

# Equity in the Provision of Palliative Care in the UK: Review of Evidence

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The Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science is a leading social care research group. Since its establishment in 1974 at the University of Kent, PSSRU has had considerable impact on national social care and mental health policy and practice in the UK and in a number of other countries.

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## **Executive summary**

### **This study**

A team from the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE) was commissioned by Marie Curie to explore the evidence on equity in palliative care and to consider the economic implications of extending palliative care to those currently under-served. This report presents the findings from a wide-ranging and comprehensive review of research literature and nationally available data, and new multivariate analyses of data from the National Survey of Bereaved People in England, 2013.

### **The history of palliative care and of inequities in provision**

Palliative care aims to ensure the best possible quality of life for people in advanced illness and at end of life, and for their families, by actively managing pain and other symptoms and providing psychological, social and spiritual support. Palliative care may be delivered by specially trained, multi-disciplinary specialist teams or by generalist providers such as GPs, district nurses, hospital doctors and nurses, allied health professionals, care home staff, social care staff, social workers, chaplains and others, who have not received accredited training in palliative care but routinely care for people with advanced illness or at end of life.

Modern palliative care began with the hospice movement, although the initial focus on providing care to cancer patients and reliance on charitable funding meant that provision was thinly and inequitably spread. Despite steps to extend specialist palliative care, inequities in provision have persisted. The importance of addressing these inequities is recognised in national end of life care strategies in England, Wales, Northern Ireland and Scotland. Currently, around 470,000 people die each year in England, 32,000 in Wales, 15,000 in Northern Ireland and 54,700 in Scotland. However, the need for palliative care is fast increasing as the population ages, particularly amongst those with non-cancer diagnoses, with the numbers of people aged 85 or over, for example, expected to more than double by 2037 in all four UK countries.

### **Reflections on the evidence base**

We found important differences in data availability in each of the four UK countries. The National Survey of Bereaved People in England contributed a considerable amount of the evidence used in our review and is a rich source of representative data on access to, and experiences of, end of life and palliative care. However, no similar survey is undertaken in Wales, Northern Ireland or Scotland, leading to gaps in the evidence base for these

countries. There are costed proposals available for extending the survey to Wales, estimated at £13,000 annually (with some additional costs for adapting the survey to Wales, administering it in Welsh and additional sample numbers to allow reporting at Health Board level). Extending the survey to Wales, Northern Ireland and Scotland would be relatively low cost and allow for country-specific findings and inter-country comparisons. The Minimum Dataset for Specialist Palliative Care Services was another important source of data for the review and provides data on availability and use of specialist palliative care services across England, Wales and Northern Ireland. No similar data, however, is available in Scotland. A survey-based study looking at the availability of specialist palliative care services was conducted by Audit Scotland in 2008 but no similar study has been conducted since. Data on generalist palliative care provision is severely lacking in England, Wales, Northern Ireland and Scotland, despite this being at the heart of evolving policy on end of life care.

Quantitative research into the outcomes from palliative care is relatively sparse in the UK, particularly in Wales and Northern Ireland, reflecting their smaller population sizes and research capacity. Systematic and other literature reviews, therefore, commonly draw on international as well as UK-based evidence. Research findings are also sometimes contradictory. Randomised controlled studies are rare and control groups in non-randomised studies are not always rigorously designed or selected. Studies that rely on retrospective data may exclude important variables such as clinical need and limited use is made of multivariate analysis. However, we did identify well-conducted studies and high-quality systematic and other evidence reviews, including a Cochrane review.

## **Palliative care across different care settings**

Many people do receive high quality end of life care. In the National Survey of Bereaved People in England, 2013, 53 per cent of those who died at home, 51 per cent of those who died in a care home, 59 per cent of those who died in a hospice and 33 per cent of those that died in hospital received '*outstanding*' or '*excellent*' overall care during their last three months of life. A further 28 per cent who died at home, 33 per cent who died in a care home, 26 per cent who died in a hospice and 36 per cent who died in a hospital experienced care that was at least '*good*'. However, we know that care should be better for many people and that there remain significant gaps in provision across all settings.

Some people who would benefit from palliative care do not receive any at all, either from specialist palliative care professionals or generalists. There are an estimated 92,000 people a year in England, 6100 people a year in Wales, 3000 people a year in Northern Ireland and 10,600 people a year in Scotland who would benefit from palliative care but are not currently receiving it.

There are known gaps in provision across all care settings. A national audit of hospitals conducted by the Royal College of Physicians in England in 2014 found that only 21 per cent

of hospitals offered face-to-face access to specialist palliative care seven days a week despite national recommendations that they do so, with the majority (73 per cent) offering such access just 5 days a week. Only two per cent of hospitals provided round the clock access. In the National Survey of Bereaved People in England, people being cared for in hospital are less likely to report high quality end of life care than people being cared for in other settings and are less likely to feel treated with dignity by hospital consultants and nurses. There is also frequent evidence of a lack of open communication with patients and their families. The need for training to improve communication between clinicians and patients is commonly referred to in the literature, but many barriers remain under-explored. These include time and resource pressures, unclear roles and responsibilities, attitudinal barriers, models for referral and forward care, the role of advance care planning, poor multi-disciplinary working and possible perverse organisational or professional incentives.

There is emphasis in policy on community-based specialist palliative care teams supporting people with more complex palliative care needs, with generalists providing wider care. However, the roles of different generalists in providing palliative care can be unclear to patients, their families and indeed to professionals themselves. GPs are meant to have a central role but sometimes expect nurses to take more active lead roles. Coordination between specialist and generalist providers can also be limited. Pain control is poorer for people being cared for at home, with only 19 per cent of respondents in the National Survey of Bereaved People in England reporting that pain was relieved '*completely, all of the time*' at home, compared to 39 per cent in hospital, 46 per cent in care homes and 63 per cent in hospices. Factors impeding good quality generalist care, in hospital or in the community, include reluctance to take responsibility for end of life care, lack of confidence or skills, lack of suitable care models for people with non-cancer conditions, time pressures, difficulties incorporating care into a generalist workload and resource pressures.

Care home residents often have complex needs, yet may not receive sufficient external palliative care or other specialist healthcare support, with evidence of poor coordination and confusion about the respective roles of care home staff and external providers. There is also wide variation between care homes in the proportion of residents who die in hospital, reflecting variation in care home policies and capacity to care for people at end of life.

Most people say they would prefer to die at home or in their usual place of residence. However, some people change their minds as they near end of life because they want to reduce carer burden or because there are difficulties in controlling pain and other symptoms at home. People who initially prefer to die in hospital, may change their mind because of unsatisfactory experiences of care in hospital. Across England and Wales, 43 per cent of people die at home or in a care home, up from 38 per cent in 2008. Where people are cared for and die is influenced by the care options available locally, with good quality, community-based palliative care increasing the chance of death in usual place of residence.

However, death in usual place of residence will not be possible or desirable for everyone and it is important to ensure that appropriate and high-quality palliative care is available in all settings.

## **The importance of diagnosis**

Having a cancer diagnosis is the primary determinant of access to specialist palliative care. Across England, Wales and Northern Ireland, in 2012-13, 88 per cent of palliative care inpatients and 75 per cent of new referrals to hospital support and outpatient services were for people with a cancer diagnosis, even though cancer accounts for only around 29 per cent of deaths. We know from research studies that the situation in Scotland is similar.

However, there is comparable symptom burden in all types of advanced illness and extending palliative care to people with non-cancer conditions is a key objective of end of life care strategies across the UK. Access to specialist palliative care for people with non-cancer diagnoses has improved recently. In 2013, across England, Wales and Northern Ireland, 20 per cent of new referrals to specialist services were for people with a non-cancer diagnosis, up from 12 per cent in 2008. But this still does not adequately reflect the proportions of people who die with non-cancer conditions. Twenty-eight per cent of people die with conditions of the circulatory system and 14 per cent with respiratory disease, while 30 per cent of people aged 65 or over will die with dementia. Cancer patients who continue to receive aggressive care at end of life and those with haematological cancers are also less likely to access specialist palliative care services.

Importantly, people with non-cancer diagnoses not only receive less specialist care, they also receive less generalist care than people with cancer (although they receive more social care). Based on data for 21,522 people who died between April 2006 and September 2011 in three London primary care trust areas, cancer patients had an average of 11.4 GP visits in their last three months of life compared 3.9 visits for people with other diagnoses, as well as, based on data from nearly 11,000 patients in a single London borough, 452 minutes contact time with a district nurse compared to 191 minutes for people with other diagnoses.

Cancer patients also experience better outcomes. According to the National Survey of Bereaved People in England, of those who are cared for at home, cancer patients are more likely to have pain relieved '*completely, all the time*'. Identifying pain in people with dementia is known to be particularly challenging, even with clinical assessment tools, but even when it is identified, people with dementia can receive less pain relief than those with other conditions.

Our analyses of the National Survey of Bereaved People in England found that, even after controlling for factors such as area deprivation and age, people with cancer were more



likely to experience overall care that was *'outstanding'* or *'excellent'* compared to those with other conditions. People with cardiovascular disease, in particular, were also less likely than people with cancer to experience *'excellent'* care (there is no *'outstanding'* category for individual services) from a GP, care home or out of hours services.

Analyses of the National Survey of Bereaved People in England also show that people with cancer are more likely, compared to people with other conditions, to die at home rather than in hospital, even after controlling for age and whether the decedent has a spouse or partner. Illnesses with a long trajectory are also associated with home death, possibly because they allow for more time to prepare.

There are many barriers to extending palliative care to people with non-cancer diagnoses. They include less predictable disease trajectories, greater difficulty in identifying a terminal stage, potential lack of clarity about appropriate palliative care goals, greater likelihood of comorbid conditions, insufficient resources, lack of condition-specific expertise, poor coordination between healthcare professionals and, in dementia, communication challenges and potential ethical and legal considerations. There is clearly a need for alternative models of care and capacity-building.

Delivering care cost-effectively is also more challenging for people with non-cancer diagnoses given the potentially longer periods of palliative care need and less predictable disease trajectories. Proposals for delivering care cost-effectively to people with non-cancer diagnoses include a 'safety net' approach involving round the clock 'on-call' emergency response services, gradual introduction of palliative care support over time, and an approach that sets clear care goals, with patients discharged once these are achieved.

## **Ethnic background and experiences of palliative care**

There are numerous potential barriers to accessing palliative care services for people from Black, Asian or minority ethnic (BAME) backgrounds identified in the literature. These include lack of cultural and religious sensitivity in how services are delivered, discrimination (and/or fear of it), absence of translation resources, different cultural views regarding the acceptability of openly discussing death, shortages of female doctors for Muslim women and assumptions that family members from BAME backgrounds will be able and willing to care for relatives at home. However, much of this research is from the US or is based on small selective samples, often in what Evans et al. (2012) refer to as *'ethnically marked places and ethnic communities'*. Proposals for addressing these barriers are also not always evidence-based.

Furthermore, quantitative evidence suggests that people from BAME backgrounds, have similar access to palliative care as people of White ethnicity. Around 6.2 per cent of people across England, Wales and Northern Ireland who receive specialist palliative care services

are from BAME backgrounds. Although 14 per cent of the total population in these three countries (14 per cent in England, 4.5 per cent in Wales and 2 per cent in Northern Ireland) are from BAME backgrounds, if we look only at people aged 65 or over, the age group in which the vast majority of deaths occur, only 4 per cent (4 per cent in England, 1 per cent in Wales and 0.3 per cent in Northern Ireland) are from BAME backgrounds. Data on access to specialist palliative care services are not available for Scotland, although people from BAME backgrounds similarly account for 4 per cent of the total population of Scotland but only 1 per cent of the population aged 65 or over.

Our examination of data from the National Survey of Bereaved People in England showed that people from BAME backgrounds were actually *more* likely than those of White ethnicity to receive support from community-based nurses, spiritual and/or emotional support, and support from home help or meals on wheels. They were also no more or less likely to receive support from Marie Curie nurses, social workers or support workers, hospice at home services or rapid response services. These analyses controlled for diagnosis, age, sex, whether the decedent had a spouse or partner and area deprivation. However, we do not know whether they received the same level of care from these services, for example, whether they received visits of the same frequency.

Evidence, primarily from the US, suggests that people from BAME backgrounds may experience less pain relief (sometimes even with the same opioid intake, a finding that is difficult to explain). However, in our analyses of data from the National Survey of Bereaved People in England, no relationship between ethnic background and pain control was found.

Our new analyses of these survey data, however, found that people from BAME backgrounds were less likely to consider overall care in the last three months of life to be '*outstanding*' or '*excellent*'. They were also much less likely than people of White ethnicity to experience '*excellent*' care (there is no '*outstanding*' category for individual services) from care homes. There remains a need to better understand the reasons for this.

A large-scale, London-based study found that BAME immigrants were more likely, compared to all other patients, to die in hospital rather than at home or in a hospice. However, new analyses of the National Survey of Bereaved People in England did not produce similar findings; people from BAME backgrounds, in this case including both immigrants and those who are British born, were no more or less likely than people of White ethnicity to die in hospital rather than at home. However, when looking at whether people die in hospital rather than a care home, people from BAME groups were more likely to die in hospital than people of White ethnicity.

## **Area deprivation**

We used the National Survey of Bereaved People in England to compare the experiences of

people living in more and less deprived areas (measured using Index of Multiple Deprivation, IMD, quintiles). We found that they received similar access to community-based support from nurses, social workers, hospice at home and rapid response teams. However, those in more deprived areas were less likely than those in the least deprived areas to feel they had sufficient support to care for someone dying at home, and were also less likely to die at home rather than in hospital. These analyses controlled for age, sex, diagnosis, whether the decedent had a spouse or partner and ethnic background. The reasons for these differences between areas are unclear. It may be that housing in more deprived areas provides a less suitable environment for end of life care, or that people from more affluent areas can pay for additional support.

There is also evidence that people from deprived areas consider care to be of less high quality. The National Survey of Bereaved People in England in 2011 found that the overall quality of care experienced in the last three months of life was less likely to be considered *'outstanding'* or *'excellent'* by people in more deprived areas compared to less deprived areas. Quality of care received from GPs was also less likely to be considered *'excellent'* (there is no *'outstanding'* category for individual services). However, quality of care from district and community nurses, care homes, out of hours services, hospital doctors and hospital nurses was considered to be of a similar quality across different areas. People in the most deprived areas were additionally less likely than those in the least deprived to report being treated with dignity *'always'* by district and community nurses and GPs.

To the degree that data on spending is available, there appear also to be unclear and variable local resourcing decisions unrelated to assessments of need. This means that area-based differences in outcomes cannot be considered in the context of variation in levels of need and/or spending on services.

These area-based differences need to be better understood and require an effective policy and/or service response if end of life care is to be delivered fairly, and if national expectations of increasing death in usual place of residence are to be fulfilled.

## **Age and experiences of palliative care**

Across England, Wales and Northern Ireland, people aged 85 or over receive proportionately less specialist palliative care than other age groups; only 16 per cent of specialist palliative care is provided to people aged 85 or over, although 39 per cent of deaths occur in this age group. The reasons for this are unclear. Research suggests that other factors, such as clinical needs, may be more important than age. However, there is also evidence that pain and other distressing symptoms are under-reported by older people and/or under-identified by healthcare professionals. There is also evidence of confusion about the role of geriatricians in providing palliative care.

