in 2007/2008/2009/2010/2011.

The ONS predicts that the UK population's median age will increase from 39.7 years in 2010 to 42.2 years in 2035¹¹. Although women are still living longer than men, the age differential has been decreasing throughout the years and the trend is expected to continue. Men are projected to represent 43.2% of all adults aged 85 years or older in 2035 (an increase from the ONS estimates of 36.8% in 2010)¹¹.

The increasing number of older people will not be the only driver of future hospice care. People are also more often living alone, often with limited support from friends and relatives²³. An increasing number of people are employed outside the home, making them unable to provide full-time care⁶⁷. Furthermore, the fertility levels in the UK have decreased throughout the years and are below “the replacement level”, meaning that the number of children per women is not enough for the population to replace itself in the long term (this is calculated without accounting for the effect of migration). Government incentives for family planning and more certainty about children surviving until adulthood had an impact on families, which started to get smaller⁶⁸. The ONS estimates that the average completed family size for women born in the UK in 2010 or later will level off at 1.84 children for women.

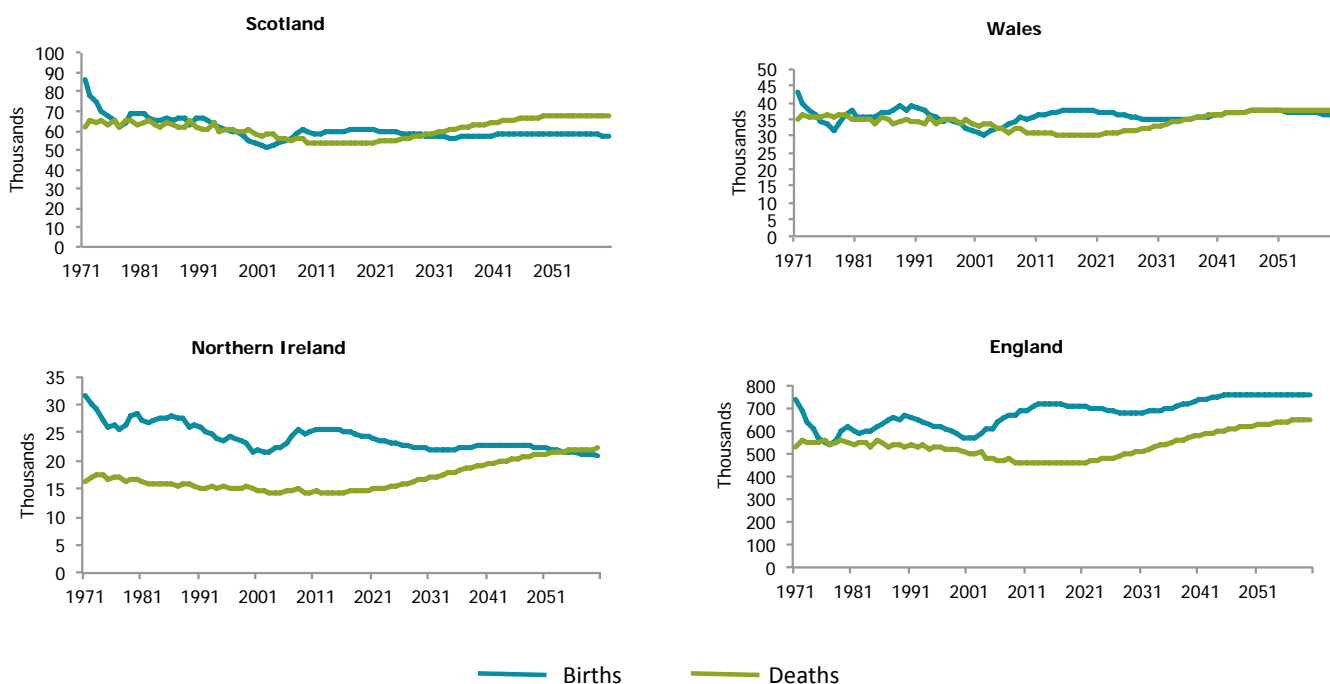
Despite the levelling off of fertility, the number of births is expected to increase in the upcoming years due to factors such as increased inward migration of women of childbearing age⁶⁹. Furthermore, although women today

have fewer babies than older generations, previous higher fertility resulted in a larger number of women entering reproductive ages⁶⁸. This growth in the number of births is relevant since it might represent more people who can potentially become caregivers, but in the later future they would also be amongst the growing number of people in need of care. The number of deaths is expected to surpass the number of births in Scotland from the late 2020s, in Wales from the late 2030s, and in Northern Ireland from mid-2050s. In England, this is not expected to happen in projections up to year 2060⁶⁹ (Figure 3).

3.6 What about the projected number of deaths?

According to the latest ONS projections, population growth will be accompanied by an increase in mortality from around 2015¹¹. This means that the decrease in mortality that we have seen in the past few years will be replaced by an escalating number of deaths. When analysing projections in 5-year trends, we see that from 2011 to 2015 there will be an average decrease of 837 deaths per year. From 2016 to 2020, there will be an annual average increase of 1,269 deaths, from 2021 to 2025 an average increase of 4,343 deaths per year, 6,971 annually from 2026 to 2030 and 8,181 from 2031 to 2035. The previous ONS projections were based on more pessimistic assumptions about life expectancy and over

Figure 3 – UK actual and projected births and deaths (thousands) – 1971 to 2060



Source: ONS. National Population Projections 2010-based Statistical Bulletin.

projected future number of deaths; this helps to explain why previously the increase of deaths was expected to happen from 2012 onwards⁷⁰.

The ONS estimates that those aged 65 and over will account for 23% of the total UK population by 2035²¹. While there were 1.4 million people aged 85 or older in 2010, this should increase to 1.9 million in 2020 and up to 3.5 million in 2035¹¹. The number of centenarians is projected to increase more than eightfold, from 12,636 in 2010 to over 100,000 in 2035 (Figure 4). This represents an additional 2.1 million very old people with increasing care needs. The oldest old will correspond to 5% of the entire population in 2035 (compared to 2% in 2010).

Will people die older?

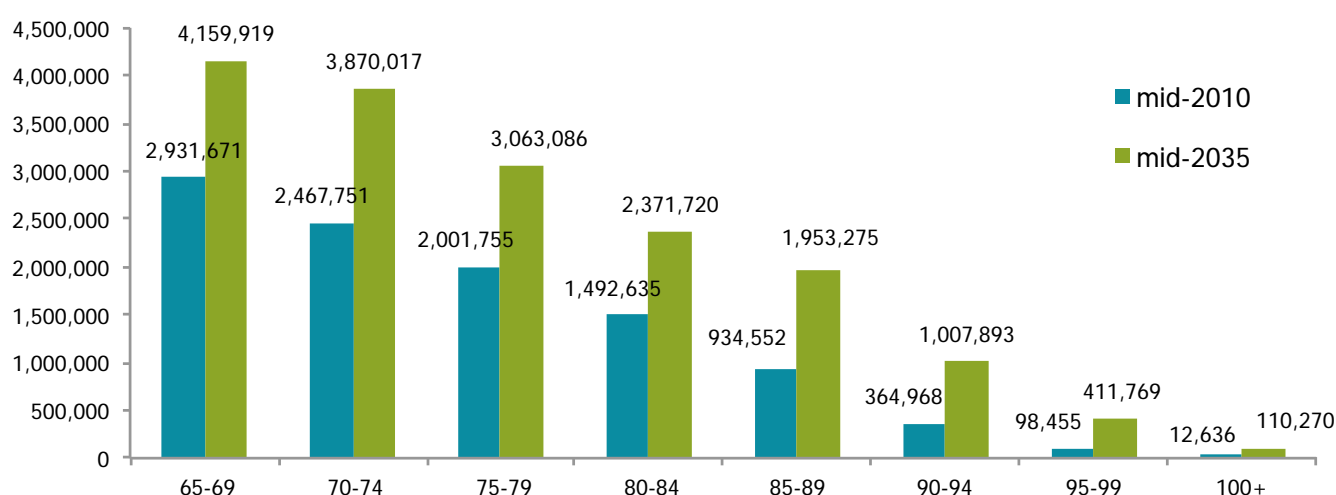
Due to the population ageing, deaths will also be increasingly happening at an older age. While in 2010 the oldest old represented 35.9% of all UK deaths (201,716 deaths), the proportion is expected to increase to 49.5%

in 2035 (a total of 328,469 deaths for this age group) (Table 6). Taking gender into account, in 2035 women will represent 55.7% (182,849) of all deaths (Appendix A).

What will people die from?

A growing number of older people means a higher demand for care to help them with multiple comorbidities and chronic conditions common in old age²³. Cancer and dementia are especially relevant conditions since a substantial number of people will be dying with them (either as the main cause of death or as a contributory cause of death) (Box 3). The demand for hospice care for the older age group is therefore expected to increase sharply in the future. Joint work with geriatric medicine and disease-specific specialties will be crucial. Increased disability is also likely to drive demand for settings such as care homes; the need for care home beds is forecast to rise by up to 150% over the next 50 years⁶⁰.

Figure 4 – Estimated and projected UK population aged 65+ and age distribution



Source: ONS. National Population Projections 2010-based Statistical Bulletin.

Table 6 – Actual and projected number and proportion of oldest old deaths in the UK (2010-2035)

85+ deaths	2010	2015	2020	2025	2030	2035
85-89	104,357 (18.6)	95,974 (17.3)	94,532 (16.8)	97,990 (16.7)	105,344 (16.9)	127,128 (19.2)
90-94	64,509 (11.5)	74,609 (13.4)	77,464 (13.7)	83,923 (14.3)	93,356 (15.0)	105,169 (15.8)
95-99	27,535 (4.9)	28,988 (5.2)	38,494 (6.8)	45,284 (7.7)	55,692 (8.9)	67,587 (10.2)
100+	5,315 (0.9)	6,423 (1.2)	8886 (1.6)	13,579 (2.3)	19,321 (3.1)	28,585 (4.3)

Source: ONS. Mortality statistics: Deaths registered in 2010. ONS. Projected number of deaths obtained upon request.

Box 3 - What are the current projections for cancer and dementia?