Analyses of data from the 2013 National Survey of Bereaved People suggests that people aged 80 or over may be more likely to have pain relieved '*completely, all the time*' when compared with people aged under 80. However, given that pain in this age group may be under-reported and under-recognised by professionals, it may also be the case that it is under-recognised by the families who completed the survey questionnaire. Older people with cancer, aged 60 or over, have also been found to receive less pain relief than younger cancer patients.

Evidence on age and quality of care is unclear. One study finds poorer quality of care in the last two days of life for those aged 85 or over, compared to people of other ages, although no differences in the quality of care over the last three months of life were found. Analyses of the National Survey of Bereaved People in England suggest that people aged 80 or over experienced higher overall quality of care than younger people, and were more likely to experience '*excellent*' care from care homes and GPs. Reasons for this are unclear. Given that people aged 85 or over receive measurably less specialist palliative care and given evidence of under-recognition of pain and other symptomatic burden, it is possible that quality of care for people in this age group is systematically over-estimated by families.

These analyses also found that, compared to younger adults, people aged 80 or over are more likely to die in hospital than at home. However, people aged 80 or over who are living in care homes are more likely to die in the care home than in hospital, when compared to people in other age groups.

### **The impact of having a spouse or partner**

People with spouses or partners are those most able to die at home and were, therefore, in analyses of the National Survey of Bereaved People in England, found to be most likely to access community-based services such as hospice at home. These analyses also found that people with spouses or partners also experienced better pain control. People with spouses or partners were also more likely to experience overall quality of care that was '*outstanding*' or '*excellent*' and more likely to experience '*excellent*' care (there is no '*outstanding*' category for individual services) from GPs, care homes and out-of-hours services. This may be because spouses and partners act as advocates, informal care coordinators and direct care providers. However, it is possible that spouses and partners are more likely than other survey respondents to over-estimate the degree to which the decedent's pain was relieved and the quality of care received.

### **The economic implications of extending the reach of palliative care**

Our review shows considerable under-provision and service gaps currently, and these will grow as the UK population ages. There will be more need for end of life care and the

challenge of extending palliative care to people with non-cancer diagnoses, chronic long-term conditions and multiple comorbidities will be even greater. It is therefore imperative to use available resources efficiently.

There is currently only a limited amount of economic evidence on palliative care. A Cochrane review of evidence on home-based palliative care services found cost-effectiveness evidence to be inconclusive. Although palliative care was consistently found to reduce costs, the impact was not statistically significant in all studies covered by the review. However, the review found that home palliative care services reduced symptom burden and more than doubled the odds of dying at home. Another review, covering all care settings, found that palliative care was usually less costly relative to the comparators studied, although again differences were not always statistically significant. A well-conducted evaluation of the Marie Curie Nursing Service in England, however, found evidence of lower total care costs for someone receiving the service compared to a similar individual in receipt of usual end-of-life care. This study identified overall healthcare savings of around £500 per person, taking into account the cost of hospital care, community and primary healthcare and social care, as well as the costs of providing the Marie Curie Nursing Service. Finally, although based on evidence primarily from the US, two reviews of hospital-based specialist palliative care found that care delivered by specially trained palliative care staff was often less costly than the care delivered by generalist or other specialist hospital staff.

It is not easy to estimate the costs of extending the reach of palliative care to those currently under-served, although it is likely that these costs can be offset by savings associated with reduced need for acute care and fewer hospital deaths.

Based on calculations in the Palliative Care Funding Review for England, extending 'specialist and core' palliative care services to those that would benefit could result in net savings of £36 million in England, £2.4 million in Wales, £1.2 million in Northern Ireland and £4.2 million in Scotland. These figures are based on costs for extending palliative care of £144 million in England, £9.8 million in Wales, £4.6 million in Northern Ireland and £16.8 million in Scotland and estimated savings of £180 million per year in England (60,000 fewer hospital deaths), £12.2 million in Wales (just over 4,000 fewer hospital deaths), £5.8 million in Northern Ireland (nearly 2,000 fewer hospital deaths) and £21 million in Scotland (nearly 7,000 fewer hospital deaths). While these estimates exclude the full costs of community-based support, including care from GPs, district nurses and others, the evaluation of the Marie Curie Nursing Service discussed above suggests that these costs are not likely to differ substantially between those in receipt and not in receipt of specialist palliative care.

If we apply the estimate of cost savings of avoiding a hospital death recommended by the National End of Life Information Network (NHS NEOF, 2012a) of £958, reducing hospital deaths by 60,000 per year in England could lead to potential savings of around £57.5 million each year. Assuming proportionate reductions in hospital deaths in the rest of the UK, we would expect savings of £3.9 million in Wales, £1.8 million in Northern Ireland and £6.7

million in Scotland. Although these figures include the estimated costs of all community-based healthcare, they only cover the costs of an episode ending in death, roughly the last week of life, whereas the cost estimates for 'specialist and core' palliative care in the Palliative Care Funding Review cover the full period over which palliative care is provided. This means we cannot readily combine or compare these figures. Nonetheless, these estimates support the view that the costs of extending palliative care may be largely, or even completely, offset by savings from reducing the number of people that avoidably die in hospital.

Furthermore, although calculations in the Palliative Care Funding Review for England take account of costs for providing palliative over a period longer than the last week of life, they only take account of savings from potential reductions in hospital deaths, although extending access to palliative care may also lead to additional savings associated with reductions in other emergency hospital admissions (those not ending in death). On the other hand, these estimates are also missing the costs of social care, out-of-pocket expenses incurred by patients and families and the economic value of unpaid family care. Incorporating these costs remains a challenge for future economic studies, and there is also a need to properly assess the quality of life effects for patients and families.

On balance, however, evidence is promising that palliative care interventions are cost-effective. Along with likely improved outcomes such as reduced symptom burden and an increase in people dying in their preferred place, it seems probable that investment in good quality palliative care can be offset by reductions in acute care costs.

## **Chapter 1: Introduction**

### **Background and aims**

A team from the Personal Social Services Unit (PSSRU) at the London School of Economics and Political Science (LSE) was commissioned by Marie Curie to undertake a review of evidence on inequity in the provision of palliative care services, and to consider the economic implications for extending palliative care to those currently under-served.

This report provides a summary of available academic and statistical evidence on inequities in palliative care for adults across the UK. In particular, we aim to identify and explore systematic differences in access or outcomes, between geographical areas, settings or different groups of service-users, and to do this, as far as possible, in the context of people's different needs and preferences. We also discuss the economic case for extending the reach of palliative care to those currently under-served, looking at the evidence on cost-effectiveness and the costs of extending palliative care to those who would benefit from it but are not currently receiving it.

We consider the evidence from the perspective of the UK as a whole and, where data allows, separately from the perspective of each of the four countries and nations of the UK – England, Wales, Northern Ireland and Scotland. We cover both generalist palliative care, delivered by non-specialist healthcare providers such as district nurses and general practitioners (GPs), as well as dedicated or specialist palliative care services.

### **Methods**

#### **Rapid review of the literature**

In order to gain an overview of research evidence, we undertook a rapid review of the academic and policy literature. Search strategies included using a range of online search engines and databases of academic articles, including PubMed; ProQuest; CINAHL Plus with Full text; EconLit; PsycINFO; SocINDEX with Full Text and International Bibliography of the Social Sciences, as well as undertaking general Google searches, reviewing websites of key organisations such as Marie Curie, Sue Ryder and the National Council for Palliative Care, accessing Government-produced data, hand searching key journals, asking knowledgeable contacts for relevant papers and searching the references in key reports.

High quality research in palliative and end of life care is not extensive and that exploring systematic inequalities is particularly sparse. Much of the evidence is also diffuse, with relevant findings dispersed across a wide range of studies and reviews, and only a small

specific literature addressing equalities issues directly. We have, wherever these exist, drawn on systematic literature reviews and high quality evidence summaries. These reviews frequently draw on international evidence as well as evidence from the UK, reflecting the limited amount of research conducted in the UK. Our review is a rapid rather than systematic review and the scope of the report is wide, and it is therefore possible that we have not identified all relevant evidence. However, we believe that our strategy has been rigorous and enabled all key sources of evidence to be identified and analysed. We have aimed to identify recent evidence, approximately that published within the last five years, particularly where this relates to service provision and use. This is where one might expect more rapid changes than, for example, in symptomology or palliative care needs. However, we have cited older research in areas where evidence is particularly sparse or where such studies have been used in recent policy documents or evidence reviews. We focus primarily on evidence from the UK as a whole or from its constituent countries and nations (England, Wales, Northern Ireland or Scotland). However, we also draw on international evidence where this is included in reviews, is particularly relevant or where evidence in the UK is particularly lacking.

### **New analyses of the National Survey of Bereaved People**

We also worked with colleagues at the Office for National Statistics (ONS) to undertake additional analyses of data from the National Survey of Bereaved People (VOICES – Views of Informal Carers: Evaluation of Services), 2013. The data set is not publicly available currently, and so colleagues at ONS undertook analyses to our specification and direction. This data is gathered in England only, with no similar survey undertaken in Wales, Northern Ireland or Scotland. However, we would expect most of the findings to be applicable across all four countries and nations of the UK. Our aim here was to address the notable lack of multivariate analysis, both in national data sources and the research literature. The reason that multivariate analysis is important is that access to, outcomes from and experiences of care are potentially influenced by many individual-level and area-based factors and we know that there are complex relationships between them. Multivariate analysis enables one to identify the independent effects of these different factors in the context of other (measured) influences. The factors we were able to consider in our analyses were.

- Age: categorized as 18-64 years, 65-79 years, or 80+ years
- Sex: Male or Female
- Diagnosis: categorized as Haematological cancers, All other (non-haematological) cancers, Respiratory illness, Neurological conditions including dementia, Heart and circulatory, Renal failure, Other conditions
- Area deprivation: Index of Multiple Deprivation (IMD) quintiles
- Spouse or partner (using proxy of whether spouse or partner is questionnaire respondent): categorized as Yes, or No



- Ethnic background: categorized as White, or Black, Asian and Minority Ethnic (BAME)

No other factors, such as clinical need, are controlled for. The survey data is weighted to account for probability of selection and response bias (ONS, 2014c). Using these different factors in logistic regression models as independent variables, we considered a range of outcomes. In particular we considered access to a range of community-based services, pain and symptom management, quality and experience of care and place of death. We discuss results from these analyses thematically throughout the report.

We provide the effect sizes for significant results that are reported in the body of the report, as well the effect sizes for all significant results in results tables in Appendix 3. Because the analyses conducted were logistic regressions, these are given as odds ratios (OR). We provide a brief explanation here for those less familiar with how to interpret an odds ratio.

An odds ratio of less than 1 for a particular category means that the probability of the dependent variable (the outcome) occurring is lower for this category when compared to an alternative (e.g. people from a BAME group, compared to those of White ethnicity). An odds ratio of more than 1 means the probability of the dependent variable (the outcome) occurring is higher for the category when compared to an alternative. To give a hypothetical example, if people from a BAME group were more likely than those of White ethnicity to receive support from community-based nurses, the odds ratio associated with BAME ethnicity would be above 1. Say the estimated odds ratio was, in fact, OR 1.39. This would be interpreted as people from a BAME group having 39 per cent higher odds of receiving support from community-based nurses compared to people of White ethnicity. Similarly, if people from a BAME group were less likely than people of White ethnicity to receive support from community-based nurses, the odds ratio would be below 1. Say the estimated odds ratio was, in fact, 0.68. This could be interpreted as people from a BAME group having 32 per cent lower odds of receiving support from community-based nurses compared to people of White ethnicity.

The survey questionnaire is included at Appendix 1 and further information about the survey and the sample are included at Appendix 2.

## **Definitions**

Definitions in the area of palliative care are important, since terms are often used inconsistently. We provide some summary definitions of key terms used in this report.

**Palliative care:** Palliative care is the active, holistic care of people with advanced progressive illness, involving management of pain and other symptoms and the provision of psychological, social and spiritual support. Palliative care aims at ensuring the best possible quality of life for individuals at end of life or with advanced illness and their families.

Palliative care is traditionally associated with a range of principles of care including the view of dying as a natural process, while at the same time affirming life, and of acting neither to hasten nor postpone death. It is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, as well as in terminal care, and includes those investigations needed to better understand and manage distressing clinical complications.

**End of life care:** Palliative care can have application in any situation where someone is experiencing distress associated with serious illness for which there is no potential cure. End of life care, with which palliative care can often be confused, refers specifically to care provided in the last phase of life. This is often defined as approximately the last year, but end of life care can also sometimes be used to refer to the last weeks or even days of life and, for carers, can include care into bereavement.

**Specialist palliative care:** Specialist palliative care is provided by multi-disciplinary teams that can include consultants in palliative medicine, nurse specialists, specialist social workers and experts in psychological care. Such staff are specifically trained to provide, and advise on, symptom control and pain relief and other forms of psycho-social and spiritual support. Specialist palliative care services include inpatient units, voluntary sector-run and NHS; hospital-based services including hospital support and outpatients; home care services; day care services and bereavement support.

**Generalist palliative care:** General palliative care is provided by the usual professional carers of the patient and family, such as GPs, district nurses, hospital doctors, ward nurses, allied health professionals, staff in care homes, social care staff, social workers, chaplains and others. These professionals have not received accredited levels of training in palliative care provision and thus are not deemed specialists, but routinely provide care for people with advanced illness, including those at the end of their lives.

**Hospice care:** In the UK, hospices are usually charities, often small-scale and local, that provide inpatient care as well as community-based services and education. They are generally funded through a combination of charitable funding and delivering NHS contracts. It is important to avoid confusion with 'hospice-at-home', which is one of several terms used for a model of community-based palliative care service and which is not necessarily delivered by a charitable hospice. In the US, however, hospice care has a narrower meaning defined in the context of Medicare eligibilities, and refers to palliative care delivered across a wide range of settings to people who are expected to live for six months or less.

**Supportive care:** Supportive care has the same aims as palliative care, but is a wider term, applying in cases of serious illness where cure is possible, as well as in illnesses that are terminal. In practice, it may not always be clear whether an illness is potentially curable or not, which can lead to the terms supportive care and palliative care being used interchangeably.

**Inequality of provision:** Dying is not a predictable or uniform experience. It can involve widely varying trajectories, with the process lasting anything from days to years, and with care delivered in different, and commonly multiple, settings. Palliative care also has application for people who are experiencing distress associated with any serious illness, not just terminal illness. This wide diversity of experience means that different types of care and support are needed by different people at different times, mitigating against any standardisation of the health and social care services with which people are provided. Inevitably this could lead to unequal provision, which is appropriately a mark of person-centred care.

**Inequity:** Inequity in care provision is inequality between different groups of people that is not justified by differences in need or preference. Inequity may arise from unjustified differences in access to care or to the same quality of care. It may also exist where there is equal provision to people who have different care needs. Inequity is associated with systematically poorer outcomes for some people compared to others. Equity in provision is a fundamental principle in the provision of health and other care that, in the UK, is protected through provisions in the NHS constitution and the Equality Act (2010).

## **The structure of this report**

In the next chapter (Chapter 2: Background) we discuss the development of palliative care as a specialism, highlighting both the unique and important contribution of the UK hospice movement in the development of modern palliative care as well as pointing to some of the historic roots of inequities in provision. We also provide background information for each of the four countries and nations of the UK, covering recent policy on end of life care, demography and mortality. Results from our literature search and data analysis are presented and critically discussed thematically in subsequent chapters, covering:

- Chapter 3: Palliative care need and preferences
- Chapter 4: Access to palliative care
- Chapter 5: Pain and symptom control
- Chapter 6: Quality and experience of care, and
- Chapter 7: Place of death.

We then, in a further chapter (Chapter 8: The costs), go on to review evidence on the economic case for, and costs of, extending the reach of palliative care and, in a final chapter (Chapter 9: Discussion and conclusions), present a summary of our findings and our conclusions.

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## **Chapter 2: Background**

This chapter briefly describes the context for the provision of palliative care across the UK and its constituent countries and nations; England, Wales, Northern Ireland and Scotland. It provides a brief history of palliative care services and sets out the historical background to current inequities in palliative care provision. It also describes attempts to address these, including the publication and implementation of national end of life strategies in all four countries and nations of the UK. Finally, it provides some contextual information about demography and mortality in the four countries and nations of the UK.

### **The history of palliative care services**

Exceptionally among medical specialties, palliative care developed within the voluntary sector, outside of the National Health Service. In 1967, Dame Cicely Saunders founded St Christopher's Hospice in south London, generally considered to be the first modern hospice in the United Kingdom, thus beginning the development of the modern hospice movement. By the end of the century there were many charity-run hospices across the UK, with their focus primarily on providing terminal care to cancer patients. The National Council for Hospice and Specialist Palliative Care Services was established for England, Wales and Northern Ireland in 1991, becoming the National Council for Palliative Care in 2004, reflecting the growing focus on the delivery of palliative care across all settings and diagnoses. The Scottish Partnership for Palliative Care was also established in 1991. Hospice UK (formerly Help the Hospices), as well as two national charitable organisations, Marie Curie and Sue Ryder (formerly the Sue Ryder Foundation), have also played an important role in providing specialised care for dying people and their families.

Although the hospice movement significantly developed the specialism of palliative care in the UK and worldwide, and attracted some Government funding from the late 1970s onwards, the primary reliance upon local volunteers and charitable funding were seen as leading to local variation in services and consequent inequities in provision. These were addressed by the 'Calman-Hine' report (Department of Health and Welsh Office, 1995), which set out a planning and commissioning framework for cancer services, a framework that was slowly extended to include, at least in principle, other diagnoses. However, inequities continued to be identified. The House of Commons Health Committee, in its 2004 report on palliative care, stated that, services were 'disproportionately needed in areas of social deprivation and disproportionately present in areas of social affluence'. The report went on to state that 'services deal predominantly with cancer patients and seem not to be geared to the palliative needs of other disease groups; services are under-used by those in black and minority ethnic communities; services favour some age groups over others; and they seem hard to access by those with complex needs' (p.18). Similarly, the Royal College of Physicians, in a 2007 working group report on palliative care services, with members from

England and Wales, stated that the reliance on charitable funding and provision ‘exacerbates inequalities, favours the model of stand-alone hospice buildings and has led to poor planning and overall integration of services (p.3)’. In recent years, there have been renewed efforts, driven by national strategies on end of life care in all four countries and nations of the UK, to extend palliative care to everyone who can benefit from it. As Gott et al. (2012) comment, ‘in a relatively short space of time, palliative care has developed from being viewed as synonymous with terminal care for cancer patients, to being regarded as having relevance at an early stage in the disease process of anyone whose death can be medically anticipated’ (p.232).

### **Recent policy on end of life and palliative care**

The UK, with its established hospice movement and statutory involvement in end-of-life care, ranks at the top of 40 countries measured in a ‘quality of death’ index developed by the Economist Intelligence Unit (2010). This is to be applauded. However, as discussed in the previous section, there have remained widely acknowledged problems and gaps in the provision of palliative and end of life care, and all four countries and nations of the UK have, in recent years, published national end of life care strategies and delivery plans in order to help address these. These include the *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life* (Department of Health/ NHS, 2008); *Together for Health, Delivering end of life care. A Delivery Plan up to 2016 for NHS Wales and its partners* (NHS Wales, Welsh Government and Macmillan Cancer Support, 2013); *Living Matters. Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland* (Department of Health, Social Services and Public Safety Northern Ireland, 2010), and *Living and Dying Well: A National Action Plan for End of Life Care in Scotland* (Scottish Government, 2008). Each of these strategies promotes the provision of palliative care on the basis of need rather than diagnosis, emphasises the importance of considering a palliative care approach from the point of diagnosis onwards and envisages an expanded role for generalist palliative care providers, supported by a smaller group of professionals who have received high-quality specialist palliative care training (Gott et al. 2012; GMC, 2010).

The 2008 strategy in England involved additional funding commitments, following the then Government’s manifesto commitment ‘to double the investment’ in palliative care, and led to a range of targeted actions including efforts to support people to die at home, raise public awareness through the work of the Dying Matters coalition, promote workforce development and produce a range of good practice and organisational guidance. Much of this was driven by the National End of Life Care Programme until it was disbanded as part of the wider NHS reforms in March 2013. The strategy also supported improvements in available data and evidence, much of this delivered through the work of the National End of Life Care Intelligence Network, now part of Public Health England (NCPC, 2014b).

In Wales, the current strategy, *Together for Health: Delivering End of Life Care* (NHS Wales, 2013) builds on earlier policy, including a key policy review, *Palliative Care Planning Group Wales: Report to the Minister for Health and Social Services* (Sugar et al., 2008), which argued that substantial investment was needed to 'ensure a level playing field across Wales'. A follow up report, *Dying Well Matters: One Wales, 3 Years On (2008-2011)* (Wales Palliative Care Implementation Board, 2011) considers the achievements resulting from the review, which have included investment in clinical nurse specialists and 7-day access to specialist services. The Welsh Government has recently made further investments in specialist palliative care services, with more than £6.4m of funding provided to hospitals and hospices in Wales during 2012-2013. Live Now, a sister initiative to Dying Matters in England, aims to encourage communities to engage in conversations and activities that promote a healthy and realistic attitude to death and dying.

The Northern Ireland national end of life care strategy, *Living Matters: Dying Matters: Palliative and End of Life Care Strategy for Adults in Northern Ireland* (Department of Health, Social Services and Public Safety Northern Ireland, 2010) includes 25 policy commitments covering a key worker for every person in need of end of life care, a focus on advance care planning for people with palliative and end of life care needs and access to 24/7 specialist palliative care advice and support. The Public Health Agency (PHA) leads an Implementation Board in taking forward these recommendations. This is supported by the *Transforming Your Palliative and End of Life Care programme*, which is an initiative of Marie Curie and the Health and Social Care Board, supported by PHA, scheduled to run until August 2015. The 25 strategic recommendations are also being delivered within the wider context of *Transforming Your Care* (DSSPSNI, 2011), a strategic review of health and social care services. The Health and Social Care Annual Commissioning Plan also sets out key strategic priorities, including for palliative and end of life care.

The Scottish national end of life strategy, *Living and Dying Well: A National Action Plan for End of Life Care in Scotland* (Scottish Government, 2008) aims to deliver a more equitable provision of services for people with any advanced, progressive or incurable condition. Through the strategy, the Scottish Government has developed a national do not attempt resuscitation order (DNACPR) policy, which has been implemented across Scotland, and has developed and published Scottish Palliative Care Guidelines (NHS Scotland, 2014), which are available online to all health and social care practitioners. In 2013, Healthcare Improvement Scotland also published palliative and end of life care indicators. The Scottish Government has committed to developing a new strategic framework for action on palliative and end of life care to replace *Living and Dying Well: A National Action Plan for End of Life Care in Scotland* in 2015. *Achieving Sustainable Quality in Scotland's Healthcare: A '20:20' Vision* (Scottish Government, 2011) intends to ensure 'that by 2020 everyone is able to live longer healthier lives at home or in a homely setting.' This strategic vision document and the associated Quality Strategy (Scottish Government, 2010) are the guiding policy documents

that lead the Scottish Government's policy in health and social care.

## **Demography**

The population of the UK, as a whole, is currently around 65 million, of whom 11.6 million are aged 65 or over and 1.6 million are aged 85 or over. These figures are set to increase, by 2037, to a total population of 73.3 million, of whom 17.8 million are expected to be aged 65 or over and 3.6 million are expected to be aged 85 or over (ONS, 2011a). If we look at each UK country separately, we find a similar pattern of disproportionate growth in the numbers of people aged 65 or over and aged 85 or over in all four countries and nations of the UK.

England has a population of nearly 55 million, with around 9.7 million people aged 65 or over and 1.3 million aged 85 or over. By 2037 the total population of England is expected to be a little over 62 million, with around 15 million people aged 65 or over and around 3.1 million aged 85 or over (ONS, 2015).

Wales has a population of just over 3 million, with around 627,000 people aged 65 or over and around 81,000 aged 85 or over. By 2037, the overall population is expected to have increased slightly to 3.3 million, while the number of people aged 65 and over is expected to increase to 878,000 and people aged 85 or over to 188,000 (ONS, 2015).

Northern Ireland's total population is around 1.9 million, with around 293,000 people aged 65 or over and 36,000 people aged 85 or over. By 2037, the total population is expected to increase to just over 2 million, with around 489,000 people aged 65 or over and around 90,000 aged 85 (ONS, 2015).

The total population of Scotland is around 5.4 million, with around 970,000 people aged 65 or over and around 119,000 aged 85 or over. By 2037 the total population is expected to be 5.8 million with around 1.5 million aged 65 or over and around 274,000 aged 85 or over (ONS, 2015).

## **Mortality**

In England, there are currently around 470,000 deaths each year (ONS, 2014a), in Wales there are around 32,000 deaths each year (ONS, 2014b), in Northern Ireland there are around 15,000 deaths each year (NISRA, 2013) and in Scotland there are around 54,700 deaths each year (General Registrar Office for Scotland, 2013).

The proportions of people in each of the main diagnosis groups who die are very similar in each of the four countries and nations of the UK. In England and Wales, around 29 per cent of deaths each year are due to cancer, 28 per cent due to circulatory conditions and 15 per cent due to respiratory illness (ONS, 2014b). In Northern Ireland, around 29 per cent of



deaths are due to cancer, 27 per cent due to circulatory conditions and 14 per cent due to respiratory disease (NISRA, 2013). And in Scotland 30 per cent of deaths are due to cancer, 28 per cent due to circulatory conditions and 13 per cent due to respiratory conditions (General Registrar Office for Scotland, 2013).

Demographic changes mean that the number of deaths in all four countries and nations of the UK is forecast to rise significantly over the next 20 years, along with the number of people with chronic illness and complex, multiple conditions (Gomes and Higginson, 2008; Mathers and Loncar, 2005). By 2037, total UK mortality is expected to rise to 675,000 deaths per year, from 548,000 deaths per year in 2015, an additional 127,000 deaths per year. This figure is made up of an additional 109,000 deaths per year (from 451,000 to 560,000) in England, an additional 5,000 deaths per year (from 30,000 to 35,000) in Wales, an additional 4,000 deaths per year (from 14,000 to 18,000) in Northern Ireland, and an additional 9,000 deaths per year (from 53,000 to 62,000) in Scotland (ONS, 2015).

### **The rest of this report ...**

The remainder of the report is structured as follows:

- Chapter 3: Palliative care need and preferences
- Chapter 4: Access to palliative care
- Chapter 5: Pain and symptom control
- Chapter 6: Quality and experience of care
- Chapter 7: Place of death
- Chapter 8: The costs
- Chapter 9: Discussion and conclusions

## **Chapter 3: Palliative care need and preferences**

As discussed in the definitions section in Chapter 1, unequal provision is not necessarily inequitable as long as it is justified by differences in need or preferences. However, authors of systematic reviews discussed in this report noted that studies were commonly limited in their usefulness by not taking account of differences in clinical or other needs (e.g. Murtagh et al., 2012; Walshe et al., 2009; Burt and Raine, 2006). Burt (2012) points out that reasons for this include the fact that research evidence is limited by reliance on retrospective data, usually provided by proxy respondents such as bereaved family members, in which details of symptoms, functional status, and the psychological and spiritual concerns of patients tend to be lacking. In this chapter, therefore, we present evidence on needs and preferences so as to provide a fuller context for the evidence presented in later chapters.

### **Overall palliative care need**

A fundamental measure is that of overall levels of palliative care need in the population. There have been a number of attempts, using different methods, to estimate the overall level of palliative care need amongst people who are seriously ill or nearing the end of life. In the Palliative Care Funding Review for England (2011), Hughes-Hallett et al. draw upon the Rosenwax method (Rosenwax et al., 2005), the Cochrane list of causes likely to require palliative care for children (Cochrane et al., 2008) and Department of Health figures on admission to hospital with conditions likely to imply palliative care need. They conclude that around 75 per cent (355,000 people) of all deaths per year have preceding palliative care needs. Using adjusted figures from the National Survey of Patient Activity Data for Specialist Palliative Care Services: Minimum Data Set (covering England, Wales and Northern Ireland), they go on to estimate that, out of the 355,000 people who would benefit from palliative care at end of life, 171,000 of these are likely to receive specialist palliative care services. There are no reliable figures on the number of people in receipt of generalist palliative care services, delivered by, for example, GPs, district and community nurses or health and social care assistants. However, Hughes-Hallett et al. estimate that, of the remaining 184,000 people, possibly around 50 per cent (92,000 people) might receive generalist palliative care services. This leaves an estimated 92,000 people who would benefit from it who are thought not to be receiving any specialist or generalist palliative care at all.

No such estimate of unmet palliative care need has been made for Wales, Scotland or Northern Ireland. However, extending the same assumptions and calculations made by Hughes-Hallett et al. to the other three countries and nations of the UK, gives estimates of around 6,200 people in Wales, 3,000 people in Northern Ireland and 10,800 people in Scotland who would benefit from, but do not receive, any palliative care services. The estimate from the Palliative Care Funding Review for England includes child deaths as well as adult deaths. In this report we focus specifically on adult palliative care, but given the

provisional nature of the estimates made by Hughes-Hallett et al. and that child deaths (ages 0 to 15) account for less than 1 per cent of all deaths, it is reasonable, for the purposes of this report, to take this estimate as a measure of overall need for adult palliative care.

In a more recent study, Murtagh et al. (2013) reviewed and developed earlier methods of assessing overall palliative care need and arrived at very similar estimates to the Palliative Care Funding Review for England (Hughes-Hallett et al., 2011), estimating that between 69 per cent and 82 per cent of deaths in high-income countries are likely to have preceding palliative care needs. From this work, Murtagh et al. also concluded that reliable estimates could be made using death registration data (utilising both underlying and contributory causes) without the need for symptom or hospital activity data.

It is also worth noting that, although Hughes-Hallett et al. estimate that 171,000 people are currently receiving specialist palliative care and that 92,000 are receiving generalist palliative care services, there is currently no way of knowing whether or not this is an appropriate balance between specialist and generalist services for meeting existing need. We also know that the need for palliative care is likely to increase in future given population ageing in England, Wales, Northern Ireland and Scotland (discussed in Chapter 2), and the associated increase in chronic conditions and complex comorbidities. Finally, there are no available figures on unmet need for non-clinical palliative care and support, such as social, spiritual and psychological needs.