Different predictions for cancer in the UK point to an increasing number of cancer deaths in the future. Olsen et al's⁷¹ projections published in 2008 show that the annual numbers of cancer deaths in the UK are expected to increase 30% for men and 12% for women by 2023. Furthermore, with an increased number of cancer cases and improvement in medicine, the number of cancer survivors is also expected to increase. Maddams et al⁷² reported that in 2040 almost a quarter (23%) of people over 65 will be a cancer survivor (compared to 13% in 2010). Current evidence suggests that cancer survivors who are not in good health have similar needs to those patients with chronic conditions⁷³. When accompanied by frailty due to old age and comorbidities, hospice care may also be required for this group. Cancer Research UK recently predicted a fall in mortality rates for some types of cancer (17% fall by 2030)⁷⁴. Mortality rates are based on the population size (number of deaths per 100,000 population, in this case). As the UK population is expected to increase, a rise in the number of cancer deaths is likely even if the mortality rates become lower. Hence, it is crucial to examine the actual number of deaths in addition to mortality rates in order to plan future provision of hospice care.

The Alzheimer's Society estimates that in the UK over a million people will have dementia in 2021, with over half a million having undiagnosed dementia if current trends continue⁵⁴. Their projections of people in the UK with dementia show 1.7 million by 2050; with one in three people over 65 expected to die with dementia (although not necessarily having dementia as the main cause of death)⁵⁴. People with dementia have a median survival of 5.0 to 9.3 years²⁷ and are high users of health and social care services²⁹. Dementia has a disproportionate impact in capacity for independent living and is one of the leading causes of non-fatal disability in the developed world^{27,29}.

Key points in section 3

- The older people get, the more likely they are to suffer from cancer and chronic debilitating conditions such as dementia, which can benefit from hospice care. Needs may vary according to disease groups, but aspects such as symptom control are a common requirement.
- At least half of people still die in hospitals in all UK countries. Non-cancer patients, women and the oldest old die at home and inpatient hospices less often than other age groups. Older women die in care homes more often than men. More than a third of deaths amongst the oldest old take place in care homes.
- The UK population is expected to escalate in the future. Since people are living longer, this will be accompanied by an increase in mortality for people in older ages. Deaths due to dementia and cancer will increase. It is likely this will translate into a much higher demand for hospice care and long-term care in settings such as care homes.
- Current statistics on hospice care capacity and usage are limited; this affects the ability to plan future hospice care provision to meet demand.

What does this mean in terms of action?

- The number and distribution of deaths (e.g. by age, gender and cause of death), the incidence and mortality of conditions such as cancer and dementia are key factors shaping the population's need for hospice care in the future. Projections help to indicate future demand. Some of these factors may vary across the UK and need to be analysed locally for hospice care planning (see section 7 for local sources of data).
- It is crucial to investigate why inequalities in place of death persist despite efforts to invert the situation, especially regarding non-cancer patients and the oldest old. These could be due to a fault in service provision or different needs/priorities for these groups, for example. Currently, the reasons are not fully understood.
- Inpatient hospices have limited numbers of beds to support an increasing demand; alongside that, many patient groups might benefit from hospice care provided elsewhere. Diversifying hospice care provision to different care settings and collaborations with different providers is required.
- More robust statistics of hospice care provision are required so potential ways of using existing inpatient hospice beds better can be investigated. The projected increase in overall numbers of deaths also suggests that more inpatient hospice beds and community hospice services will be needed to meet demand.

4. Where people wish to be cared for and die: meeting preferences

4.1 Where would people prefer to be cared for and die?

Enabling people to make genuine choices about the care they receive towards the end of life is one of the core values of hospice care³². Meeting people's preferences has also been a goal of the End of Life Care Strategy in the UK¹. This includes addressing people's preferences and priorities for treatment, and also where they would like to live and die.

Published studies on preferences for place of care and death in the UK and worldwide show that most people would prefer to die at home. Higginson and Sen-Gupta's systematic review of preferences for place of care in advanced cancer published in 2000¹³ found that home was the most common preference (ranging from 49% to 100%); this was followed by an inpatient hospice preference. The reported proportions varied considerably, possibly due to issues such as different populations (patients, general public, caregivers), care settings, type of illness, service availability and cultural differences. Murtagh et al also reported that preferences differed markedly between individuals and across conditions⁷⁵. Higginson and Sen-Gupta emphasised that preferences were recorded and elicited in different ways, an issue also raised by a recent methodological review investigating the congruence between preferred and actual place of death⁷⁶.

For the purposes of this report, we carried out a literature review to provide a clear picture on preferences for place of care and place of death in the UK and found a total of 27 studies (Appendix B). More than half (15 studies) refer to internal audits or quality assessments in specific care settings. We also found that home was the most frequently chosen place of death in most studies (except for one study in a teaching hospital in London where home was the second choice, with 33%, following hospice with 37%); across studies,

home preferences ranged from 32% to 85%. Inpatient hospices and palliative care units were the second most frequently chosen place in all studies, except for an audit of Preferred Priorities for Care (PPC) documents where hospice was the most frequent choice with 37% of patients wishing to die there, and three studies where hospices were the third most commonly chosen place. Across all studies, inpatient hospice preferences ranged from 2% to 38%. It is possible that, similar to home preferences, differences in settings, service availability and cultural issues might have played a role in the variation of estimates.

In order to meet people's preferences and develop individualised care plans when preferences cannot be met, it is crucial to understand the reasons underlying these preferences. This will be considered in the next section.

4.2 Who prefers to die at home or in inpatient hospices/palliative care units, and why?

"Well it's your home, it's your home, you're not among strangers. You can get up when you want to, you're comfortable, you can sit in comfort and watch the television, you can read when you want to, you don't have the discipline at home and that is a big, big thing"⁷⁷

"If I did get to the stage where J [my husband] couldn't look after me, I wouldn't mind going in the hospice at all, now I've seen how good they are and how capable they are. And they look after you so well. I wouldn't mind going there"⁷⁸

Reasons for preferring to be cared for and to die at home are widely discussed in the literature. Home is a familiar place; it also allows people to be surrounded by their

things and loved ones⁷⁷⁻⁸⁰. Home death is also considered an attribute of a “good death”, although dying at home does not necessarily mean dying well. Hence, it is crucial to assess whether home deaths are indeed associated with better outcomes for patients and families, and which factors help to achieve these outcomes.

There is less evidence on who prefers to die in inpatient hospices or palliative care units and why this happens. Higginson’s 2003 telephone survey with 950 members of the general public in England, Wales and Scotland showed that preferences for inpatient hospice deaths increased with age, were higher for women and for those with a professional and management background⁸¹. Qualitative studies with patients in inpatient hospices and their families report peaceful deaths, individualised care and a “home like environment”^{82,83}. Some also see inpatient hospices as the best alternative to home since they would not be able to manage on their own, or would be too much of a burden to their family if they remained in their own home⁷⁸. Seymour et al⁸⁴ interviewed 77 White and 92 Chinese older adults living in the UK about their views on end of life care. The authors found that while for White participants inpatient hospice care seemed to be symbolic of the hope for a “good death”, Chinese participants identified their concerns that being in an inpatient hospice would mean having the word death “thrown in your face all the time”. Other participants showed resistance towards inpatient hospices (especially those from more deprived areas), for whom going to an inpatient hospice was a clear sign that death was inevitable and imminent. Studies assessing the quality of care and patient/caregiver satisfaction with care found that inpatient hospices are usually considered the “gold standard” (see section 5) and this might be an influencing factor for choosing this setting as the preferred place to die. Unlike hospitals and care homes, reports of inadequate care and subsequent media coverage are not common for inpatient hospices⁸⁵.

Evidence of factors independently associated with the choice of a place of death is limited and not conclusive¹³. Gomes et al¹⁹ investigated whether preferences for home death were associated with previous experiences of serious illness, death and dying and socio-demographic characteristics in seven European countries. Previous experiences were not found to have an influence. The odds of preferring home decreased as age increased (up to 60 years old), and also for those aged 70+ (except in England). In a country-specific model for England, the authors found that preferences were associated with retirement (those who were retired were less likely to choose home), while those who gave higher priority to dying in the preferred place were more likely to choose home.

Following the need to investigate further which

factors are associated with preferences, we have used the PRISMA data to do a similar analysis, this time investigating factors associated with choosing hospices or palliative care units as the place to die.

4.3 Factors associated with choosing inpatient hospices or palliative care units as the place to die: results from the PRISMA survey

“The care in the hospice where my mother was cared for was second to none...They were absolutely fantastic, everybody was looked after, including the whole family.”
Female PRISMA participant, 45 years old, chose hospice as her preferred place to die

A total of 1,351 adult members of the general public (64% women, median age 56) were interviewed in England in 2010. Most had some experience with illness, death or dying: 13% had been diagnosed with a serious illness in the last five years; 71% had lost a close relative/friend to death and 63% had a close relative/friend diagnosed with a serious illness in the last five years. Half of the participants (51%) had supported/cared for a friend or close relative in their last months of life.

Home was the most commonly chosen place to die in all regions (63% of 1,351 participants). Hospices or palliative care units were the second most frequently chosen option (29% of 1,351 participants would prefer to die in a hospice or palliative care unit). Less than 10% of participants chose the home of a relative or friend (1%), hospital (3%), nursing home or residential home (2%) or somewhere else (2%) as their preferred place to die¹⁹.

There were no significant differences in a preference for hospice/palliative care unit according to geographical region, gender, living arrangements (alone or with others), being at work, in education, unemployed, sick or disabled or being diagnosed with a serious illness. There were also no differences in terms of education level or self-perceived financial/health status.

However, we found that those who had cared for ($p=0.002$) or experienced the death of a relative or friend ($p=0.021$) more frequently chose hospice as their preferred place to die. The same was true for participants who belonged to a religion or denomination ($p=0.035$), were retired ($p<0.001$), lived in a city or in its outskirts ($p=0.035$), were widowed or married ($p<0.001$) or were older (with the exception of those aged 55–64, who preferred to die at home in 67% of cases; $p<0.001$).

People for whom having as much information as wanted was the most important priority for care at the end of life chose hospice/palliative care unit more frequently as their preferred place to die ($p=0.010$). Those for whom dying in

the preferred place was not their most important priority chose more frequently hospice/palliative care unit as their preferred place to die ($p < 0.001$). All significant variables ($p < 0.05$) are shown in Figure 5.