## **Diagnosis**

Around 30 per cent of all deaths are due to cancer (ONS, 2014b; General Registrar Office for Scotland, 2013; NISRA, 2013). Non-cancer conditions therefore account for the majority of deaths. These include respiratory illness, including chronic obstructive pulmonary disease (COPD), diseases of the circulatory system including heart attacks and congestive heart failure (CHF), and neurodegenerative diseases, in particular, dementia. Of these, diseases of the respiratory system account for around 13-15 per cent of deaths annually (ONS, 2014b; General Registrar Office for Scotland, 2013; NISRA, 2013). COPD accounts for between 4 and 5 per cent of deaths a year. It is associated with cigarette smoking and inhaled irritants in the work-place (NHS, 2012; North East Public Health Observatory (NEPHO), 2011) and, as a result, mortality from COPD is concentrated in urban areas and areas of social deprivation in all countries and nations of the UK (NEPHO, 2011; British Lung Foundation, 2007; Burnley and Jarvis, 2006). It is also known to be significantly under-diagnosed, consequently affecting access to care (Stone et al., 2014). In all four countries and nations of the UK, round 28 per cent of people die from diseases of the circulatory system, including heart attacks and heart disease, with this figure having fallen from somewhere around 37 per cent in 2004 (NEoLCIN, 2013; General Registrar Office for Scotland, 2013; NISRA, 2013). People who die of cardiovascular diseases frequently have comorbidities and complex end of life care needs (NEoLCIN, 2013; NHS Information Centre, 2010). Of neurodegenerative

conditions, the most common requiring palliative care is dementia. It is not possible to identify the number of people who die as a result of dementia from death records, since many deaths are not directly attributed to dementia, but, rather, to the immediate cause of death (Sachs et al., 2004; NCPC 2014a). However, we know from the Cognitive Function and Ageing Study (CFAS), a longitudinal, multi-centre study in England and Wales (covering five sites, in Cambridgeshire, Nottingham, Gwynedd, Newcastle and Oxford), that as many as 30 per cent of people aged 65 or over die with dementia (Brayne, 2006). The prevalence of dementia increases with age and the median length of survival from diagnosis to death is estimated to be around 4.5 years, although people can live much longer (Xie et al., 2008). The number of people with dementia is expected to more than double by 2050 (Prince et al., 2014).

Although specialist palliative care has traditionally focused on people with cancer, there is plentiful evidence that people with these other diagnoses have comparable symptom burdens and palliative care needs. As long ago as 1963, Hinton observed that it was not solely people dying from cancer who experienced significant discomfort and distress, but also those dying from non-cancer illnesses such as heart failure and renal disease. Non-cancer conditions may involve different but equally serious symptoms. For example, Burt et al. (2010b) conducted a postal survey of a random sample of 1,266 people who had registered a death of someone aged 65 or over. Their findings suggested that cancer decedents were significantly more likely than non-cancer decedents to have experienced pain, nausea and vomiting and constipation, whilst a greater proportion of non-cancer decedents were significantly more likely to have experienced breathlessness.

However, there is also evidence of considerable overlap in symptomology between conditions. In a systematic review of palliative care needs among those with advanced cancer and eight non-cancer conditions, Moens et al. (2014) found that pain, fatigue, anorexia, breathlessness, and anxiety were highly prevalent across all of the conditions. Solano et al., 2006, in a systematic review looking at the prevalence of 11 common symptoms among people with five different conditions, covering advanced cancer, acquired immunodeficiency syndrome (AIDS), CHF, COPD and renal disease, found that the symptoms were prevalent in all conditions, with pain, breathlessness, and fatigue found among more than 50 per cent of patients. Other studies show that most conditions involve a wide range of common symptoms. For example, in COPD the primary symptom is breathlessness, and with many people also experiencing associated fear, anxiety and sometimes panic. However, in common with many other conditions, symptoms may also include pain, difficulty sleeping, thirst, general anxiety and depression, weight loss, cough, constipation and incontinence, as well as poor mobility, difficulty with activities of daily living (ADLs), difficulty leaving the house and social isolation (Gardiner et al., 2010; NHS, 2012). Similarly, the symptoms associated with CHF include breathlessness, fatigue and limited mobility, as well as restricted social life, poor quality of life and complex medication regimes (Pattenden et al., 2007; Kavalieratos et al., 2014).

There are, however, different disease trajectories associated with different conditions. One of these, typical of cancer, is a trajectory with a relatively short period of rapid decline towards the end of life. The trajectory typical of dementia and frailty involves a long period of gradual decline often known as ‘dwindling’, commonly with serious episodes of ill-health towards the end of life. Finally, some conditions such as organ failure have less predictable trajectories with intermittent health crises (Murray et al., 2005). The less predictable disease trajectories associated with non-cancer conditions make it more difficult to identify a terminal stage. For example, in a systematic review of appropriate timing of palliative care for adults with terminal, non-malignant conditions, Coventry et al. (2005) found that prognostic models that attempt to estimate survival of six months or longer in people with non-cancer diagnoses have generally very poor discrimination. However, there is evidence of highly varied disease trajectories amongst people with the same condition. Moens et al. (2014), in their systematic review, report finding ‘as much variation within diagnostic groups as between groups in relation to prevalence of palliative care related problems’. Murtagh et al. (2011), in a study of symptoms and concerns in advanced kidney disease, for example, found that the last year of life is commonly characterized by three distinct trajectories; 50 per cent have broadly stable symptoms, 24 per cent have steadily increasing symptoms and 21 per cent have highly fluctuating or unpredictable symptoms. Similarly, Gott et al. (2014), in a study looking at dying trajectories in CHF in four areas of the UK, found a variety of trajectories, with only a minority of people conforming to what is considered the ‘typical’ trajectory for people dying of CHF.

In addition to potentially less predictable disease trajectories, some other features of non-cancer conditions can further complicate the provision of care. In dementia, for example, communication issues can make identifying needs challenging (Birch and Draper, 2008). Dementia also commonly co-exists with comorbid conditions, with, for example, conditions such as cardiovascular disease and diabetes associated with the development of mild cognitive impairment, Alzheimer’s disease and vascular dementia (Biessels et al. 2006; Velayudhan et al. 2010). Other conditions are also associated with comorbidities. For example, around 19 per cent of people dying of cardiovascular disease also have type II diabetes (NEoLCIN, 2013). The importance of comorbidities is that they increase clinical complexity and the likelihood of hospital death (Murtagh et al., 2012). Finally, preference for a home death is also known to vary with diagnosis, whereby people with a non-cancer diagnosis are less likely to prefer to die at home, possibly reflecting the more unpredictable nature of disease trajectories and the intermittent health crises commonly experienced in non-malignant conditions (Murtagh et al., 2012).

## **Ethnic background**

Much of the research evidence on palliative care needs for Black, Asian and minority ethnic (BAME) groups in the UK is amply summarised by Calanzani et al. (2013b) in their recent

review. This draws upon systematic and non-systematic reviews and includes evidence from the UK as well as international evidence. Much of the evidence we include in this report is therefore referenced directly from this review. Calanzani et al. note that BAME groups have a younger age profile than the White British population and, consequently, that proportionately fewer people from BAME groups are aged 65 or over. Census data shows that while 85.4 per cent of the total population in England is of White ethnicity, for those aged 65 and over, this proportion is 95.2 per cent (ONS, 2011b). While BAME populations in Wales, Northern Ireland and Scotland are much smaller, these populations also have a younger age profile than the White population. For Wales, the White population makes up 95.5 per cent of the total population but 98.9 per cent of the population aged 65 or over (ONS, 2011b). In Northern Ireland, 98.2 per cent of the total population are of White ethnicity, while 99.7 per cent of the population of people aged 65 and over are of White ethnicity (NISRA, 2015). Finally, for Scotland, 96 per cent of the total population is White, while just over 99 per cent of the population of people aged 65 and over are White (National Records of Scotland, 2011). Given that most chronic disease and death occurs in older age groups, the different age profile has implications for estimating current palliative care need amongst BAME groups. Even within England, which has the largest proportion of people from BAME backgrounds, these are not evenly spread across the country, with populations concentrated in major conurbations and with London having the highest number of older people from BAME groups (Calanzani et al., 2013b).

Need for palliative care amongst BAME populations is likely to increase in future as younger cohorts of people from BAME backgrounds age. Calanzani et al. cite three separate population projections for England (they do not report this information for Wales, Scotland and Northern Ireland), each estimating an upward trend in the numbers and proportions of people from BAME groups requiring palliative care in the future. Calanzani et al. note that there are some epidemiological differences between people from different ethnic backgrounds that may affect palliative care needs. For example, people from BAME backgrounds record lower levels of cancer than the White population (Elkan et al., 2007; Wild et al., 2006; Aspinall and Jacobson, 2004) while rates of other life-limiting illnesses, such as coronary heart disease, cardiovascular disease, and diabetes are comparatively higher than in the population as a whole (Netuveli et al., 2005). However, these differences are highly complex and Calanzani et al. identify studies suggesting that changes in lifestyle amongst BAME groups and acculturation affect inherited epidemiological characteristics. Understanding these shifts in the age and disease profiles of people from different ethnic backgrounds is important for monitoring equality of access to palliative care and other end of life services.

With regard to differences of preference, Calanzani et al. (2013), in their review, conclude that, while there may be culturally- or religious-based preferences, these cannot be directly assumed from ethnic background and will vary considerably across individuals. They note that evidence in the literature on whether people from BAME groups do, in fact, have

different preferences is actually very limited. For example, there is some evidence that Chinese people living in the UK have a preference for hospital care and have concerns about being in a hospice (Seymour et al., 2007). In addition, preferences held by people from a particular ethnic background are also likely to change over time with, on the one hand, new immigrants entering the UK and, on the other, second, third or later generations being likely to hold attitudes and values that are less distinct from other British-born groups. Evans et al. (2012), in a systematic review of the primary research on minority ethnic groups and end of life care in the UK, note that few studies actually attempted to explore how people with advanced illness or at end of life and their carers define their own cultural needs.

Some people from BAME groups may also experience language barriers. In England, in 2011, just over 90 per cent of people had English as their first language, while in Wales and Northern Ireland the figure was somewhat higher, at around 97 per cent and, of those that did not have English as their first language, only around one in five could not speak it well or could not speak it at all. No similar information is provided for Scotland (Calanzani et al., 2013b). These individuals are likely to be older and, even though the numbers of such people are relatively small, they may need special support, both to access services and in the provision of services. Evans et al. (2012) have suggested that dominance of discussion about linguistic barriers in the literature is likely to be due to the frequent use of non-representative sampling of subjects from minority ethnic groups (e.g. community groups, snowball sampling, etc.), leading to the over-representation of people from 'ethnically marked places and ethnic communities', including areas of first-generation settlement and places in which language and cultural maintenance are more likely.

## **Personal preferences**

Evidence shows that, when faced with the later stages of terminal illness, most people would prioritise quality of life over the extension of life. Higginson et al. (2014), in a random sample telephone survey of 9344 households in seven European countries, asked respondents about their priorities if faced with 'a serious illness, like cancer, with limited time to live'. Most people in all countries, ranging from 57 to 81 per cent, chose 'improve quality of life for the time they had left', with only 2 per cent of people in England saying that they thought extending life was most important. Evidence from the Health and Retirement Study (HRS) in the US also suggests that the vast majority of people completing advance directives elect for limited or comfort care rather than all care possible if decisions need to be made about their medical treatment after they have lost capacity (Nicholas et al., 2011; Silveira et al., 2010). Many people also express a preference for dying at home. Higginson et al. (2014) found that 69 per cent of people in their sample (64 per cent in England) would prefer to die at home, and in the most recent National Survey of Bereaved People in England (ONS, 2014c), 81 per cent of those that expressed a preference, preferred to die at home. Gomes et al. (2013b), in a systematic review of international evidence,

found that estimates of those preferring a home death ranged from 31 per cent to 87 per cent for patients (nine studies), 25 per cent to 64 per cent for caregivers (five studies) and 49 per cent to 70 per cent for the general public (four studies).

However, not everyone wants to die at home, nor are people's preferences necessarily stable. For example, Gomes et al. (2013b), in their review, found that 20 per cent of 1,395 people across ten studies (two of high quality) changed their preference as they neared end of life. Qualitative literature, included as part of the review, indicated that people changed their mind from wanting to die at home to wanting to die in hospital because of factors such as uncontrolled pain and other symptoms, for treatment of reversible conditions, to reduce caregiver burden, because of an inability of carers to safely care for the person at home, increased dependency and possible traumatic effects on children. Johnston (2014) point to the various challenges of caring safely at home including moving and handling or, for example, safety in administering treatment subcutaneous fluids. A number of studies have also found that people are socialised to expect to go to hospital when ill. People may request a hospital admission and clinicians may believe that it is unethical to refuse them. They and/or their family or carer may feel fearful, anxious and possibly over-whelmed. In this context, the hospital environment can represent a familiar, 'safe space' (Reyniers et al., 2014; Gott, 2014). This evidence suggests that the benefits of being cared for and dying at home can be offset by disbenefits, especially for carers, although a systematic review of the evidence suggests that, on balance, holistic well-being may be greater at home (Higginson et al. 2013). Gomes et al. (2013b) also found that sometimes people changed their minds the other way, from preferring a hospital death to preferring to die at home. The reasons for this included unsatisfactory experiences in hospital such as fighting for pain control. There is some evidence that more people would prefer to die at home if access to pain relief, round the clock care, and support for family and carers could be guaranteed (NCPC/Macmillan, 2011).

Most of the available evidence on personal preferences focuses on preference for place of death, with death in usual place of residence used as a proxy or shorthand way of indicating a 'good death', and implying a range of associated benefits such as fewer aggressive treatments in the last weeks, days and hours of life, being close to family and friends and being in a familiar environment (Wood and Salter, 2013; Gomes et al., 2013b). Downey et al. (2009), in the US, undertook research to refine a 'quality of death and dying' questionnaire and, in the course of this research, identified key areas of importance for people in advanced illness or at the end of life. They found that, across all sub-groups, time with family and friends and pain control ranked highest and that there were differences between sub-groups on only a few items, with those with higher education valuing having a means to hasten death, those with cancer or in hospice care valuing pain control more than other groups, those in a clinical trial involving massage therapy valuing human touch highly and BAME groups giving greater value than other groups to having funeral arrangements in place. There is limited research evidence about these preferences.



## Chapter 4: Access to palliative care

As we discussed in the previous chapter, in the Palliative Care Funding Review for England, Hughes-Hallett et al. (2011) estimate that around 92,000 people with advanced illness in England would benefit from, but are not currently receiving, palliative care, either specialist or generalist. While no equivalent estimate has been published for Wales, Scotland or Northern Ireland, by extending the same assumptions and calculations made by Hughes-Hallett et al. we estimated that 6,142 people in Wales, 2,919 people in Northern Ireland and 10,666 people in Scotland would similarly benefit from, but do not currently receive, palliative care. Evidence suggests that some groups are more likely to be amongst those not receiving care than others. In this chapter we present the evidence concerning access to palliative care in relation to:

- geography
- care setting
- diagnosis
- age
- ethnic background, and
- having a spouse/partner

### Geography

There is no data available on how much generalist palliative care is provided in different geographical areas, since this is delivered in the course of the general provision of health and social care services. There is, however, some information about geographical variation in the provision of specialist palliative care services. The National Survey of Patient Activity Data for Specialist Palliative Care Services: Minimum Data Set is a key source of information about specialist palliative care services in England, Wales and Northern Ireland. The report for 2012-2013, based on a voluntary survey of all specialist palliative care providers (response rate, 66 per cent), reports on both the number of provider organisations and the number of individual specialist services per 1000 deaths in each of the twelve regionally-based strategic clinical networks in England, as well as at a national level in England, Wales and Northern Ireland (NCPC, 2014a). Figures nationally are similar in each of the three countries; in England, there are an average 0.9 organisations and 2.6 specialist services per 1000 deaths, 1 organisation and three specialist services per 1000 deaths in Wales, and 0.9 organisations and 2.7 specialist services per 1000 deaths in Northern Ireland. However, at a local level in England, where this data is available, there is greater variation. Across all of the English strategic clinical networks, the number of provider organisations per 1000 deaths ranges from 0.5 organisations per 1000 deaths in Wessex to 1.5 in the East of England, while the number of individual specialist services per 1000 deaths ranges from 1.8 services in London to four in the East of England (NCPC, 2014a, p.21). As the report acknowledges, it is difficult to determine whether this variation represents inequity of provision or not. Firstly,

the figures themselves are not completely reliable, with data quality known to be variable across different providers, and, secondly, no adjustment is made for the size of services or for relative levels of need (NCPC, 2014a).