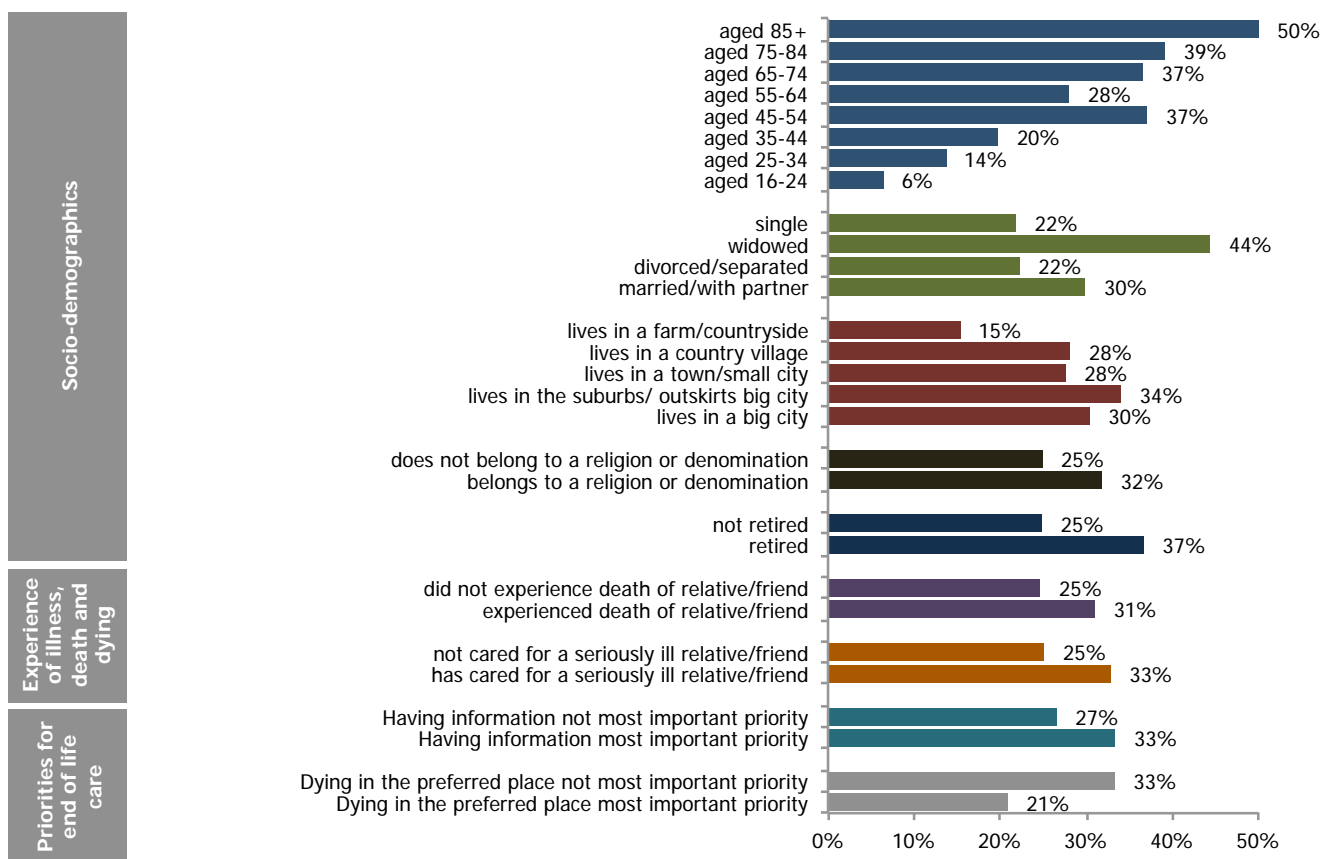
All the nine variables found to be significant in bivariate analysis were included in a logistic regression model, but almost all lost significance after accounting for the influence of other factors. The only factors independently associated with choosing hospice/palliative care unit as the preferred place of death were younger age (those aged 16-24 years were less likely to choose hospice than their older counterparts) and not choose dying in a preferred place as the most important priority (more likely to choose hospice) (Appendix D). The same two factors were found to be associated with a preference to die at home in our previous analysis, but in the opposite direction¹⁹, which suggests that they may influence decisions that involve these two settings as potential places to die.

Other factors might have lost significance because people who live longer might have had more experiences caring for someone who was ill. Older people are also

more likely to be retired and to be widowed, especially if they are women (since they live longer than men)⁵⁸. Likewise, older people are more likely to belong to a religion⁸⁶ and the number of older people in big cities and outskirts of big cities is increasing⁸⁷.

The results from PRISMA suggest that dying well, regardless of where it happens, can be more important than dying in the preferred place for people who chose hospice/palliative care unit. This highlights the importance of listening to people's preferences for place of death, but also to understand how important those preferences are for them in the bigger scheme of things. Issues such as having good symptom control, being at peace and not burdening their families might be seen as more important priorities, regardless of the place of death. There is further evidence supporting this idea⁸⁸⁻⁹⁰. On the other hand, studies (including the PRISMA survey) also show that older people are more likely to prefer to die in a hospice or palliative care unit than their younger counterparts. An increasing number of older people is therefore likely to be accompanied by a growing demand for inpatient hospice and hospice-supported beds.

Figure 5 – Preference for dying in a hospice/palliative care unit by participant characteristics



4.4 Are people's preferences being met?

There are several studies reporting whether patients and families' preferences for place of care or death are met⁹¹⁻⁹⁴. However, most refer to audits in a particular region or setting. Moreover, congruence between preference and actual place of death is usually reported for a group instead of for each particular individual. Some studies only report the proportion of patients who died in their preferred place, without mentioning where the preferred place was⁷⁶. Others compare preferences from a certain group to actual place of death from different groups with similar characteristics⁹⁵. Bell et al's⁷⁶ review found that most studies did not provide data on both preferred and actual place of death for all settings (e.g. while eleven studies provided complete data for preferred and actual home deaths, only six studies provided complete data for nursing home deaths). Due to all these differences, it is difficult to accurately estimate how often people's preferences are being met.

A few studies in the UK report complete data on meeting preferences (i.e. preferences and actual place of death for home, hospitals, inpatient hospices and care homes). In 2009, Holdsworth et al⁹⁶ investigated achievement of death in the preferred place for 124 community and inpatient hospice patients in the South East of England who had expressed a preference. The percentage of patients who wanted to die at home and actually died there was 53%; percentages were lower for care homes (50%), but higher for hospice (86%) and hospital (two patients wished to die in a hospital and both died in this setting). Gerrard et al's¹⁶ retrospective review in a hospital in London in 2007 and 2009 (315 comparisons) had slightly higher proportions of preferences being met for home (55%) and care home (59%), lower for hospice (68%) and the same for hospital (100%).

Bell et al⁷⁶ found that overall congruence between preferences and actual place of death ranged from 30% to 90% across all 18 included studies. Six studies (two

from the UK and one from Ireland) allowed comparisons by place of death for cancer patients. Findings supported that preferences were more frequently met for those dying at home (ranging from 68% to 100%) than for those who died in other settings (0% to 31% for hospital, 25% to 85% for hospice and 7% to 100% for nursing home). Other studies in the UK seem to support the same findings^{93,96,97}. The authors emphasise in most cases that the data were obtained retrospectively from bereaved relatives (instead of patients themselves). Furthermore, most studies assessed preferences only at one point in time, and there is conflicting evidence about whether people's preferences change as they come closer to death^{93,98}, with reasons being poorly understood at the moment.

There is strong evidence that expressing preferences can influence dying in the place of choice⁹⁹. Hence, adopting standardised tools to assess preferences can be beneficial, provided measures are in place to allow preferences to be met whenever possible. Some initiatives in the UK are also helping more people to die in their preferred place, although further evaluation is needed. The Marie Curie Delivering Choice Programme and the Electronic Palliative Care Coordination Systems (EPaCCS) are examples. Both involve cooperation and coordination between different service providers in order to provide more comprehensive support for patients and allow them to die where they wish (Box 4).

Assessing patients' preferences and priorities for care is very important to allow them to die where they wish, but also for other decisions regarding care (such as treatment options). Documents such as the PPC are used to register advance care plans, crucial in a context of increased cognitive impairment and inability to make decisions at the end of life. Advance care plans can be sensitively initiated at early stages of illnesses/ conditions³². When adopted, these have been shown to reduce anxiety, depression, and post-traumatic stress in surviving relatives and to improve patient and family satisfaction with care in hospital settings¹⁰².

“Dying well, regardless of where it happens, can be more important than dying in the preferred place for people who chose hospice/palliative care units.”

“Older people are more likely to prefer to die in a hospice or palliative care unit than their younger counterparts.”

Box 4 – Which UK models might allow more people to die in their preferred place?

Marie Curie Delivering Choice Programme:¹⁰⁰

The Marie Curie Delivering Choice Programme works in partnership with the NHS, the voluntary sector, social services and other health care providers in order to provide patient-focused 24-hour service to meet needs and ensure that people's preferences for place of care are met. They implemented a range of services in Lincolnshire based on an investigation of barriers to providing choice and high-quality hospice care. These included the creation of a Palliative Care Coordination Centre to book packages of care for patients in the community, education activities and videoconferencing for those involved in care provision, wider support for patients and caregivers via support groups at a local hospice, a community-based Rapid Response Team (RTT) to provide nursing services to patients requiring hospice care and professionals during twilight and out-of-hours periods (this included guidance over the telephone) and appointment of Discharge Community Link Nurses (DCLNs) to facilitate speedy discharge of patients to their preferred place of care. An evaluation of the programme found that it was associated with a statistically significant increase in the proportion of death at home (19% to 23%) and a decrease in the proportion of hospital deaths. This happened without additional overall costs. The proportion of home deaths amongst patients who accessed the programme services rose even more dramatically (19% to 42%). 54% of the patients with cancer who accessed the DCLNs and were supported by the RRT to remain in the community were able to die at home. So far, the programme has funded and managed seven projects across the UK, while other localities are adopting the programme methodology independently by using the programme toolkit and consultancy service. More information is available on their website: <http://deliveringchoice.mariecurie.org.uk/>.