There is also wide area-based variation in the types of palliative care provided. For example, Wales provides more community-based specialist palliative care (61 per cent) compared to England (40 per cent) and Northern Ireland (40 per cent), with figures across England's strategic clinical networks ranging from 17 per cent to 50 per cent (NCPC, 2014a, p.22). Some or all of this variation may reflect legitimate area-based considerations, such as rurality, but relevant data is not available to clarify this.

While in Scotland there is no similar data collection to The National Survey of Patient Activity Data for Specialist Palliative Care Services: Minimum Data Set, Audit Scotland (2008) undertook surveys of all NHS boards and of samples of district nurses, bereaved families and informal carers in 2007. Based on this evidence, it reports wide variations in specialist palliative care availability. For example, specialist palliative care staff per 100,000 population were found to range from 4.1 to 22.3 across NHS Boards. Audit Scotland concluded that, 'the availability of specialist palliative care services and the ease with which these can be accessed by patients varies significantly across Scotland' (p.12). There has been no more recent data collected.

Other estimates of area-based variation have focused on the primary care trust (PCT) level (now replaced by clinical commissioning groups, CCGs) in England. In its report on end of life care, the National Audit Office (NAO, 2008) uses a Department of Health survey of spending on specialist palliative care services to identify an 11-fold variation in spending, ranging from a per person (per decedent) figure of £154 to £1,684 (with a mean of £504). Hughes-Hallett (2011) cite a Department of Health survey to estimate 30-fold variation, ranging from £186 to £6,213 per decedent, with most PCTs (61 per cent) spending less than £1,000 per decedent. Similar cautions, however, apply as with the data from the National Survey of Patient Activity Data for Specialist Palliative Care Services: Minimum Data Set, discussed above. These include concerns about the quality of the data. The National Audit Office report that their figures were not subject to audit and that it is likely that they were not calculated in the same way in every area with, for example, the costs of voluntary sector hospice staff included in some figures but not others (NAO, 2008, figure 11). Furthermore, the figures are not adjusted to reflect differences in levels of need. It may also be worth noting that some differences in spending could reflect local choices about the balance between specialist and generalist care, as these figures represent only spending on specialist services.

Finally, in new multivariate analyses of data from the National Survey of Bereaved People in England, 2013, specifically undertaken for this review, we explored the relationship between area deprivation and access to a range of community-based support services. We found that families of decedents who lived in the most deprived or second most deprived

IMD quintiles were less likely (at the 99 per cent significance level), compared to those in the least deprived IMD quintile, to say that they received sufficient help and support from health and social services to care for the decedent at home (OR 0.75 and OR 0.79 respectively). This finding may reflect the fact that people in the most deprived areas required greater levels of support than those in the least deprived areas to care for someone dying at home. People living in the three most deprived IMD quintiles were less likely (at the 99 per cent significance level) to receive spiritual or emotional support than those in the least deprived IMD quintile (OR 0.65, OR 0.63 and OR 0.73 respectively). Those in the second most deprived IMD quintile were, compared to those in the least deprived IMD quintile, more likely to receive support from a social worker or support worker (OR 1.23). There was, however, no clear association between area deprivation and whether people received support from Marie Curie Nurses, other community-based nurses, home help or meals on wheels, hospice at home or rapid response services. All of these analyses controlled for diagnosis, age, sex, whether the decedent had a spouse or a partner and ethnic background.

## Care setting

Current policy is focused on extending generalist care, with specialist palliative care services reconfigured for more complex cases and to provide support to generalist colleagues (Willis et al., 2014; Gott et al., 2012). However, in practice, there is evidence of variability in the availability of both generalist and specialist services.

## Primary care

Where people do not receive specialist palliative care services in the community, they are likely to be reliant on services delivered by primary care staff, including GPs and district nurses. However, evidence suggests that the roles of primary care staff in relation to palliative care can be unclear and that there can be inconsistency and gaps in provision. Oishi and Murtagh (2014) conducted a systematic literature review of views about the provision of palliative care for people with non-cancer diagnoses in the community, identifying 30 relevant studies, 27 of which were from the UK. Based on this evidence, they concluded that the roles of primary care professionals are commonly unclear to patients, carers and professionals themselves, with poor communication and collaboration between different professionals, and with carers frequently having to act as unofficial coordinators of care. They found that, while many patients, carers and other healthcare providers regard GPs as having a central role in delivering end of life and palliative care for people in the community, GPs themselves are frequently juggling competing priorities in the context of considerable time pressures and may expect nurses to take more active and lead roles. Oishi and Murtagh's review also identified lack of resources and lack of palliative care expertise as barriers to effective care in primary care settings. Oishi and Murtagh conclude that 'On the

whole, inter-professional work in primary palliative care settings is relatively ineffective despite the importance of collaboration having been repeatedly emphasised. This is even more relevant for non-cancer patients because the fluctuating trajectory of their illnesses can cause frequent exacerbations and admissions’.

Gott et al. (2012) argue that while the balance between generalist care and specialist care, with its focus on complex cases and providing support to generalist providers, may be understood in policy, there has been little attention given to how this has been interpreted and implemented in practice by frontline staff. They conducted a series of face-to-face interviews and focus groups with 58 healthcare staff in England and 80 healthcare staff in New Zealand, including generalists and specialist palliative care providers from both primary care and other settings. In both countries, Gott et al. found that generalist staff ‘struggled to define palliative care and none were familiar with the term “generalist palliative care”’. Many generalist providers also experienced difficulty in integrating palliative care into their overall workload. In another study, Burt et al. (2006) found, in a survey of 353 London GPs, that 65 per cent were providing palliative care to patients on their list, with 72 per cent agreeing or strongly agreeing that palliative care was a central part of their role. However, as many as 27 per cent wanted to hand care over to specialists, and knowledge about local out-of-hours, district nursing and specialist palliative care services was poor, with the potential for gaps in services as a result, particularly in small practices.

### Care homes

In England, in 2013, 21 per cent of all deaths occurred in care homes (ONS, 2014a). In Wales this figure was 15 per cent of all deaths (ONS, 2014a) in Northern Ireland it was 20 per cent of all deaths (NISRA, 2013) and in Scotland it was 22 per cent of all deaths (National Records of Scotland, 2013).

Residents of care homes, particularly nursing care homes, have increasingly complex healthcare needs (British Geriatrics Society, 2010). Three studies in England point to the increasing frailty of care home residents, with the proportion of residents dying within a year of entering a care home increasing from around 28 per cent in 1997 (Sidell et al., 1997), to 47 per cent in 2006 (Froggatt and Payne, 2006), and 56 per cent in 2014 (Kinley et al., 2014). There is also evidence that increasing numbers of people are dying in care homes, particularly with dementia. Sleeman et al. (2014) in an analysis of ONS mortality data for 388,899 people in England with a mention of dementia on their death certificate, found that, since 2006, the trend towards hospital deaths for people with dementia has reversed, with a growing proportion now dying in care homes, and with the current proportion of people with dementia dying in a care home estimated to currently be around 55 per cent. These data and studies suggest a need for increased palliative care expertise in care homes.

However, evidence suggests that there may often be insufficient support given to care homes by external healthcare providers. In a study involving two case studies and a survey of 180 nursing homes, Seymour et al. (2011) found reports of variable support provided by GPs to residents in care homes, including reluctance to prescribe appropriate medication, as well as lack of support from other agencies, lack of out of hours support, barriers in terms of affording and gaining access to syringe drivers, for delivering a steady flow of liquid medication, and a lack of access to training. More recently, in one of the largest studies of end of life care in nursing homes in the UK, Kinley et al. (2014) explored the care provided to 2,444 residents during their last six months of life. The study took place over a three-year period in 38 nursing care homes in south-east England, all of which were implementing the Gold Standards Framework in Care Homes programme (GSFCH). Kinley et al. found that the provision of healthcare services by external specialists from outside the homes was variable. Overall, they found that, while 96 per cent of residents were seen by a GP in their last six months of life, far fewer (20 per cent) were visited by palliative care nurses and there was considerably less contact than might be expected, given the profile of diagnoses amongst residents, with clinical nurse specialists or the mental health team. The authors argue that 'care homes acting as isolated providers of care is not an option if residents' health and social care needs are to be met' and state that commissioning bodies 'have a responsibility to fully fund the increasing demand for end of life care for frail older people dying in care homes' (p.378).

Other evidence suggests a confusion about the respective roles and responsibilities of care home staff and external healthcare providers. For example, a report of inspections of Scottish care homes published by the Care Commission (2009) found that only 44 per cent of care homes had policies in place to guide staff on when and how to contact members of the primary healthcare team. The inspections also found that 43 per cent of care homes claimed not to provide palliative care, apparently considering this to refer solely to care given in the last days of life, and 54 per cent of care homes provided no training at all to staff on end of life care. In a recent study, exploring the experiences of 121 residents from six care homes in the East of England and involving interviews with care home and NHS staff, Handley et al. (2014) found that, while all respondents stated that they were committed to supporting residents to die in their care home if they wanted, the process was complicated by an ongoing lack of clarity about roles and responsibilities in providing end-of-life care and concerns about the ability of care home and primary healthcare staff to work together when residents' trajectories to death were unclear.

## **Hospices**

As discussed in Chapter 1, access to traditional inpatient hospice care is known to vary geographically. Gatrell and Wood (2012) undertook an analysis to map and describe variation in geographic access to the 189 specialist adult inpatient hospices in England and

Wales, based on estimated drive times from Local Super Output Areas (LSOAs), controlling for 'demand' (using cancer mortality as a proxy measure). Their findings suggest that rural and more deprived areas were comparatively under-served compared to urban centres and more affluent areas. An ONS statistical bulletin (2013c) reporting on analysis of the National Survey of Bereaved People, 2011, by area deprivation shows that 7 per cent of people die in a hospice in the least deprived quintile of areas, compared to 5 per cent in the most deprived quintile. Similarly, a National End of Life Care Information Network report on deprivation and place of death, based on ONS mortality data, found that death in hospices was most common in the least deprived quintile, 6.4 per cent compared to 4.5 per cent in the most deprived (NEOLCIN, 2012). Hospices, in response to concerns that they do not serve different communities equally, as well as in response to recent strategic developments in the delivery of end of life care generally, are in the process of redefining their role, collectively and as individual providers, with a focus on increasing their outreach activities and acting as centres of excellence and support for other, both specialist and generalist, providers of palliative care (Calanzani et al, 2013a).

## **Hospitals**

A national audit of care for the dying in hospitals in England conducted by the Royal College of Physicians (2014) found generally poor access to specialist palliative care services, with only 21 per cent of hospitals providing face-to-face palliative care services seven days per week, despite national recommendations that they should do so. The audit also reported that spiritual care was not generally provided, with case notes documenting discussions about spiritual needs for only 21 per cent of people capable of participating in such discussions, and documenting that relatives and carers were asked about their own needs in only in 25 per cent of cases. In another study involving interviews and focus groups with a range of healthcare providers in both England and New Zealand, Gott et al. (2012) identified common issues of poor coordination between hospital-based generalists and specialist palliative care providers, with a view expressed that generalist clinicians sometimes saw referral to specialists as a 'quick fix' for passing on patients that they 'can't do any more with'.

## **Diagnosis**

### **Cancer versus other diagnoses**

A cancer diagnosis has traditionally been, and continues to be, the main determinant of access to specialist palliative care services (Grande et al., 2006; NCPC, 2014a). The National Survey of Patient Activity Data for Specialist Palliative Care Services: Minimum Data Set for 2012-13 (covering England, Wales and Northern Ireland) (NCPC, 2014a) reports that 88 per

cent of palliative care inpatients and around 75 per cent of new referrals to hospital support and outpatient services in England, Wales and Northern Ireland are for people with a cancer diagnosis, although cancer accounts for only around 29 per cent of deaths. Although Scotland has no parallel data collection to The National Survey of Patient Activity Data for Specialist Palliative Care Services: Minimum Data Set, research studies suggest that the situation is similar. For example, in a study of six general practices in Scotland, Harrison et al. (2012) found that two-thirds of patients with cancer were on the palliative care register compared with only 20 per cent of those with non-malignant conditions. In qualitative interviews, Harrison et al. found that GPs described existing services, guidelines and documents as being developed with cancer patients in mind, and being less applicable to people with non-cancer diagnoses. In another study of nine general practices in Scotland, Zheng et al. (2013) found that only 20 per cent of decedents diagnosed with dementia or organ failure (heart, lung, liver or kidney) either requested or were identified for specialist palliative care, compared to 75 per cent of cancer patients. In new multivariate analyses of data from the National Survey of Bereaved People in England, 2013, undertaken specifically for this review, a diagnosis of (non-haematological) cancer was, when compared to other diagnoses, independently associated (at the 99 per cent significance level) with receipt of sufficient help and support from health and social services to be cared for at home, as well as receipt of support from Marie Curie Nurses, other community-based nurses, spiritual and emotional care, hospice at home, rapid response services and home help/meals on wheels (see Appendix 3 for detailed results). This analysis controlled for age, sex, whether the decedent had a spouse or partner, ethnic background and area deprivation.

There are a range of barriers identified to extending palliative care to people with non-cancer diagnoses identified in the literature. One is the less predictable nature of most non-malignant disease and the associated difficulty of identifying a terminal stage, discussed in Chapter 3. Cochrane et al. (2008), reporting on a pilot project in Dundee, Scotland, also identified a range of organisational barriers to extending, in this case, day hospice care to people with non-malignant conditions. These included a lack of skills and knowledge in caring for those without cancer, fear of being overwhelmed with referrals and the potential impact on the service. It is possible that those with non-cancer diagnoses are having their palliative care needs met through generalist services. However, given that the symptomatic burden of non-cancer conditions can be just as significant, it is unclear why proportionately less specialist care would be appropriate. A number of studies have also found people with non-cancer diagnoses accessing less, rather than more, generalist care compared to people with cancer. For example, in a random survey of 1,266 adults registering a death of someone aged 65 or over in England (response rate 41.6 per cent), Burt et al. (2010b) found that non-cancer patients were significantly less likely to receive district nursing, care from a GP and other health and social care services, and they were also likely to report less satisfaction with the quality of this care. Georghiou and Bardsley (2014) found similar differences in access to community-based services between cancer and non-cancer patients.

Using data for 21,522 people who died between April 2006 and September 2011 in three London primary care trust areas, they found that, over the last three months of life, the cost of GP consultations for cancer patients cost an average of £365 per person (11.4 visits) compared to £125 per person (3.9 visits) for people with other diagnoses. Similarly, using data for 10,779 people who died between April 2006 and September 2011 in a single London Borough, Georghiou and Bardsley found that the average cost of district nursing for a cancer patient in the last three months of life was £588 per person (452 minutes contact time) compared to £249 (191 minutes) for people with other diagnoses. However, social care use for people with cancer was considerably lower than for those without cancer, even when standardised for age.

Opening up specialist palliative care services to people with a range of conditions other than cancer has been a key aim of national end of life strategies in all four countries and nations of the UK. In 2013, people with non-cancer diagnoses accounted for 20 per cent of new referrals in England, Wales and Northern Ireland (NCPC, 2014a), steadily increasing from 5 per cent in 2000, through 12 per cent in 2008 to 17 per cent in 2010-2011 (NCPC, 2012). In 2012-2013, specialist palliative care services delivered through hospital outpatients treated the greatest proportion of non-cancer patients (27 per cent, up from 24 per cent in 2010-2011), while the lowest percentage was for community-based care (17 per cent, up from 10 per cent in 2010-2011) (NCPC, 2014a). These proportions vary by diagnosis. In 2010-2011 (the most recent year for which relevant figures were published), the highest level of access was for people for chronic respiratory conditions (18 per cent of those with a non-cancer diagnosis), followed by people with motor neurone disease (13 per cent), other neurological conditions (10 per cent), heart failure (11 per cent) and chronic renal conditions (6 per cent). These percentages are based on 65 per cent of all non-cancer diagnoses, since the remaining 35 per cent are submitted with incomplete information about diagnosis. These proportions are also likely to vary considerably at a local level. The figures also only take account of primary diagnoses, so that the proportion of people dying with conditions such as dementia receiving specialist palliative care, a condition which is both under-diagnosed and commonly recorded as a secondary diagnosis, may well be significantly underestimated (NCPC, 2014a). There is currently no similar information available in Scotland.

However, having a cancer diagnosis is not a guarantee of receiving specialist palliative care. A palliative approach to terminal cancer can be compromised by continuing aggressive treatments, including up until the last weeks and days of life. There is evidence of overly aggressive care at end of life and late, or no, referral to palliative care for people with cancer in studies from Northern Ireland (Johnston, 2008) and England (O'Brien et al., 2006), and in an enquiry covering England, Wales and Northern Ireland (NCEPOD, 2008), as well as in research studies internationally (Braga, 2011). Walshe et al. (2009), in their literature review of access to community-based palliative care services, found, drawing upon one UK study (Addington-Hall and Altman, 2000) and four further studies published between 1998 and 2007 from Australia, Canada and Italy, that people with haematological cancer are likely



to receive more aggressive treatments and are less likely to be referred to specialist palliative care services, reflecting haematological cancer's less predictable disease trajectory compared to other cancers. Similar findings are to be found in more recent international research, including from Australia (Manitta et al., 2010) and the US (Hui et al., 2014 ; Epstein et al., 2012). Epstein et al., in the US, identified the barriers to introducing palliative care into the care of people with haematologic cancer as 'persistent health professional confusion about the role of palliative care and its distinction from hospice, inadequate availability of palliative care provider capacity and widespread lack of physician training in communicating about achievable goals of care with patients, family caregivers, and colleagues'. These barriers are similar to those identified for people with non-cancer conditions, discussed in other parts of the report, including in the following sections on CHF, COPD and neurodegenerative conditions. Epstein et al. also suggest that symptom distress during intensive treatments, such as haematopoietic stem cell transplantation, may be under-appreciated or, because of the dire nature of the illness, considered more acceptable in what Epstein et al. describe as a 'no pain, no gain' conceptual framework. This view is supported by findings from a cross-sectional survey of haematopoietic stem cell transplantation physicians, also from the US, which found that most physicians thought people would be willing to accept a poor quality of life in return for a small chance of cure (Lee et al., 2004).

In the following sections, we discuss condition-specific evidence about access to palliative care covering CHF, COPD and neurodegenerative conditions (including dementia).

### **Congestive heart failure (CHF)**

Various studies have identified a wide range of barriers for people with CHF in accessing palliative care. In a survey of 233 adult specialist palliative care services in England in 2006, Gibbs et al. found that one in ten specialist palliative care services did not accept people dying of CHF, with the most common reasons given for this being lack of resources, including limited availability of beds and concerns about the lack of training for staff working in an unfamiliar area. Referral for specialist palliative care for people with CHF is also complicated, as with other non-malignant conditions, by the condition having a less predictable trajectory than cancer, but also a high risk of sudden death. In analyses of data from the US Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), for example, it was found that, as late as the day before death, people with CHF were predicted as having a 62 per cent chance of surviving a further two months (Lynn et al. 1997).

The prognostic uncertainty and high risk of sudden death can mean that end of life conversations are avoided (Barclay et al., 2011; Barnes et al., 2008; Gott et al., 2007). A systematic literature review of international evidence on the perceived needs and experiences of people with advanced CHF and the perspectives and understanding of health

professionals, carried out by a UK-based team and based on 48 studies, with 18 out of the 32 qualitative or mixed methods studies from the UK, found that patients commonly reported having little discussion with health professionals about their clinical status. This resulted in a lack of timely support as their healthcare needs evolved. Healthcare professionals, for their part, reported poor communication with other care professionals and a lack of self-confidence, both in their ability to effectively prognosticate and in their ability to communicate a poor prognosis to those affected (Low et al., 2011). Similar findings were identified in a small-scale qualitative study in Scotland. Denvir et al. (2014) reported that people with advanced heart disease and their carers experienced fragmented services, difficulty in accessing specialist care and felt that time for discussion with healthcare providers was inadequate, while, for their part, healthcare providers highlighted uncertainty of prognosis, explaining mortality risk to patients and switching from curative to palliative approaches as key challenges in providing care to people with advanced heart disease. A systematic literature review of international evidence on end of life conversations between people with CHF and healthcare professionals, carried out by a UK-based team, found that conversations largely focused on disease management and that end of life care was rarely discussed. Sometimes this was because patients preferred to avoid having end of life conversations, although it also appeared that many did not realise the seriousness of their condition, potentially raising questions about the information and support provided to patients (Barclay et al., 2011). There is other evidence suggesting professional reluctance to have end of life conversations with people with CHF. For example, Matlock et al. (2010) administered a postal survey in the US in which they asked questions about a series of hypothetical scenarios to a random sample of 614 cardiologists (62 per cent response rate). The survey presented scenarios for two older patients with advanced CHF. It was found that, despite professional guidelines for cardiologists suggesting that they discuss palliative care with patients with late-stage heart failure, less than half chose to do so, a choice that was found to be correlated with regions using more healthcare in the last six months of life.

### **Chronic obstructive pulmonary disease**

The NHS Outcomes Strategy notes that people with COPD ‘receive far less palliative care input as an essential part of their ongoing disease management than in other disease areas’ (NHS, 2012, p.47). In a narrative review of international evidence, covering 15 relevant studies and carried out by a UK-based team, Gardiner et al. (2010) concluded (with this finding based on four key studies, published between 2000 and 2008, three of which were from England and one of which was from Canada) that, although people with COPD have regular contact with health services, access to specialist services and palliative care is poor. In a study undertaken since this review, White et al. (2011) report on research conducted with 163 people (mean age of 72 years) attending 44 GP practices in south London. They found that 30 per cent were receiving sub-optimal treatment and more than half had never been referred to pulmonary rehabilitation.

A number of barriers for people with COPD in accessing palliative care are identified in the literature. Gardiner et al. (2010) concluded that information provision to people with COPD is often lacking and that the implications of diagnosis and prognosis are not routinely discussed. As part of a technology assessment, a systematic review and narrative synthesis of international qualitative literature was carried out by a Canadian-based team (Giacomini et al., 2012). Of the 82 identified studies, 30 were from the UK. The review found that people with COPD tend to be poorly informed about the long-term prognosis of their condition and what to expect towards the end of life, and that this lack of understanding impairs quality of life as the disease progresses. They also note that, as with other non-malignant conditions, an important barrier is the unpredictable disease trajectory and difficulty in identifying a terminal phase. In a longitudinal qualitative study of people with COPD and carers in Scotland, for example, Pinnock et al. (2011) identified what they referred to as a 'chaos narrative' to describe patients' and families' accounts of their disease progression, and in the US SUPPORT study, it was found that, compared to people with lung cancer, people with COPD were given higher median 2-month and 6-month survival prognoses, even days before death (Claessens et al., 2000). Giacomini et al. (2012), in their systematic review, also found evidence of confusion amongst professionals about the definition and goals of palliative care in COPD, and a lack of clarity about roles and responsibilities, leading to confusion about whether palliative and supportive care is the responsibility of home care, primary care, specialist care, or even critical care. In the recent UK-wide National COPD Audit, covering acute care in England, Wales, Northern Ireland and Scotland, the Royal College of Physicians (2008) noted that, although there had been a welcome increase in the provision of on-site palliative care services for people with COPD, from 50 per cent of hospital sites to 87 per cent since 2008, the level of service was variable with 19 per cent of sites having less than a 0.5 whole time equivalent member of staff.

### **Neurodegenerative conditions**

People with dementia also commonly receive less palliative care than people with other diagnoses. In narrative reviews of international literature, with an emphasis on UK literature, both Rowlands and Rowlands (2012), a team based in Wales, and Birch and Draper (2008), a team based in England, found, that people with dementia have symptoms that are commonly not effectively addressed and note that the dying phase may frequently go unrecognised. Sampson et al. (2006), in a study of 122 people, who died in an acute ward in a London hospital, 28 per cent of whom had dementia, found that those with dementia were considerably less likely to be referred to palliative care teams than those who are cognitively intact and were prescribed fewer palliative medications.

In common with other non-malignant diagnoses, care for people with dementia is complicated by an unpredictable disease trajectory, although one generally characterised by progressive decline precipitated, in later stages, by acute infections and illnesses (van der

Steen, 2013). So, for example, in a study of nursing home deaths in the US, Bayer (2006) found that as many as 71 per cent of residents with dementia who were expected to live more than six months, in fact died within this period. In another US study involving 375 hospice patients, Rothenberg et al. (2014) found that those with a primary diagnosis of dementia or debility were most likely to outlive the Medicare and Medicare prognostic criterion for hospice of six months life expectancy.

Dementia also presents a range of special challenges. These include communication difficulties making it difficult to identify palliative care needs (Grisaffi and Robinson, 2010; Rowlands and Rowlands, 2012; Birch and Draper, 2012; Robinson et al., 2011). Care professionals may also feel concern about ethical, regulatory and legal issues when dealing with the difficult decisions and situations that are often encountered when providing palliative care for people with dementia. This may discourage them from taking a palliative approach and lead them to admit people to hospital or to administer aggressive treatments, even where these are of marginal benefit or medically futile (Harrison et al., 2012; Davies et al, 2014; Rowlands and Rowlands, 2012; Birch and Draper, 2012). These fears may be further heightened by public controversies around the ethics of palliative care, including that, for example, surrounding the Liverpool Care Pathway, an approach to care in the last days and hours of life (O'Dowd, 2012). Grisaffi et al. (2010), in a qualitative study with GPs, also identified challenges associated with discontinuity of care where people move into nursing homes at a late stage.

Parkinson's disease, which is incurable and progressive but often not considered terminal, may be overlooked for palliative care (Waldron et al., 2011). Other neurological conditions which may merit palliative care include Huntington's disease, motor neurone disease and multiple sclerosis. There is evidence that access for people with these conditions is generally poor (NCPC, 2010).

## Age

Across all four countries and nations of the UK, around 18 per cent of deaths occur in people aged 25 to 64 (ranging from 17 per cent in Northern Ireland to 19 per cent in England), 80 per cent of deaths occur in people aged 65 or over (ranging from 80 per cent in England and Wales to 81 per cent in Scotland and Northern Ireland) and deaths amongst the oldest old, those aged 85 or over, account for around 30 per cent of all deaths (ranging from 28 per cent in Wales to 34 per cent in Northern Ireland). These figures are total figures and include deaths from external causes (ONS, 2014a; General Registrar Office for Scotland, 2013; NISRA, 2013).

When mortality figures are compared to the proportions in receipt of specialist palliative care, the levels of receipt for the oldest old (those aged 85 or over) appear disproportionately low. The most recent National Survey of Patient Activity Data for

Specialist Palliative Care Services: Minimum Data Set (covering England, Wales and Northern Ireland) reports that around 29 per cent of people who access specialist palliative care are in the 25 to 64 age group, although only 13 per cent of deaths (when deaths from external causes are excluded) occur in this age group. Just over 54 per cent of people who access specialist palliative care are in the 65 to 84 age group, while people in this age group account for only 46 per cent of deaths (excluding deaths from external causes). Finally, people aged 85 or over account for 39 per cent of deaths (excluding deaths from external causes) but only 16.4 per cent of people in this age group access specialist palliative care services (NCPC, 2014a), although this proportion has increased from 8.8 per cent in 2000 (NCPC, 2014a) and 11 per cent in 2012 (NCPC, 2013). The greatest increases in provision of specialist palliative care for this oldest age group are in hospital support teams (13.4 per cent in 2005-2006 to 22.6 per cent in 2012-2013) and in community-based services (11.7 per cent in 2005-2006 to 19.5 per cent in 2012-2013) (NCPC, 2014a).

We find similar patterns of access for these different age groups in a number of research studies. Based on a survey of 1,351 randomly selected adults in England (median age 56) and analysis of mortality statistics, Gomes et al. (2011) concluded that people aged 75 or over have the highest preference of any age group for hospice care at end of life while also having the least chance of achieving it. In another study of 123 people with advanced illness in England, Grande et al. (2006) found, in a multivariate analysis, that both younger patient and carer age predicted use of Macmillan nurses. Younger carer age, but not patient age, predicted Marie Curie nursing use. Younger patient age, but not carer age, predicted admission to an inpatient hospice.

One reason for the apparent under-provision of palliative care to the oldest old may be that they are less likely than younger age groups to have a cancer diagnosis, a condition which is better served by palliative care services (NCPC, 2014a; Luddington et al. 2001). However, Burt and Raine (2006), in a systematic review of international evidence on referral to specialist palliative care services, based on 14 studies, five of which were from the UK, concluded that people with cancer aged 65 or over accessed palliative care less frequently than younger people with cancer.

There is also debate in the literature about whether the oldest old may have different needs and/or preferences. Walshe et al. (2009), in a systematic review of international evidence on access to community palliative care services, conclude that there is no evidence of differences in needs or preferences amongst older people, citing a prospective study of 181 patients in the Netherlands by Teunissen et al. (2006) that concludes, 'elderly cancer patients admitted to a hospital have more or less the same symptoms, problems and needs as their younger counterparts'. However, in their systematic review of international evidence on referral to specialist palliative care services for cancer, Burt and Raine (2006) noted that few studies controlled for potential differences in clinical need and, in a later study involving a survey of 252 people with lung cancer and 137 carers in England, Burt et

al. (2010a) found that, in multivariate analyses, age was not, in fact, associated with receipt of specialist palliative care services, although measures of need, including metastatic disease and global quality of life, and the clinic where treatment was provided were. In another study, involving a sample of 1,000 people with advanced cancer in the US and using multivariate analysis to explore the effects of age, sex and functional performance on symptoms, Walsh et al. (2000) found, in fact, that younger people had more complex needs and were more likely than older people to experience 11 specific symptoms.

If older people do have less clinical need for palliative care, however, the reasons for this are unclear. Walsh et al. found that younger people with advanced cancer had more anxiety, depression and sleep problems, which they thought to be potentially associated with greater levels of psychosocial distress. However, the greater prevalence of symptoms such as pain, headache, nausea, constipation, and vomiting was more difficult to explain. The possibility that these results reflect methodological limitations rather than real differences of need or preference should be considered. Even where multivariate analysis is conducted to understand the independent effects of variables, age may be strongly associated with another variable, and fail, for this reason, to appear as statistically significant (Grande et al., 2002). There may also be response effects, in particular, the possibility that people age 85 or over might under-report their symptoms, perhaps to healthcare staff as well as to researchers. To the best of our knowledge, there has been no research undertaken to test these hypotheses.