Electronic Palliative Care Coordination Systems (EPaCCS):

EPaCCS provide a means of recording and communicating key information about people's wishes and preferences for end of life care⁵⁶. These systems aim to improve coordination of care so that people's wishes can be met (including their preferences for where to die). EPaCCs have been piloted in several regions in England, including in the London area (where they are called “Coordinate My Care”)¹⁰¹. A healthcare professional (such as GP, hospital doctor or nurse) discuss with the patient their condition and their views on future care. If the patient agrees, his/her details (age, address, diagnosis, medications and preferences) are included in an electronic network. An alert is also sent to the London Ambulance Service and the out-of-hours GP service in the patient's area. The database is frequently updated and the records can be accessed 24/7 by health and social care professionals responsible for the patient's care. As a result, all relevant professionals know about the patient's preferences. Up to August 2011, 73% of all patients with a record died in their preferred place, while 25% died in hospital (compared with the London proportion of 59%). More information can be found in the 4th Annual Report of the End of Life Care Strategy: <http://www.dh.gov.uk/health/files/2012/10/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version.pdf>; a training pack for Coordinate My Care can be found here: <http://www.royalmarsden.nhs.uk/SiteCollectionDocuments/coordinate-my-care/cmc-training-pack.pdf>.

Key points in section 4

- Preferences for place of care and place of death can vary according to characteristics such as age, health conditions and priorities for care. Cancer patients choose home more frequently than non-cancer patients. However, home remains the most commonly preferred place; this is usually followed by an inpatient hospice preference.
- PRISMA findings report that older people choose hospice or a palliative care unit more frequently than their younger counterparts. Since people are living longer and will represent a higher proportion of the population in the future, it is likely that both the absolute number and the proportion of those wishing to die in an inpatient hospice bed or palliative care unit will increase.
- There is some evidence suggesting that a substantial group of people prefer to die in an inpatient hospice (available evidence shows a range from 2% to 38% in the proportion of people expressing this preference) because it has a “home like environment” and is the best place when home is not feasible. People also see hospices as “the gold standard” of end of life care.
- It is not fully clear how often people’s preferences for place of care and place of death are met (available evidence points to a range from 30% to 90%), but it is known that those who die at home have their preferences met more often than those who die elsewhere. If we contrast this with mortality data shown in section 3, it is reasonable to say that most people are not dying in their preferred place.
- Considering the large proportion of people who wish to die at home and in hospices or palliative care units, it is unlikely that preferences can be met for everyone (in terms of capacity, but also individual and environmental circumstances).
- Priorities for care can be as important as preferences for place of care and place of death. Documenting these is crucial so that people’s wishes can be respected in the context of the increasing cognitive impairment that accompanies conditions such as dementia.
- Collaboration between different services and specialties may help to allow more people to die where they wish.

What does this mean in terms of action?

- Although a diversification of hospice care provision is required, evidence on preferences suggests that more hospice beds (in inpatient hospices, palliative care units and similar settings) and/or better ways to use the existing inpatient hospice beds will be needed to meet preferences, especially for older people.
- Listening to people’s preferences and priorities for care can help to plan adequate hospice care in different settings, even when preferences for place of death are impossible to be met. Listening to patients and caregivers allows for the creation of adequate and realistic care plans.
- The use of standardised tools to record preferences and priorities for care is encouraged. It is also important to try to assess preferences more than once and understand the reasons underlying people’s preferences.
- It is paramount to seek closer collaborations between hospices and other care providers. Local practices such as the Marie Curie Delivering Choice Programme show that these collaborations are possible. Adequate communication between care providers might allow for timely coordination of transfers so that people can die where they wish.

5. Evidence that hospice care makes a difference to patients and caregivers

5.1 What do we know about people's experiences of hospice care?

With a growing number of people having hospice care needs, it is crucial to assess the care provided in different settings in order to inform service planning decisions and the implementation of best practice. Patients' and families' experiences are critical to understanding the quality of the care provided. In order to advocate for the need to expand hospice care provision, one needs evidence showing that hospice care is an effective and also cost-effective model of care when compared to standard care, while also meeting patients' and families' preferences. However, there is still a long way to go to understand the effectiveness and cost-effectiveness of hospice care. There should be a much stronger research focus on understanding and assessing the quality of hospice care provided to patients and their families.

It is well known that conducting controlled evaluations comparing hospice care with standard care for patients at the end of life is challenging. Ethical concerns are frequent and loss of participants is common due to the deterioration of conditions or death¹⁰³. Definitions of what constitutes hospice care and standard care vary across countries, across studies and care settings. Measured outcomes (e.g. quality of life, pain, other symptoms) and the chosen tools to assess these are also variable¹⁰⁴. As a result, the existing evaluations of hospice care have many different designs and there are several observational studies, some without a comparative element. The outcomes measured also vary considerably across studies¹⁰³. It is therefore not surprising that results across studies are not always consistent. Furthermore, most studies on the effectiveness of hospice care for patients and their families focus on cancer, only a few have studied the impact for people facing other illnesses such as human immunodeficiency virus/acquired

immunodeficiency syndrome (HIV/AIDS), heart/renal failure or chronic obstructive pulmonary disease (COPD). Patients with illnesses other than cancer are more likely to fail to receive timely referrals to hospice care, making it even more important to understand their experiences of care¹⁰⁵.

What is the benefit for patients and family caregivers?

Despite these limitations, several reviews of the literature have reported the benefits of hospice care for patients when compared to standard care in a variety of care settings^{102, 106, 107}. However, a critical gap remains: there is a lack of evidence on which models of hospice care work better. Studies comparing different care models are needed to understand which care components have the best results for patients and their families. Close collaboration between different services, and interventions which are strongly based on evidence and piloted, have produced positive results (Box 5). Gardiner et al¹⁰⁸ investigated factors supporting good partnership working between generalist and specialist palliative care services. They enumerated several factors such as: good communication between providers, clear definition of rules and responsibilities; opportunities for shared learning and education; appropriate and timely access to specialist palliative care services; and coordinated care.

Published systematic reviews describe improvements in symptom control^{103, 110-112}, particularly in pain^{103, 110, 112-114}. There are also reports of increased patient satisfaction with care^{112, 115-118}, increased chances of home death^{118, 119} or of dying in the preferred place¹¹¹. However, review authors also report insufficient evidence about improvements on other physical and psychological symptoms¹²⁰, mixed results about the effects on psychosocial and spiritual problems¹¹³, no differences on patients' functional status, psychological well-being or cognitive status¹¹⁸ and conflicting evidence on patients' quality of life^{114, 120, 121}. Smeenk et al's review investigating

Box 5 - A novel palliative care service for patients with multiple sclerosis (MS) in London, UK

Edmonds et al³⁷ carried out a fast-track RCT (two groups received the intervention, but at different times) with 52 MS patients in a teaching hospital in London. The intervention team included a consultant in palliative medicine with training in neurology and special interest in MS, a clinical nurse specialist and an administrator. There were weekly multi-professional MS clinics with a consultant neurologist and also meetings to discuss caseload and for consultant input. The team worked closely with the local hospital palliative care team (specifically with their psychosocial worker).

The intervention was grounded in previous systematic reviews of evidence and followed the Medical Research Council framework for the evaluation of complex interventions¹⁰⁹. For each patient there was an initial comprehensive assessment (which included assessment of caregiver concerns and advance care planning), development of an action plan and follow-up. Calls and visits followed depending on needs. The specialist palliative care service appeared to positively affect some key symptoms (pain, nausea, vomiting, mouth problems and problems sleeping) and also reduced informal caregiver burden. The authors emphasised that the palliative care intervention is unlikely to replace the key role of MS and rehabilitation services, but palliative care services may have an important role in short-term interventions. Furthermore, they highlighted the need to conduct a larger study to test their findings and verify which aspects from their intervention were most useful.

the effectiveness of home care programmes for patients with incurable cancer¹¹⁷ found “some significant positive influence” on patient’s quality of life and psychosocial dimensions. Harding et al’s systematic review on AIDS¹²² found limited evidence that home palliative care and inpatient hospice care significantly improved outcomes for patients with HIV (pain and symptom control, anxiety, insight and spiritual well-being).

Evidence on the effectiveness of hospice care for family caregivers is scarcer. Reviews have reported that specialist palliative care significantly improved caregivers’ anxiety¹¹⁰ and satisfaction^{112, 116, 120, 121}. There is limited evidence on the improvement of psychological symptoms^{113, 118, 120} and mixed results about the effects on spiritual problems of patients and relatives¹¹³. Stajduhar’s review¹²³ on home-based caregiving at the end of life reports limited positive effects of palliative care interventions improving caregiver quality of life, perceived burden, preparedness, perceived competence, caregiving rewards and having informational needs met. Harding et al^{124, 125} highlighted the need to increase the number of robust interventions with tested outcome measures in order to generate evidence on effectiveness of care for family caregivers.

One of the most needed research areas is the impact of hospice care on family caregivers, in terms of bereavement outcomes. Being a core component of hospice care, bereavement services are mostly funded by the voluntary service¹²⁶, and services for those who do not have access to hospice care are lacking¹²⁷. Most available evidence of effectiveness is from case studies in hospices^{127, 128}. An exception is Grande et al’s RCT¹²⁹ conducted with patients referred to a hospital at home service in Cambridge (UK). The authors found no difference in grief scores (measured with the Texas Revised Inventory of Grief) when comparing patients receiving hospital at home services with those receiving standard care. Field et al¹²⁸ surveyed UK hospices and specialist palliative care services providing adult bereavement support and found variation on the way needs were assessed, showing the need to evaluate the effectiveness of the services provided. Semi-structured interviews and focus groups in five English hospices showed that participants were “largely satisfied” with the support they had received¹³⁰, but there was no clear evidence to suggest what should be considered “best practice” in terms of bereavement support¹³⁰.

Is hospice care cost-effective?

Assessing the costs of hospice care is challenging for several reasons, especially when these involve costing a range of community services⁵. It is possible that some models of hospice care are more cost-effective than others, but at the moment there is not enough information to confirm this; evidence on comparative cost-effectiveness is lacking. A limited number of reviews have investigated the costs and/or cost-effectiveness of hospice care. While Hearn et al¹¹¹ found evidence showing a reduction of costs, others have pointed to scarce evidence of significant costs reduction¹²¹ or found mixed results on the use and costs of health services¹¹³. Reduction effects in resource use have been reported,

Box 6 - What is the role of family caregivers?