There is, however, evidence that the palliative care needs of older people may not be identified effectively in practice. For example, a study of transitions to palliative care in two acute hospitals in England involving 514 older people, found that 36 per cent of these met the criteria for palliative care need, according to the Gold Standards Framework (GSF) prognostic indicator, while medical staff estimated that only 15.5 per cent had palliative care needs and nursing staff estimated that only 17.4 per cent had palliative care needs (Gott et al. 2013; Gardiner et al. 2013b). Based on interviews with medical professionals, Gott et al. (2013) concluded that older people were commonly seen to have less need for specialist input as a consequence of death being 'more expected' and the view that older people will be more able to come to terms with a terminal diagnosis. In a qualitative study involving 58 medical professionals from primary, acute and hospice settings in England, Gardiner et al. (2011) identified the barriers to accessing palliative care for older people in hospitals as attitudinal barriers, lack of resources for both specialist and generalist palliative care, difficulties in switching from a curative or interventionist approach, and confusion over roles and responsibilities, in particular, a lack of clarity regarding the role of the geriatrician in providing palliative care.

New multivariate analyses of data from the National Survey of Bereaved People in England, 2013, undertaken for this review, are inconclusive with regard to the effects of age on accessing a range of community-based services, with dying at age 80 or over associated with

less receipt of some community services and greater receipt of other services. Hence, decedents aged 65 to 79, compared to decedents aged 80 or over, were found to be more likely (at the 99 per cent significance level) to receive community-based nursing services (OR 1.17) and hospice at home services (OR 1.32). However, the families of decedents aged 80 or over were more likely to report having received sufficient help and support from health and social services to care for the decedent at home, with the families of those aged 18 to 64 and 65 to 79 consequently being less likely to receive such support (OR 0.67 and OR 0.81 respectively). Decedents aged 80 or over were also more likely to receive spiritual and emotional support, compared to people aged 65 to 79, who had lower odds of receiving this support (OR 0.80). They were also more likely to receive rapid response services, compared to people age 18-64, who had lower odds of receiving this service (OR 0.48). A similar pattern was observed for receipt of home care/meals on wheels, with those 18 to 64 and 65 to 79, when compared to people aged 80 or over, being less likely to receive this service (OR 0.45 and OR 0.70 respectively). Age made no difference to receipt of Marie Curie nurse services. These analyses controlled for diagnosis, sex, whether the decedent had a spouse or partner, ethnic background and area deprivation.

## **Ethnic background**

Traditionally, people from BAME backgrounds have been considered under-represented in hospice and palliative care provision, although it has not always been clear why this should be the case (Gaffin et al., 1996; Koffman, 2006). Much of the literature looking at BAME groups and access to palliative care, both in the UK and internationally (primarily the US), is qualitative and/or relies on small selective samples. This literature also focuses on identifying a range of potential barriers to accessing palliative care. These include language barriers; cultural issues and culturally insensitive services, for example, concerning dietary requirements and religious observances; poor communication between providers and people from BAME backgrounds; problems in identifying anxiety and depression in some BAME populations; a lack of female doctors for Muslim women; and assumptions about families of people from BAME backgrounds being willing and able to care for family members at home. Barriers to effective advance care planning include fear of discrimination or being denied treatment, different cultural views regarding the acceptability of openly discussing death, and different cultural belief systems that may place less emphasis on autonomy and more emphasis on family decision-making (Calanzani et al., 2013b).

There is, however, limited quantitative evidence that people from BAME backgrounds access proportionately less palliative care, in practice, than people of White ethnicity. In recent data from the National Survey of Patient Activity Data for Specialist Palliative Care Services, Minimum Data Set (covering England, Wales and Northern Ireland), 6.2 per cent of people receiving specialist palliative care services were described as non-white, of whom 1.5 per cent were Black (African Caribbean or other), 1.1 per cent Indian, Pakistani or

Bangladeshi, 1.5 per cent mixed race, and 1.4 per cent of other ethnicity, including Chinese (NCPC, 2013). This is a smaller proportion than the overall proportion of people from BAME backgrounds in the population, currently 14 per cent across England, Wales and Northern Ireland. However, as we noted in Chapter 3, a smaller proportion than this of people who are age 65 or over are from BAME backgrounds, currently less than 4 per cent in England, Wales and Northern Ireland together. Given that most need for palliative care is concentrated amongst people age 65 and over, it does not, therefore, seem likely that people from BAME groups receive proportionately less palliative care than people of White ethnicity.

There is, however, some evidence, although from North America, of people from BAME groups receiving proportionately more aggressive treatments at end of life. For example, Mack et al., 2010, in a multi-institutional, prospective longitudinal cohort study of 261 White and 71 Black people with advanced cancer in the US, found that Black patients tended to receive life-extending measures at the end of life even when they had do-not-resuscitate (DNR) orders or had stated a preference for symptom-directed care. In a meta-analysis of data from over a million patients in 30 studies, primarily from the US and Canada, Henson et al. (2014) also found that people of Black ethnicity are significantly more likely than other groups to have more than one Emergency Department (ED) attendance in the last month of life, a recognised indicator of overly aggressive care at end of life.

New multivariate analyses of data from the National Survey of Bereaved People in England, 2013, undertaken specifically for this review, found that (at the 99 per cent significance level) decedents from BAME backgrounds were actually more likely than those of White ethnicity to receive support from community-based nurses (OR 1.39), to receive spiritual or emotional support (OR 2.31), possibly because of being more likely to belong to a church, and more likely to receive support from home help/meals on wheels (OR 1.40). They were no more or less likely to receive Marie Curie nurses, support from a social worker or support worker, hospice at home and rapid response services. This analysis controlled for diagnosis, age, sex, whether the decedent had a spouse or partner and area deprivation. However, we do not know whether or not people from BAME backgrounds received the same level of service from these services, for example, the same frequency of visits. The families of decedents from BAME groups were also less likely to feel they received sufficient help and support to care for the decedent at home compared to the families of White decedents, but only at the 95 per cent rather than the 99 per cent significance level. This may be related to experiences associated with the quality of care received, a topic that is discussed further in a later chapter.

### **Having a spouse or partner**

New multivariate analyses of the National Study of Bereaved People, 2013, undertaken specifically for this review, found that decedents without a spouse or partner were far less



likely to access a range of community-based services. They were found to be less likely to have sufficient help and support from health and social services to be cared for at home (OR 0.48), as well as to be less likely to receive support from Marie Curie nurses (OR 0.75), other community-based nurses (OR 0.86), spiritual or emotional support (OR 0.53), hospice at home (OR 0.54) and rapid response services (OR 0.73). These analyses controlled for diagnosis, age, sex, ethnic background and area deprivation. These results are likely to reflect the fact that people with spouses or partners are those most able to be cared for and die at home (Murtagh et al., 2012). People without a spouse or partner were, however, more likely to receive help from a social worker (OR 1.33).

## Chapter 5: Pain and symptom control

Although palliative care is a much wider concept, pain and symptom control is central to palliative care. Evidence concerning inequities in this area is sparse, particularly with regard to the control and management of non-pain symptoms. There is, however, some limited evidence on differences in pain control. This evidence is augmented by findings from new multivariate analyses of the National Study of Bereaved People in England, undertaken specifically for this review. We discuss this evidence by:

- care setting
- diagnosis
- age
- ethnic background, and
- having a spouse/partner.

### Care setting

In the most recent National Survey of Bereaved People in England, pain was reported as being relieved ‘completely, all of the time’ in hospices for 63 per cent of respondents, in care homes for 46 per cent of respondents, in hospital for 39 per cent of respondents and at home for 19 per cent of respondents (ONS, 2014c). These differences suggest inequity in the provision of pain relief across settings. However, the smaller proportion of respondents reporting that pain was relieved ‘completely, all of the time’ at home may reflect the fact that effective pain relief is harder to achieve in this setting, while the smaller proportion for hospitals compared to hospices may reflect the fact that hospitals are likely to be providing care to more people without cancer, those admitted following a health crisis and those with more challenging symptoms that cannot be managed readily at home. However, we identified no research studies that systematically explored these issues.

### Diagnosis

There is limited evidence on the relationship between pain control and diagnosis. However, there is some research evidence that people with dementia experience poorer pain control than other patient groups. For example, a review of international research evidence on community services for people dying with dementia, in their own homes or in care homes, found that people with dementia were more likely to experience persistent, untreated pain, when compared to other patient groups, even where they had been assessed using a recognised tool such as the Abbey Pain Scale or the Pain Assessment in Advanced Dementia (PAINAD) Scale. This finding was based on six studies published between 1997 and 2005, one from England, one from Japan and four from the US (Goodman et al., 2010). It reflects, the fact that, even with the aid of clinical assessment tools, recognising when someone with

dementia is in pain is difficult (Achterberg et al., 2013), although the review by Goodman et al. concluded that, in care homes, residents with dementia experienced improved comfort and fewer adverse symptoms when dementia-specific structured approaches to providing care were used.

There is evidence, however, that, even when need is identified, people with dementia may receive less pain relief. In a narrative review of evidence on palliative care in dementia, Hughes et al. (2007) found that hip fracture patients with dementia received less analgesia than other patients. The review cites a study of 113 nursing home residents from 15 nursing homes in the north of England by Closs et al. (2004), which found that, although there was no difference between residents with regard to scores on pain scales, those with higher levels of cognitive impairment nonetheless received significantly less opioid and non-opioid analgesics. Similar results have been found in US studies. In one US single-site, hospital-based study, for example, a sample of 38 dementia patients received, on average, only a third of the pain relief given to the sample of 59 patients without dementia (Morrison and Siu, 2000). In another US study of 88 hip fracture patients (53 cognitively impaired, 35 cognitively intact) from three hospitals, Feldt et al. (1998) found that, while self-report of pain was similar between those cognitively impaired and intact, those with cognitive impairment received significantly less opioid analgesics than cognitively intact subjects in the first and second 48 hours post-operatively and scored significantly higher on the Checklist of Nonverbal Pain Indicators observed with movement (CNPI-m). In more recent evidence, Lord et al. (2013), in a study of 230 dementia patients in two London hospitals, found that only 17 per cent of those that subsequently died were referred to the palliative care team during their admission, even though 27 per cent died with a pressure sore (grades 1–4) and 50 per cent were noted by clinicians to be in pain during the last 48 hours of their life.

New multivariate analyses of data from the National Survey of Bereaved People in England, 2013, explore the relationship between diagnosis and pain and symptom control while simultaneously controlling for age, sex, whether the decedent had a spouse or partner, ethnic background and area deprivation. We found that decedents who died with a neurological condition such as dementia, compared to those with (non-haematological) cancer, were more likely (at the 99 per cent significance level) to have had their pain controlled 'completely, all the time' while in hospital (OR 1.46). Reasons for this are not clear. Given the difficulties of identifying pain in people with dementia even when using clinical assessment tools, it is possible that pain was under-recognised by family members. People with dementia were not, however, more likely to have had their pain controlled 'completely, all the time' while at home or in a care home.

Compared to decedents with (non-haematological) cancer, decedents with cardiovascular disease, respiratory disease or 'other' conditions were less likely (at the 99 per cent significance level) to have had their pain controlled 'completely, all the time' at home (OR

0.47, OR 0.62 and OR 0.49 respectively). This is likely to reflect that there are well-established community-based care services for people with cancer, as well as potentially, the greater challenges of managing symptoms in conditions with less predictable trajectories in the home setting.

## Age

There is some evidence that suggests a relationship between older age and receipt of less, or less effective, pain relief. For example, in a study of 29,825 people with cancer from the General Practice Research Database (GPRD), using a representative sample drawn from across England, Wales, Northern Ireland and Scotland, Higginson and Gao (2012) found that 43.6 per cent received at least one prescription of opioids from their GP and that prescription rates increased over time. However, people aged over 60 had a significantly lower chance, adjusted for comorbidities, compared to those aged under 50, of receiving opioids.

In a pilot study for the first National Survey of Bereaved People in England, Hunt et al. (2014) surveyed those registering the death of all 1422 deaths registered between October 2009 and April 2010 in two English health districts. For the 473 people (33 per cent) who responded, there was no reported difference in the reported quality of pain or symptom management in the last three months of life between decedents aged 85 and over and decedents under 85. Similarly, there were no differences in the reported quality of pain management in the last two days of life. The only difference found was that respondents for those aged 85 and over were less likely to consider the management of non-pain symptoms to have been excellent or good in the last two days compared to respondents for decedents under 85.

New multivariate analyses of data from the National Survey of Bereaved People in England, 2013, undertaken for this review, found that people aged 80 or over appeared to have their pain relieved 'completely, all the time' more frequently than younger decedents, at home or in a care home. Hence decedents aged 18 to 64, who spent time being cared for at home during the last three months of their lives, were less likely (at the 99 per cent significance level) to have had their pain controlled 'completely, all the time' than decedents aged 80 or over (OR 0.74). This analysis controlled for diagnosis, sex, whether the decedent had a spouse or partner, ethnic background and area deprivation. In similarly adjusted analyses, decedents aged 65-79, who spent time being cared for in a care home during the last three months of their lives, were less likely (at the 99 per cent significance level) to have had pain controlled 'completely, all the time' than decedents aged 80 or over (OR 0.76). It is not clear why this should be the case and the possibility that these results could be due to a response effect such as a tendency on the part of respondents to underestimate pain in older decedents should perhaps be considered. There was, however, no relationship found

between age and having pain controlled 'completely, all the time' in hospital.

### **Ethnic background**

Calanzani et al. (2013b) found that the only available studies on ethnic background and pain control were from the US. These found that people from BAME backgrounds experience higher pain scores, interestingly even sometimes without a significant difference in opioid intake, and tend to receive less treatment for pain. Reasons for this are not well understood, although Calanzani et al. highlight evidence that suggests that opioid medication is relatively scarce in the US, particularly in regions with higher concentrations of people from BAME backgrounds. In our new analyses of data from the National Survey of Bereaved People in England, 2013, we found no relationship between ethnic background and pain identified in any setting.

### **Having a spouse or partner**

Looking at data collected in the National Survey of Bereaved People in England, 2013, we found that people without spouses or partners were less likely (at the 99 per cent significance level) to have pain controlled 'completely, all the time' than people with spouses or partners, including at home, in a care home and in hospital (OR 0.57, OR 0.64 and OR 0.78 respectively). These analyses controlled for age, sex, diagnosis, ethnic background and area deprivation. It remains unclear whether having a spouse or partner improves pain control, possibly because they can act as an advocate and/or an informal coordinator of care, or whether, potentially, this is a response effect, with respondents who are spouses or partners being more likely to report that pain was well-controlled, perhaps to avoid feelings of guilt or distress.

## **Chapter 6: Quality and experience of care**

This chapter focuses on systematic differences in the quality and experience of care people receive from palliative care providers. This covers, for example, services being suitable for need, people being treated with dignity and respect, and overall satisfaction with care. In practice, there is overlap with the evidence presented in Chapter 4, with systematic differences in access sometimes leading to a combination of poor care and gaps in care. This chapter should therefore be read in the context of this earlier chapter on access. In this chapter, we explore inequalities in service quality and people's experiences of care associated with:

- generalist palliative care
- diagnosis
- area deprivation
- ethnic background
- age
- sexual identification,
- having a spouse/partner.