Carer UK estimates that there are over six million people providing unpaid care to frail, ill or disabled people in the UK. According to the charity, the economic value of the contribution made by carers in the UK reaches £119 billion a year¹³¹.

Caring for someone can be rewarding and fulfilling, but can also be a huge burden for family caregivers. They frequently neglect their own health; more than a third of caregivers experience psychological distress, some can also become socially isolated. Financial difficulties are also common due to high costs of care and the need to leave work in order to become a full time caregiver^{67,132}. With an ageing population, it is very likely that many caregivers have their own health problems. Older family caregivers also provide longer hours of care than their younger counterparts and have fewer social, economic and hospice care resources to cope¹³².

It is clear that family caregivers need more help; evidence shows that this should encompass psychological and emotional support, information, help with personal, nursing and medical care of the patient, out-of hours and night support, respite and financial help⁶⁷. Population ageing and changes in society are likely to further increase caregiver burden; it is therefore even more worrying that we still do not know which aspects of hospice care are effective to help them.

Studies also show that family caregivers have a central role in allowing people to die at home^{17,99}. This has strong implications for future care planning. Without appropriate support for caregivers, it is very likely that more patients will need institutionalised care; and less of them will be able to die at home.

Most caregivers do not get enough help from the formal care system¹³¹. It is extremely urgent to understand which models of care are more efficient to support family caregivers; further assistance (such as compassionate care benefits currently provided in countries such as Canada and Sweden¹³³) is also required. The Department of Health is currently working on better understanding and supporting caregivers; more information can be found on their website: www.dh.gov.uk/health/files/2012/07/White-Paper-Caring-for-our-future-reforming-care-and-support-PDF-1580K.pdf.

especially in terms of hospital admissions or days in hospital^{110,111,134}, but also of general healthcare use¹¹⁶.

Individual studies have reported cost savings when using hospice care teams instead of standard care, although most of the recent studies are not from the UK. An exception is the fast-track RCT in South East London (UK)¹³⁵, which evaluated the cost-effectiveness of a new service for people with MS described in Box 5. Caregiver burden was found to be significantly lower in the intervention group compared with the control group, with no statistically significant differences in total costs amongst both groups. The authors found there to be a trend toward lower community costs in the intervention group and no differences in costs to family caregivers. The intervention potentially offered savings of £1,195 in community costs per patient over three months and a total cost saving per patient of £1,789 (including inpatient and informal caregiver savings). This was found to be mainly due to a lower use of primary and acute hospital services. An in-home program with terminally ill patients in the US¹³⁶ improved patient satisfaction at 30 and 90 days after enrolment, increased the probability of dying at home, and significantly reduced the overall and average day costs

of care. Costs for those receiving the program were 33% lower than for those receiving usual care (average savings of US\$ 7,552 per patient).

5.2 Do outcomes for patients and families differ according to place of death?

Is dying at home better?

At the moment, there is not enough evidence to suggest that a home death is associated with better outcomes for patients and their families. The evidence is contradictory on pain, grief and other symptoms. Tang¹³⁷ found that pain was more likely for patients who died at home (compared to hospital deaths), while Pinzon et al¹³⁸ found the opposite (even when accounting for confounding factors). Addington-Hall and Karlsen¹³⁹ reported greater grief for relatives of patients who died at home (compared to those who died elsewhere), while Wright et al¹⁴⁰ found that the relatives of patients who died in hospital were more likely to have a prolonged grief disorder. In an earlier study, Parkes et al have reported worse symptom control

for people who died at home (as opposed to hospital)¹⁴¹. Systematic reviews report that evidence is also lacking on whether hospice care provided at home is more effective than hospice care provided elsewhere^{142, 143}.

In 2011, a national mortality followback survey with 22,292 bereaved relatives⁹⁷ showed that involvement in decisions about care was more frequent for relatives of patients who had died at home (92%). This group also had the highest proportion expressing preferences for place of death (67%) and was more likely to be reported as having had enough choice on where to die (88%). On the other hand, only 17% of relatives of patients dying at home reported pain relief being provided “completely, all of the time” (contrasted with 36% in hospital, 45% in care home and 62% in hospice).

What about dying in an inpatient hospice?

“Her room would beat the finest hotel room all to pieces—it was fully equipped, radio, television, a private bath, glass doors that opened onto a little place outside. The furniture was—well of course the bed itself was only a sick bed you know—but the other furniture was just comfortable as it could be—recliners and all that⁸³”

Publications and studies on patients’ and families’ experiences with inpatient hospice care started being carried out in the UK shortly after the start of the modern hospice movement¹⁴⁴⁻¹⁴⁸. Perhaps due to the voluntary aspect of inpatient hospices, reports usually refer to a single hospice or a small group of hospices. Exceptions are postal surveys carried out with bereaved relatives^{97, 149}. Most available studies seem to indicate that inpatient hospice care is the “gold standard” compared to care in other settings. However, caution should be taken since the study design and setting affect the extent to which results can be generalised to other hospices. More robust studies are needed in order to verify the effectiveness and cost-effectiveness of inpatient hospice care, and how it compares to care in other settings.

Early studies at St. Christopher’s Hospice¹⁴⁶ found that patients suffered less from pain when at the hospice (compared to hospital), although throughout the years there was a remarkable improvement for hospitals, until the difference no longer existed¹⁵⁰. Patients were often less confused at the hospice, although the proportion reporting confusion also decreased in both settings throughout the years. Spouses seemed to be “significantly less anxious” when patients were in a hospice as compared to other settings¹⁵⁰.

In the early 1990s, Seale et al¹⁵¹ compared 45 patients receiving inpatient hospice care with 126 receiving standard care and interviewed relatives of the deceased patients. Respondents’ levels of satisfaction with

hospice care (both inpatient and at home services) were significantly higher than for other types of care. During final admissions, hospice patients also had less medical interventions.

A study using the VOICES questionnaire¹⁵² with 382 bereaved relatives of patients who died in 2002 in London found eight statistically significant differences when measuring levels of satisfaction with inpatient hospice and hospital care. All of them favoured inpatient hospice care (these included better pain control, better communication and better medical, nursing and personal care). More recently, with an adapted VOICES questionnaire used nationwide with 22,292 bereaved relatives across England⁹⁷, inpatient hospice care received the highest scores in several measures of satisfaction and quality of care (settings included home, hospital, hospices and care homes). Rates were also the highest in categories such as “being shown dignity and respect by staff”, “having pain relieved”, “having their personal and nursing needs met” and “having had adequate privacy”. Patients who died in an inpatient hospice (along with those who died at home) were also more likely to be reported as having had as much support as they wanted, having had enough choice of where they might die and to have died in the right place according to respondents. Relatives of patients who had died in an inpatient hospice were most likely to report having received adequate support at the time of death (for both patients and families) and having been dealt with in a sensitive manner after the patient died. They were also the most likely group to have talked to someone about their loss after the patient died.

“It is crucial for inpatient hospices to assess which aspects of their care are more effective and cost-effective and verify how these can be transferred to other care settings.”

Key points in section 5

- There is evidence that hospice care is associated with better outcomes for patients (such as improvement in symptom control, satisfaction with care and increased chances of dying at home), regardless of the care setting. However, findings are mixed regarding improvement in patients’ quality of life and impact of hospice care on family caregivers (including bereavement). Furthermore, we do not know which models of hospice care work better.
- Although individual studies suggest that hospice care can reduce care costs, there is not enough evidence to support the statement that hospice care is more cost-effective than other models of care. Studies on cost-effectiveness are urgent.
- Evidence is also lacking on whether dying at home is better than dying elsewhere, research findings are still conflicting on symptoms such as pain.
- Inpatient hospice care is recognised by the quality of care provided, judged by patients and their caregivers. In a recent national survey, inpatient hospice care was rated better in several categories such as satisfaction with care, better care quality and receiving adequate support at the time of death. However, the evidence is still limited, particularly on what specific attributes make inpatient hospice care so good.

What does this mean in terms of action?

- It is crucial for inpatient hospices to assess which aspects of their care are more effective and cost-effective and verify how these can be transferred to other care settings. Voluntary hospices can be major providers of evidence-based practices proven to be effective. Research should also identify which aspects of care can be improved. Local audits are helpful, but partnerships with universities and research centres can aid the design of robust interventions.
- Further evidence on the effectiveness of hospice care for family caregivers is required so they can be better supported.
- Hospice care has been shown to be effective in different care settings (such as people’s homes, hospital wards, nursing homes, assisted living facilities, etc.). It is important to remember that a great proportion of people will still die in hospitals and care homes. Therefore, collaborations with hospital clinicians and other health care professionals in care homes need to be developed.

6. Take home messages

“We also need to improve our evidence base for inpatient hospice care. Our assumption that hospices are centres of excellence does not mean that we should not assess their care and aim to improve it. Furthermore, where excellent care exists, there should be further impetus to rigorously assess what makes it excellent to establish whether some of its components may be translated to other settings” (Grande, Palliat Med 2009¹⁵³)

6.1 Limitations and need for more evidence

The UK population has been ageing, and the trend is expected to continue in the following decades. Older age is often accompanied by cancer and chronic, debilitating conditions, shaping the patterns in death and dying. Those in need of hospice care will be increasingly more likely to be older and fragile, demanding flexible, specialised care in a variety of settings, which is dependent on local resources, but also on patient’s personal circumstances, needs and preferences. Older people with conditions other than cancer need special attention.

Mortality trends from the past five years show that at least 50% of people in the UK still die in hospitals, although the number and proportion of home deaths have increased (in 2010 a fifth of all deaths happened in this setting). Place of death varies according to age (with older people less likely to die at home and in inpatient hospices and more likely to die in care homes), gender (with women more likely to die in care homes) and cause of death (with cancer patients more likely to die at home and in inpatient hospices).

Although the majority of people would prefer to die at home there is a substantial proportion of people who would prefer to die elsewhere, with inpatient hospices or palliative care units being the second most frequent setting of choice. People’s preferences

seem to be influenced by the need to be in a familiar place and surrounded by family and friends, but are also underlined by personal conditions and concerns about burdening loved ones. The fact that inpatient hospices are considered a “gold standard” in terms of care might also influence the preference to die in this setting. Emerging evidence suggests that younger people are less likely to choose inpatient hospices, while those who do not choose dying in a preferred place as their most important priority are more likely to choose hospices. We also see that there is evidence showing that hospice care provided in diverse settings is beneficial to patients compared to standard care. Reports on the congruence between preferences and actual place of death show that preferences are more often met for those who die at home, and less for those who die elsewhere.

It is clear from the data, however, that more evidence is needed in several areas. We still do not know how beneficial hospice care can be for family caregivers. It is known that family caregivers are crucial to allowing patients to die at home when possible; and that people living alone are less likely to die at home^{75,99}. Furthermore, due to population ageing, current and future family caregivers are likely to need support themselves²³, and this needs to be considered in any care plan that aims to be sustainable.

Further evaluation of the cost-effectiveness of hospice care, regardless of setting, is crucial for future hospice care planning. Not being able to cost community care is a big setback since this is expected to be one of the main sources of hospice care provision in the future. We also still do not know if dying at home is better than dying elsewhere, or which models of hospice care are more effective and cost-effective.

We also need to better understand the needs and preferences of older people and those with non-malignant conditions so they can be better supported.

“The growing number of older people with chronic conditions needs to be accompanied by a corresponding increased availability of care services to provide adequate hospice care.”

Older people, although often preferring to die in an inpatient hospice (and at home), tend to die in hospitals and care homes. The preferences of people with non-malignant conditions are less studied, but recent evidence indicates they choose home less often than cancer patients. Perhaps these groups are in greater need of specialised care that only hospitals and care homes are providing at the moment (due to comorbidities or their need for intensive care). It might be that new models of care are needed for these patients. It is possible that they are admitted to hospital due to serious complications, or due to misdiagnosis (for example, in the case of patients with dementia during a crisis). It can also be that it is difficult for older people and those with non-malignant conditions to access services; evidence suggests that these groups are less likely to receive timely referrals to hospice care¹⁰⁵. This could limit their ability to die at home. Furthermore, it is crucial to remember that these two groups are closely related. In light of the ageing trends we are likely to see increasing numbers of older people with non-malignant conditions.

This report has further limitations in addition to those that derive from a lack of evidence. There are other factors influencing hospice care needs that we have not considered in detail. Social inequity is a crucial issue which deserves a separate report. It has an impact on all aspects of health, from birth until death – with implications for hospice care. Life expectancy for those who are socially deprived is lower than for wealthier counterparts. Furthermore, when socially deprived groups manage to reach older age they are more likely to suffer from chronic conditions and to spend more of their later years of life with a disability¹⁵⁴. The extent to which the British society will be affected by certain conditions and the corresponding needed investment in health and social care is therefore dependent on addressing social inequalities. The Marmot Review is core reading on the

topic¹⁵⁴. We also recommend interested readers to consult the reports on deprivation published by the NEOLCIN (available at www.endoflifecare-intelligence.org.uk), Tebbit’s reports on palliative care needs according to UK regions⁸ and additional literature on the topic^{155, 156}.

Another area not thoroughly analysed in this report is the importance of social care when planning to meet the future care needs of older people. Social care provided in the community can help reduce inappropriate hospital stays⁵⁶, and with the ageing of population and more people living alone, the demand for social care is expected to increase.

We have also focused mainly on two causes of death: cancer and dementia. These are key conditions for future hospice care planning, representing more than a third of all deaths in each UK country. However, they are not the only ones. Anyone with a life-limiting illness can potentially benefit from hospice care. This is the case for patients with conditions such as end-stage renal disease and long-term neurological conditions (which include Alzheimer’s, Parkinson’s disease, MS, motor neurone disease, Huntington’s disease and stroke)^{157, 158}.

We have provided a general picture of the current and future hospice care needs, usually referring to the UK as a whole. Local areas can have different socio-demographic characteristics. The number of deaths, mortality rates, the incidence of specific illnesses and the number of older people living alone are examples of factors that influence hospice care needs⁸. Rural areas with a scattered population might need more resources per head of population⁸. Cultural variations can play a role, and there are issues regarding cultural equivalent translations of terms¹⁵⁹ such as “hospice”. All these factors need to be locally examined in each UK region before making any strategic planning for the future. In section 7 and in the reference list at the end of this publication we provide local sources of information, but they are by no means exhaustive.

6.2 What are the next steps?

The growing number of older people with chronic conditions needs to be accompanied by a corresponding increased availability of care services to provide adequate hospice care. This will need to be done in a variety of settings (e.g. home, hospitals, care homes and other places), with home as a priority but increasing the number of hospice beds (in inpatient hospices and palliative care units) is also needed as preferences for these settings come second and are expected to increase. Ways to better use available hospice beds should be investigated; this involves obtaining more robust information on hospice capacity and usage. Further investment in hospice care is urgently required to meet future demand.

We have made recommendations throughout the report based on the available evidence. It is very positive that the current evidence shows hospice care being effectively implemented in different settings and making a difference to patients and their families. It is also encouraging that inpatient hospice care is seen as a “gold standard” by those who receive or might receive such care. Evidence also suggests that diversification and collaborations (including training to share best practices) are a step forward, and successful stories can already be seen. However, while this is true, it is certain that more robust research is needed in the area.

There is no doubt that the upcoming years will be challenging. Much needs to be done to meet future demand and we hope that this report clarified some of the main challenges to be faced. We hope it can also provide encouragement in discussions currently taking place about the UK health care system as a whole. Decisions being made now will affect all of us as health providers and recipients of care.

“There is no doubt that the upcoming years will be challenging. Much needs to be done to meet future demand and we hope that this report clarified some of the main challenges to be faced.”

7. Where can I find local population data?

Key local population indicators can be found here:

- Current population estimates (local and unitary authorities) for England and Wales, by age and sex. Publication has links for reference tables in Excel. Estimates based on the 2011 Census: www.ons.gov.uk/ons/dcp171778_270487.pdf.
- Life expectancy by UK regions: www.ons.gov.uk/ons/dcp171778_238743.pdf
- Number of deaths by place of death and by age according to health authority (tables 11 and 13, year 2010): www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-230730.
- Local end of life care profiles (England only) available in an interactive atlas and pdf files. These are shown by local authorities and primary care trusts. Population and deaths by age, place of death, place of death by underlying cause of death and other causes; annual expenditure for those over 65+, amongst other indicators: www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/default.aspx.
- Interactive mapping tool with trends in mortality at the local level: www.neighbourhood.statistics.gov.uk/dissemination/
- People with dementia (diagnosed and undiagnosed) are available from the UK Dementia map. Searches by Health Authority, city and address: <http://alzheimers.org.uk/dementiamap>.
- Projected numbers of dementia by PCT - www.nepho.org.uk/uploads/doc262_1_brief003_10.pdf
- Cancer incidence by Health Authority in England, also references for further statistics and where to find statistics for Wales, Scotland and Northern Ireland: www.ons.gov.uk/ons/dcp171778_267154.pdf.
- Variations of place of death in England (data on different Health Authorities): www.endoflifecare-intelligence.org.uk/view.aspx?rid=71
- Health and Wellbeing reports for Scotland. Local area reports covering 67 indicators of a range of health

outcomes: www.scotpho.org.uk/comparative-health/profiles/2010-chp-profiles

- The NHS information centre has several health and mortality indicators for England and Wales, plus data by strategic health authorities, government office regions, local authorities, primary care organisations and counties: <https://indicators.ic.nhs.uk/webview/>
- The website Projecting Older People Population Information (POPPI) provides population data by age band, gender, ethnic group, religion, tenure, transport, living with no central heating, household growth and by state pension for English local authorities. Registration (free) is required: www.poppi.org.uk/

These sources provide relevant local data on preferences for place of care and place of death:

- PRISMA survey on local preferences for place of death. National telephone survey with the general public. Results shown by Government Office Regions in England: www.endoflifecare-intelligence.org.uk/view.aspx?rid=157
- Studies in Appendix B which are relevant to your local area
- Local PCT/ research group sites –for published results from audits/research. One example is a report by NHS Lanarkshire (www.nhslanarkshire.org.uk/Services/PalliativeCare/Documents/PPC%20Audit%20Final.pdf)
- Department of Health's page with results from the VOICES survey. National coverage. Table 29 in main file and Appendix B has benchmarking results by PCT cluster on whether patient expressed preference on where to die and whether relative thought patient had died in the right place: www.dh.gov.uk/health/2012/07/voices/
- Critical success factors that enable individuals to die in their preferred place of death – study in seven PCT areas (Croydon, Blackpool, Bath and North East Somerset, East Sussex Downs and Weald, Bradford

and Airedale, County Durham, Oxfordshire): www.endoflifecareforadults.nhs.uk/assets/downloads/EoLC_CSF_Report_for_Publication_2.pdf

Here you can find local sources of data on care experiences, best practices and quality ratings for hospice care:

- Examples of good hospice care practice across the country: www.kingsfund.org.uk/document.rm?id=8802
- Survey of specialist palliative care in Sheffield: www.nao.org.uk/publications/0708/end_of_life_care.aspx
- Benchmark ratings for PCT clusters in end of life care (national VOICES survey): www.dh.gov.uk/health/files/2012/07/First-national-VOICES-survey-of-

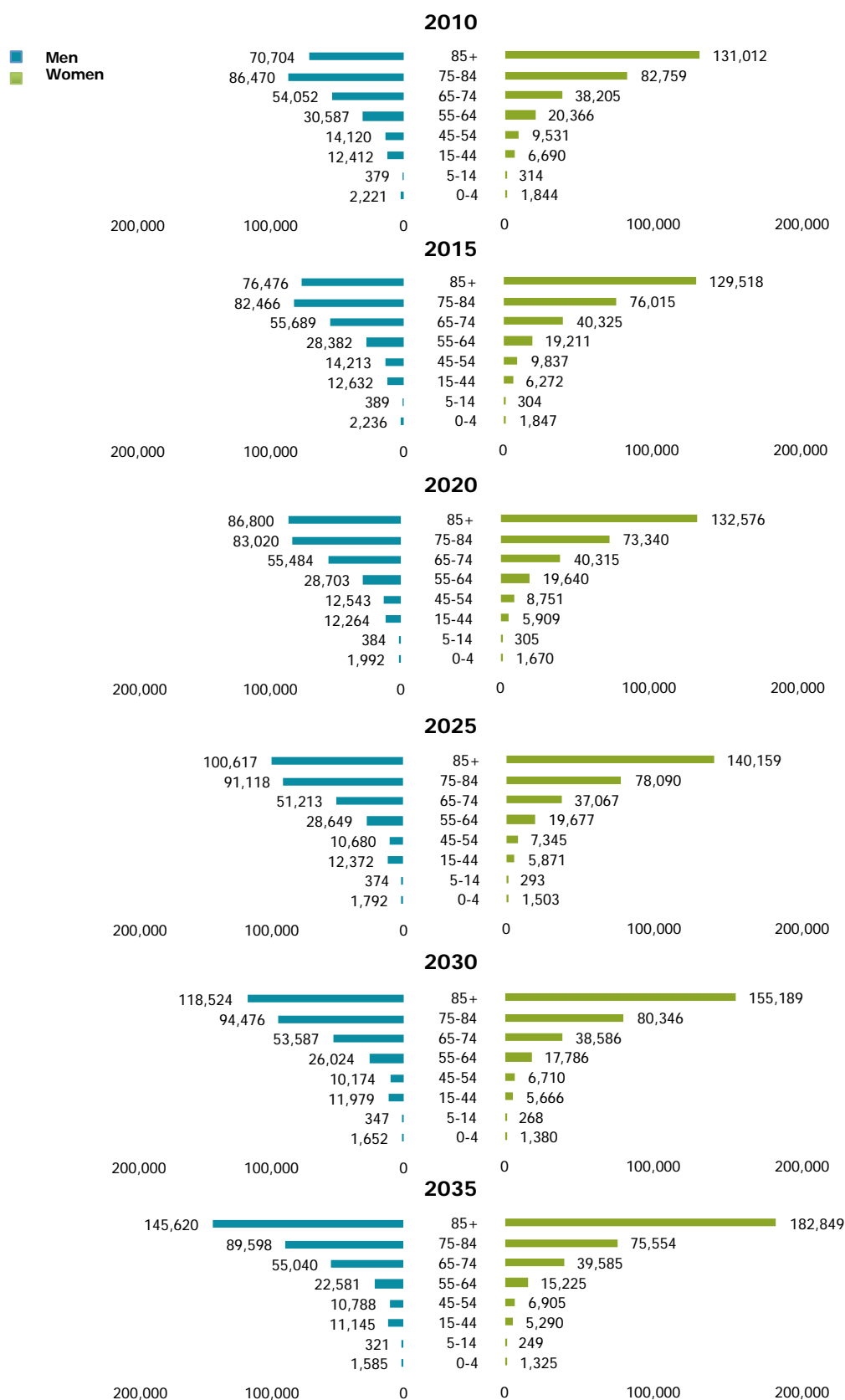
[bereaved-people-key-findings-report-final.pdf](#)

- Review the End of Life Care Pathway in the South West of England with particular emphasis on the gaps in information available on the provision of services - www.endoflifecare-intelligence.org.uk/view.aspx?rid=19
- Adaptation of the King's Fund's Enhancing the Healing Environment (EHE) in eight UK pilot sites (including Marie Curie Hospices in Glasgow and Hampstead) - www.kingsfund.org.uk/document.rm?id=7601
- The Care Quality Commission (CQC) is inspecting 50 NHS sites and 500 care homes on dignity, nutrition and social care. The report on the inspections is expected to be published soon: www.cqc.org.uk/

“Local areas can have different socio-demographic characteristics. The number of deaths, mortality rates, the incidence of specific illnesses and the number of older people living alone are examples of factors that influence hospice care needs.”

Appendices

Appendix A – Actual and projected number of deaths by age group and gender (2010-2035)



Source: Office for National Statistics (2012). Projected number of deaths obtained upon request.

Addington-Hall et al 1999¹⁶⁰

Lambeth, Southwark and Lewisham, London, EN

Bereaved relatives of patients who died of lung cancer, coronary heart disease or stroke. Deaths registered in 1998

Survey with bereaved relatives using the VOICES questionnaire

17 valid cases: 77% home, 23% hospice

Bowers et al 2010¹⁶¹

GP practice covering rural villages and an urban area in Cambridge, EN

Patients who died in the six months following changes to follow Gold Standards Framework. Deaths registered in 2009

Audit on PPC documents

21 valid cases: 52% home; 19% hospice; 14% NH; 14% hospital

Brettle 1995¹⁶²

City Hospital in Edinburgh, SCT

HIV patients who had attended the city hospital and died from 1986 up to the end of 1992

Audit of case notes (medical and nursing)

47 valid cases: 32% home; 32% hospice; 32% hospital; 4% other

Charlton et al 1991¹⁶³

Nine GP waiting rooms in South West SCT and a large semi-rural/urban practice in EN; Derby GP practices in EN

Patients attending the GP waiting rooms; control group chosen at random from Derby GP practices; group P with patients who had close personal experience of death or dying. Data collection within a ten-month period, year not stated

Survey using questionnaire on aspects of care of the dying

3690 valid cases (public): 70% home; 19% hospice; 11% hospital

77 valid cases (control): 69% home; 17% hospice; 14% hospital

61 valid cases (Group P): 54% home; 38% hospice; 8% hospital

Cox et al 2011¹⁶⁴

Hospital Specialist Palliative Care service, a GP practice service, a Heart Failure Community Matron service and a Nursing Care home, "Regional Cancer Network", EN

Sample of patients (cancer and non-cancer) who died over a 12 month period; Year of data collected not stated

Audit of case notes and complementary group interviews with healthcare professionals

31 valid cases: 55% home; 10% hospital; 3% hospice; 32% care home

Daley et al 2006¹⁶⁵

Specialist palliative care services in Bradford and Airedale, West Yorkshire, EN

Patients in receipt of the palliative care services who died during the study period. Deaths from Oct 2004 to Sep 2005

Audit on PPC documents

243 valid cases: 59% home; 27% hospice; 8% hospital; 6% NH

DoH 2012⁹⁷

All regions in EN by using death registration data

Bereaved relatives of patients who died of cancer, cardiovascular diseases and others. Deaths from Nov 2010 to Jun 2011

Survey with bereaved relatives using the VOICES questionnaire

7723 valid cases: 71% home; 7% hospice; 3% hospital; 5% CH; 14% elsewhere

Dunlop et al 1989¹⁶⁶

Major teaching hospital in London and surrounding areas, EN

Consecutive patients who died after being referred to a hospital support team. Deaths from Dec 1986 to Aug 1987

Analysis of recorded data on place of death

90 valid cases: 53% home; 29% hospice; 14% hospital; 3% NH

Gerrard et al 2010¹⁶

A teaching hospital in London, EN

Patients referred to the hospital palliative care team who died during the audit period. Deaths in 2007 and 2009

Audits on PPC documents

315 valid cases: 37% hospice; 33% home; 21% hospital; 9% NH

Gomes et al 2012¹⁹

All regions in EN

Random sample of households, members of the general public. Public surveyed from May to Dec 2010

Telephone survey, questions on end of life preferences and priorities

1316 valid cases: 64% home; 29% hospice, 3% hospital; 2% NH; 2% elsewhere

Grande et al 2008¹⁷

Three hospice at home (H@H) services in Cambridge, EN

Patients (and carers) referred to the H@H services who died within the study period (four months, date not stated)

Analysis of anonymous patient records

255 valid cases: 79% home; 15% hospice, remaining not specified

Higginson 2003⁸¹

All regions in EN, SCT and WAL

Random sample of households, members of the general public. Public surveyed in Apr 2002

Telephone survey; questions on end of life preferences and priorities

950 valid cases: 59% home; 25% hospice; 12% hospital; 4% NH

Higginson et al 2010¹⁶⁸

One hospital in London, EN

Relatives of patients who died of cancer purposively selected for a pilot study. Data collected from Apr to Aug 2009

Survey with bereaved relatives using the QUALYCARE questionnaire

18 valid cases: 39% home; 28% hospice; remaining not specified

Holdsworth et al 2010⁹⁶

Three hospice units with an inpatient ward of 16 beds, a community outreach service and day hospice. South East EN
Patients visited for the first time by a staff member employed by the hospice group. Deaths between 1 Jul and 31 Dec 2009

Search of the hospice electronic and paper records
 124 valid cases: 65% home; 23% hospice; 3% CH, 2% hospital; 7% other

Ingleton et al 2004¹⁶⁹

Rural county of Powys, WAL
Bereaved carers of patients who died of cancer between Apr 1999 and Jun 2001

Survey with bereaved relatives using the VOICES questionnaire
 132 valid cases: 78% home; 12% community/general hospital; 2% NH; 2% hospice, 6% other

Karlsen et al 1998⁹¹

Camden and Islington Health Authority, EN
Cancer deaths registered by residents in the districts from Jul 1995 to Jun 1996

Survey with bereaved relatives using the VOICES questionnaire
 80 valid cases: 74% home; 16% hospice; 5% hospital; 3% CH; 3% other

Koffman et al 2004¹⁷⁰

Three inner-London boroughs, EN
Relatives of patients who died of advanced disease identified via Health Authority death registrations (native-born White and Black Caribbean). Data collected from 1999 to 2000

Survey with a semi-structured questionnaire administered via interview
 20 valid cases (Black Caribbean): 85% home; 10% Jamaica; 5% hospice - 12 valid cases (White): 75% home; 8% CH; 17% hospice

Lindsay et al 2010¹⁷¹

Area covered by the Macmillan Community Team (MCT) of South Downs Health NHS Trust, EN
Patients referred to the MCT who had died during the study. Data collected from Apr to Sep 2009

Survey with data collection form filled in after death of patient
 231 valid cases: 53% home; 33% hospice; 3% hospital; 11% NH

McKeown et al 2008¹⁷²

Large teaching hospital in the north-west of EN
Patients with end-stage renal failure referred to specialist palliative care team. Referrals from Mar 2004 to Apr 2006

Audit of a database used to record referrals information
 14 valid cases: 50% home; 29% hospice; 14% hospital; 1% NH

Newton et al 2009¹⁸

Hospices, hospital specialist beds, hospice at home, hospital/community palliative care teams urban/ suburban area in the South Essex Cancer Network, EN
Patients referred to palliative care services in the area who had a completed PPC document. Data collected from Oct 2005 to Sep 2007

Analysis of PPC document
 211 valid cases (missing data unknown): 64% home; 7% hospital; 25% hospice; 4% CH

Pearse et al 2005¹⁷³

Hospital with a palliative care team, Leeds, EN
Patients referred to the team with prognosis of >1 month/ died unexpectedly. Time period not stated
 Patient survey on preferred place
 61 valid cases: 53% home; 30% hospice; 28% hospital

Spiller et al 1993¹⁷⁴

Regional Palliative Care Unit in Aberdeen, SCT
Consecutive cancer patients admitted to the unit; not resident for > than four days. Year of data collected not stated
 Patient survey using a questionnaire
 18 valid cases: 56% home; 17% palliative care unit; 1% hospital; 22% other

Thomas et al 2004⁷⁸

Specialist palliative care services in the Morecambe Bay area in North West EN
Terminally ill cancer patients living in the area referred to the research team by specialist palliative care professionals. Observational study from 2000 to 2002. Cancer deaths from 1993 to 2000
 Study involved qualitative interviews with patients and spatial statistical analysis of deaths
 30 valid cases: 33% home; 27% hospice; 9% home or hospice; 0% hospital, 10% other

Tiernan et al 2002¹⁶⁷

Hospice Home care team in Dublin, Ireland
Patients referred to the hospice home care team followed up until death. Deaths in a 5 month period, year not stated
 Analysis of records of preferred place of death
 148 valid cases: 82% home; 12% hospice; 3% hospital; 3% NH

Townsend 1990⁹⁸

Northwick Park Hospital and local community nursing services in London, EN
Patients with cancer from hospital and the community; expected to die within a year. Patients referred from Aug 1986 to Sep 1987
 Patient survey with a structured questionnaire
 58 valid cases (final realistic preferences): 50% home; 24% hospital; 26% hospice

Walker et al 2011¹⁷⁵

A hospice in the Midlands, EN
Sample of adults with cancer and other diseases who had died in Jan 2008, 2009 and 2010
 Audit of case notes using a data capture form.
 28 valid cases: 79% home; 21% hospice

Wood et al 2007¹⁷⁶

Two NHS primary care trusts in North West EN
First 100 cases of deceased patients living within the trusts who had a PPC document. Analysis from Feb 2003 to Feb 2005
 Assessment of PPC document
 100 valid cases: 73% home; 12% home or hospice; 9% hospice, 6% others

List of abbreviations: PPC – preferred priorities for care, CH – care home, NH – nursing home, EN – England, WAL – Wales, SCT – Scotland, NI – Northern Ireland, H@H – hospice at home, MCT – Macmillan Community Team

Appendix C– Deaths by age, gender, cause of death and place of death in England and Wales (2007–2011)

		2007	2008	2009	2010	2011
		n (%)	n (%)	n (%)	n (%)	n (%)
Home deaths						
Age						
All ages	98,271 (19.5)	101,090 (19.9)	99,592 (20.3)	102,416 (20.8)	105,354 (21.8)	
Up to 4 years	256 (6.5)	232 (5.9)	215 (5.7)	201 (5.5)	206 (5.6)	
5–14	160 (22.2)	163 (25.2)	144 (22.5)	129 (20.8)	133 (24.3)	
15–44	4,991 (28.7)	5,290 (30.0)	5,313 (31.0)	5,066 (31.3)	4,976 (32.4)	
45–64	20,020 (30.5)	20,540 (31.2)	20,175 (31.4)	20,455 (31.9)	20,603 (32.9)	
65–74	20,994 (25.7)	21,606 (26.4)	21,488 (27.0)	21,967 (27.6)	22,669 (28.8)	
75–84	30,896 (19.3)	30,915 (19.6)	29,923 (20.0)	30,893 (20.9)	31,315 (21.8)	
85 and over	20,954 (12.0)	22,344 (12.3)	22,334 (12.7)	23,705 (13.1)	25,452 (14.1)	
Gender						
Male	54,871 (22.8)	56,534 (23.3)	56,148 (23.6)	57,654 (24.2)	58,942 (25.1)	
Female	43,400 (16.5)	44,556 (16.7)	43,444 (17.2)	44,762 (17.5)	46,412 (18.6)	
Cause of death						
Cancer	34,669 (24.7)	36,383 (25.8)	37,345 (26.6)	38,558 (27.3)	41,040 (28.7)	
Non-cancer	63,602 (17.5)	64,707 (17.6)	62,247 (17.7)	63,858 (18.2)	64,314 (18.9)	
Hospice deaths						
Age						
All ages	25,353 (5.0)	24,878 (4.9)	24,998 (5.1)	25,615 (5.2)	26,361 (5.4)	
Up to 4 years	71 (1.8)	62 (1.6)	57 (1.5)	65 (1.8)	67 (1.8)	
5–14	30 (4.2)	37 (5.7)	39 (6.1)	61 (9.9)	36 (6.6)	
15–44	1,049 (6.0)	1,020 (5.8)	936 (5.5)	969 (6.0)	974 (6.3)	
45–64	6,800 (10.4)	6,626 (10.1)	6,765 (10.5)	6,876 (10.7)	6,935 (11.1)	
65–74	7,024 (8.6)	6,893 (8.4)	6,922 (8.7)	7,141 (9.0)	7,388 (9.4)	
75–84	7,612 (4.8)	7,431 (4.7)	7,385 (4.9)	7,455 (5.0)	7,670 (5.3)	
85 and over	2,767 (1.6)	2,809 (1.5)	2,894 (1.6)	3,048 (1.7)	3,291 (1.8)	
Gender						
Male	12,767 (5.3)	12,543 (5.2)	12,680 (5.3)	13,076 (5.5)	13,443 (5.7)	
Female	12,586 (4.8)	12,335 (4.6)	12,318 (4.9)	12,539 (4.9)	12,918 (5.2)	
Cause of death						
Cancer	23,690 (16.9)	23,111 (16.4)	23,189 (16.5)	23,610 (16.7)	24,185 (16.9)	
Non-cancer	1,663 (0.5)	1,767 (0.5)	1,809 (0.5)	2,005 (0.6)	2,176 (0.6)	
Hospital and care home deaths						
Age						
All ages	331,693 (65.8)	332,425 (65.3)	317,055 (64.5)	N/A	N/A	
Up to 4 years	3,544 (90.4)	3,602 (91.8)	3,489 (91.9)	N/A	N/A	
5–14	484 (67.1)	404 (62.4)	420 (65.7)	N/A	N/A	
15–44	8,186 (47.1)	8,122 (46.1)	7,942 (46.3)	N/A	N/A	
45–64	35,667 (54.3)	35,405 (53.8)	34,216 (53.2)	N/A	N/A	
65–74	50,486 (61.8)	49,994 (61.2)	47,892 (60.2)	N/A	N/A	
75–84	110,291 (68.9)	107,887 (68.4)	101,405 (67.6)	N/A	N/A	
85 and over	123,035 (70.4)	127,011 (69.9)	121,691 (69.1)	N/A	N/A	
Gender						
Male	155,360 (64.5)	155,490 (64.0)	150,836 (63.4)	N/A	N/A	
Female	176,333 (67.0)	176,935 (66.5)	166,219 (65.6)	N/A	N/A	
Cause of death						
Cancer	74,540 (53.2)	74,006 (52.4)	71,878 (51.2)	N/A	N/A	
Non-cancer	257,153 (70.7)	258,419 (70.2)	245,177 (69.9)	N/A	N/A	

N/A: Not available. Percentages in each age group refer to proportion of deaths within that age group occurring in each setting. For example, in 2007 only 12.0% of deaths from those over 85 years old occurred at home.

Source: Office for National Statistics. Mortality statistics: Deaths registered in 2007/2008/2009/2010/2011)

Appendix C– continued

	<u>Hospital deaths</u>		<u>Care home deaths</u>	
	2010 n (%)	2011 n (%)	2010 n (%)	2011 n (%)
Age				
All ages	264,962 (53.7)	249,387 (51.5)	89,320 (18.1)	92,386 (19.1)
Up to 4 years	3,337 (91.7)	3,369 (91.9)	8 (0.2)	2 (0.1)
5-14	390 (63.0)	351 (64.2)	2 (0.3)	3 (0.5)
15-44	7,337 (45.3)	6,740 (43.9)	137 (0.8)	108 (0.7)
45-64	31,994 (49.9)	30,371 (48.4)	1,926 (3.0)	1,892 (3.0)
65-74	43,445 (54.6)	41,386 (52.7)	5,482 (6.9)	5,536 (7.0)
75-84	84,432 (57.0)	78,746 (54.9)	23,352 (15.8)	23,720 (16.5)
85 and over	94,027 (51.9)	88,424 (49.1)	58,413 (32.3)	61,125 (33.9)
Gender				
Male	131,473 (55.3)	124,861 (53.2)	28,779 (12.1)	30,421 (13.0)
Female	133,489 (52.3)	125,526 (49.9)	60,541 (23.7)	61,965 (24.8)
Cause of death				
Cancer	59,954 (42.4)	57,688 (40.3)	17,216 (12.2)	17,980 (12.6)
Non-cancer	205,008 (58.3)	191,699 (56.2)	72,104 (20.5)	74,406 (21.8)

Appendix D – Factors independently associated with choosing hospice/palliative care unit as the preferred place to die

Variables	p-values n (%)	OR (95% CI) n (%)
Socio-demographics		
Age	<0.001	
85+		reference
75-84		0.81 (0.28-2.36)
65-74		0.78 (0.28-2.21)
55-64		0.65 (0.22-1.88)
45-54		1.11 (0.36-3.36)
35-44		0.47 (0.15-1.48)
25-34		0.31 (0.09-1.05)
16-24		0.13 (0.03-0.57)
Priorities for end of life care		
Dying in the preferred place	<0.001	
most important priority		reference
not most important priority		1.95 (1.40-2.72)

Only significant variables are shown. Marital status, living arrangements, religion, retirement, experiences of illness, death and dying and priorities for information were all included in the logistic regression model, but were found not to be significant.

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