### **Generalist palliative care**

Many people receive palliative care, not from specialist palliative care services, but from generalists such as GPs, community and district nurses, care home providers and general hospital inpatient and outpatient services, with the national end of life strategies placing particular emphasis on supporting generalist models of care (Department of Health/NHS, 2008; NHS Wales, 2013; Scottish Government, 2008; Department of Health, Social Services and Public Safety Northern Ireland, 2010). The quality and consistency of generalist care is therefore important to the equitable provision of palliative care.

### **Primary care**

As discussed above, distinguishing clearly between factors that influence people's access to care and factors that affect the quality and experience of care is difficult and, consequently, some of the evidence relevant to considering the quality of generalist palliative care services has already been discussed in the earlier chapter on access (e.g. Oishi and Murtagh, 2014; Gott et al., 2012). This evidence highlighted the wide range of challenges faced in the provision of generalist palliative care, including the reluctance of some GPs to provide palliative care, lack of confidence, lack of skills and knowledge, poor coordination between care professionals and confusion about roles and responsibilities.

Although there may be good generalist care provided to many people at the end of life, there is also evidence of care that is inconsistent and evidence of gaps in care. Shipman et

al., 2008, for example, conducted a consultation involving 210 invited health and social care staff from primary, secondary, and tertiary services and from specialist palliative care, as well as service commissioners, policy makers, academics, and representatives from user and voluntary groups. Sessions were held in London, the east of England, Warwickshire, and Scotland. The report of the consultation sessions noted that generalists usually cared for relatively few people nearing the end of life and did so in the context of many competing and incentivised activities in the community, and that, in some areas of generalist care, there were high levels of staff turnover. As a result, developing and maintaining skills was identified as a key issue, with some generalists, particularly GPs, thought to be 'disengaged'. The consultation report also noted a lack of robust evidence and variable practice around models of care such as the Gold Standards Framework (Shaw, 2010; SCIE, 2013) and practices such as advance care planning (Brinkman-Stoppelenburg et al., 2014). Consultees also thought that condition-specific expertise in the community was often limited and identified gaps in provision, such as a shortage of senior community nurses and out-of-hours services. Poor integration between health and social care was also identified as inhibiting effective practice and continuity of care, and there was also a view expressed that good end of life care could not be provided without increasing overall resources, especially for people with non-malignant diseases.

### Hospital care

There are well documented differences in quality of care by care setting, with acute settings consistently judged to provide poorer quality end of life care. In the National Survey of Bereaved People in England (ONS, 2013b), only 32.7 per cent of respondents considered the quality of care in hospitals to be 'outstanding' or 'excellent', compared to 53.2 per cent in relation to care at home, 50.8 per cent in relation to care in a care home and 59 per cent in relation to care in a hospice. The degree to which people were treated with dignity was also poorer in hospital than in other settings, with 56.8 per cent of decedents reported as being treated with dignity 'always' by hospital doctors and 47.7 per cent as being treated with dignity 'always' by hospital nurses. This compares to 78.7 per cent as being treated with dignity 'always' by district and community nurses, 72 per cent by GPs, 61.4 per cent by care home staff, 86.7 per cent by hospice doctors and 80.5 by hospice nurses (ONS, 2013b).

In the recent independent review of the now withdrawn Liverpool Care Pathway, Neuberger et al. (2013) describe the 'ambition to transpose hospice-like standards of care into the hospital setting' as admirable given the 'many examples of poor care' that preceded its introduction but conclude that 'the LCP is not being applied properly in all cases' and that it had at times 'been used as an excuse for poor quality care' (p.47). The consultation by Shipman et al. in 2008, already described, took place well before the review by Neuberger et al. but noted then that tools such as the Liverpool Care Pathway are difficult to

implement at scale in generalist palliative care practice, given the requirement for extensive investment in training and education.

In a national audit of care in hospitals for the dying in England, the Royal College of Physicians (2014) identified that mandatory training in care of the dying was only required for doctors in 19 per cent of trusts and for nurses in 28 per cent, despite national recommendations that this be provided universally. The audit also found considerable evidence of a lack of open communication with patients about their care. For example, it found that assessment for clinically assisted (artificial) hydration was recorded for 59 per cent of patients, but discussions about this were documented for only 17 per cent of those capable of participating in such a discussion and with only 36 per cent of carers. Similarly, an assessment for clinically assisted (artificial) nutrition was recorded for 45 per cent of patients, but discussions were documented with only 17 per cent of those capable of participating in such a discussion and with 29 per cent of carers. It was also documented for 87 per cent of patients that they were in the last hours or days of life, but discussions were documented with only 46 per cent of those thought capable of participating in such a discussion, although discussions occurred with carers in as many as 93 per cent of cases. These discussions occurred, on average, 34 hours before the patient's death. In a review of the care of 1,293 patients in hospitals across England, Wales and Northern Ireland, who died within four days of admission, Cooper et al. (2009) found that in almost 17 per cent of cases where, on admission, patients were not expected to survive, there was no evidence that any discussion between the healthcare team and either the patient or relatives on treatment limitation had taken place.

SCIE (2013), in their briefing, *Dying Well at Home: The Case for Integrated Working*, argue that it may be difficult to ensure the same quality of end of life care in hospitals as in other settings, such as hospices, since hospitals are generally not well set up to serve the holistic needs of patients and cannot offer personalised care or provide continuity in staffing. However, SCIE note that some people will always be cared for and die in hospitals. These will not be a representative group of people. Rather they are likely to disproportionately include people, for example, without spouses or partners or with non-cancer diagnoses. For reasons of equity, therefore, as well of ensuring acceptable minimum standards of care, it is important that the quality of care in hospitals is as high as it possibly can be.

## **Diagnosis**

In the National Survey of Bereaved People in England, of all people with cancer who died at home, 62.8 per cent experienced 'outstanding' and 'excellent' care in their last three months of life. This compares to 39.3 per cent of all people with cardiovascular disease who died at home and 46.2 per cent of people with other diagnoses who died at home. However, such differences between people with different diagnoses were not found in other settings. For people who died in hospital, the proportions that experienced



'outstanding' or 'excellent' care were 36.9 per cent for cancer patients, 36.5 per cent for people with cardiovascular disease, and 30.9 per cent for people with other diagnoses. In care homes the figures were 46.6 per cent, 50.4 per cent and 54.3 per cent respectively. In hospices the figures were 57.9 per cent, 58.2 per cent and 59.9 per cent (ONS, 2013b). However, when asked, not about overall quality of care, but specifically about care provided by particular providers, 39.6 per cent of people with cancer experienced care from GPs that was 'excellent' (there is no 'outstanding' category for these questions), compared to 30 per cent of those with cardiovascular disease and 29.4 per cent of people with other diagnoses. For care provided by a care home, figures were similar at 49.9 per cent, 42.8 per cent and 46.3 per cent respectively. For care provided by a hospice, however, people with a cancer diagnosis reported higher quality of care, with 83.8 per cent reporting care that was 'excellent' compared to 60.2 per cent for those with cardiovascular disease and 58.6 per cent of people with other diagnoses (ONS, 2013b)

The multivariate analyses of data from the National Survey of Bereaved People in England, 2013, that we undertook for our review confirm that people with cancer tend to experience higher quality care. These found that people with cardiovascular, respiratory or 'other' conditions were less likely (at the 99 per cent significance level), compared to those with (non-haematological) cancer, to experience overall quality of care in the last three months of life that was 'outstanding' or 'excellent' (OR 0.62, OR 0.64 and OR 0.60 respectively). People with cardiovascular disease appeared to experience poorer quality of care than people with other non-cancer diagnoses. Compared to those with (non-haematological) cancer, they were also less likely (at the 99 per cent significance level) to experience GP services, care provided by a care home or out of hours services that were 'excellent' (questions about individual services, in contrast to the question about overall quality, have no 'outstanding' category) (OR 0.72, OR 0.75 and OR 0.75 respectively).

## **Area deprivation**

A published analysis of data from the National Survey of Bereaved People found a statistically significant difference (at the 99 per cent significance level) between the least and most deprived IMD quintiles in overall quality of care, after controlling for age, sex and diagnosis, with respondents in the least deprived IMD quintile being more likely to consider care 'outstanding' or 'excellent' (OR 1.23) compared to respondents in the most deprived IMD quintile (ONS, 2013c). There was also a statistically significant difference (at the 99 per cent significance level) in the quality of care provided by GPs, with those in the least deprived IMD quintile being more likely to report that care from GPs was 'excellent' (OR 1.37) compared to those in the most deprived IMD quintile. People in the least deprived IMD quintile were also more likely to report that care received from care homes or district and community nurses was 'excellent' (OR 1.23 and OR 1.16 respectively) compared to respondents in the most deprived IMD quintile, although only at the 95 per cent significance

level. The quality of care provided by out of hours services, hospital doctors and hospital nurses was similar across different areas. In these same analyses, people in the least deprived IMD quintile had higher odds (at the 99 per cent significance level) of 'always being treated with dignity and respect' by district and community nurses (OR 1.32) and GPs (OR 1.76) when compared to those in the most deprived IMD quintile. The proportions of people reporting 'always being treated with dignity and respect' by care home staff, hospital doctors and nurses did not vary significantly between IMD quintiles (ONS, 2013c).

In new multivariate analyses of data from the National Survey of Bereaved People in England, 2013, undertaken specifically for this review, after controlling for age, sex, diagnosis, whether the decedent had a spouse or partner and ethnic background, we found that those living in the most deprived and second most deprived IMD quintiles were significantly less likely (at the 99 per cent significance level) to rate overall quality of care as 'outstanding' or 'excellent' compared to those living in the least deprived IMD quintile (OR 0.81 in the most deprived IMD quintile and OR 0.88 in the second most deprived IMD quintile). Respondents in the most and second most deprived IMD quintiles were also significantly less likely (at the 99 per cent significance level) to rate GP services as 'excellent' compared to those from the least deprived IMD quintile (OR 0.72 and OR 0.79 respectively). Finally, respondents in the most deprived IMD quintile were significantly less likely (at the 99 per cent significance level) to rate care provided by care homes as 'excellent' compared to those from the least deprived IMD quintile (OR 0.80).

## Age

In a study already discussed in Chapter 5 that aimed to compare the experiences of end of life care for people age 85 or over with those of younger people, Hunt et al. (2014) undertook a survey of 473 people (33 per cent response rate) who registered a death between October 2009 and April 2010 in two English health districts. Forty-eight per cent of these decedents were age 85 or over. Respondents were sent the Views of Informal Carers: Evaluation of Service (VOICES) Short Form questionnaire, six to 12 months following the death. No differences in care quality were reported for the last three months but, in the last two days, people age 85 or over experienced less emotional and spiritual support and were more likely to have had unwanted treatment decisions made.

In new multivariate analyses of data from the National Survey of Bereaved People in England, 2013, we found that, compared to people aged 80 or over, people aged 65 to 79 were less likely (at the 99 per cent significance level) to consider the overall quality of care they received to be 'outstanding' or 'excellent' (OR 0.87) or to find the care provided either by care homes or by GPs to be 'excellent' (OR 0.79 and or 0.87 respectively). This analysis controlled for sex, diagnosis, whether the decedent had a spouse or partner, ethnic background and area deprivation.

## **Ethnic background**

Calanzani et al. (2013b), in their evidence review, identify issues such as lack of cultural and religious sensitivity in how services are delivered, lack of translation resources, lack of advocates, problems with using family and friends as translators, low numbers of minority doctors and low availability of professional training in 'cultural competency'. This research evidence suggests that there is poor care for people from BAME backgrounds, unmet cultural and religious needs and uncertainty and stress created for professionals. However, much of this research comes from the US and the majority of studies exhibit a number of methodological limitations. For example, Calanzani et al. note that research reporting on systematic differences in outcomes for people from BAME backgrounds is much less common in the literature than research focused on identifying barriers. Furthermore, where outcomes are discussed, these are rarely considered in the context of patients' and their families' own stated cultural needs and preferences. Research in this area also suffers from small, selective and unrepresentative samples (Calanzani et al., 2013b; Evans et al., 2012). While the existing research evidence may be useful in highlighting potential barriers and good practice in delivering palliative care to people from BAME groups, the generalisability of much of this evidence remains unclear.

However, in new multivariate analyses of data from the National Survey of Bereaved People in England, 2013, we found that people from BAME backgrounds were less likely than people of White ethnicity (at the 99 per cent significance level) to rate overall care as 'outstanding' or 'excellent' (OR 0.74), particularly in sub-samples of decedents who spent some time in a care home (OR 0.45) or a hospice (OR 0.50) in the last three months of life. In a separate question about care received directly from a care home, people from BAME groups were also much less likely than people of White ethnicity to rate this care as 'excellent' (OR 0.48).

## **Sexual identification**

In a systematic review of evidence on end of life care for people who identify as lesbian, gay, bisexual and transgender, Harding et al. (2012) identify 12 relevant papers, the majority of which focus on the cancer experience of gay men and lesbian women, with only a few papers addressing the experiences of the bisexual population, while there were no studies on the experiences of transgender people. Notwithstanding the limited evidence base, the authors conclude that existing evidence highlights the educational needs of healthcare professionals to avoid making assumptions about people's sexual preferences and identities and to recognize the importance of same sex partners in decision making. They also identify a significant need to research LGBT experiences and refine services for patients and their carers.

## **Having a spouse or partner**

Looking at data from the National Survey of Bereaved People in England, 2013, we found that those with spouses or partners were significantly more likely than those without spouses or partners (at the 99 per cent significance level) to receive overall care in the last three months of life that was considered 'excellent' or 'outstanding', with those without spouses or partners being less likely to experience overall care as 'excellent' or 'outstanding' (OR 0.65). People without spouses or partners were also significantly less likely to experience care from care homes, GPs and out of hours services that was 'excellent', (there is no 'outstanding' category for questions about individual services) (OR 0.80, OR 0.55 and OR 0.57 respectively). All of these analyses controlled for age, sex, diagnosis, ethnic background and area deprivation.

## Chapter 7: Place of death

The National Audit Office (2008) states that ‘most people wish to be cared for and die in their home but the number of people who are able to do so varies with age, geographical area and, most significantly, by condition’. Increasing the ability of individuals to be cared for, and to die, in their place of choice is a key aim of the national end of life care strategies in England, Wales, Northern Ireland and Scotland. Improving access to community-based services is identified as key to supporting this aim, and is also seen as important for reducing the number and frequency of emergency admissions in the last year of life (NAO, 2008; Department of Health/ NHS, 2008). In England, the Quality, Innovation, Productivity and Prevention (QIPP) programme for end of life care established an indicator for death in usual place of residence (e.g. own home or care home). In 2012, 43.7 per cent of people died in their usual place of residence, up from almost 37.9 per cent in 2008 (PHE, 2013a). Currently, there is no similar indicator in Wales, Northern Ireland or Scotland, although Health Improvement Scotland has published proposals towards one (Healthcare Improvement Scotland, 2013). We do know, however, that across England and Wales, in 2013, 22 per cent of people currently die at home and 21 per cent in a care home, up from 21 per cent and 18 per cent respectively in 2010 (ONS, 2014b). In Northern Ireland, in 2013, 49 per cent of people died in hospital, 18 per cent died in a care home and 33 per cent died in ‘all other places’, which includes home. In 2008, 51 per cent of people died in hospital, 16 per cent died in a care home and 33 per cent died in ‘all other places’ (NISRA, 2012) No place of death data is published in Scotland.

Although, emphasis is placed on increasing death in usual place of residence rather than in hospital, trends in hospitalisations and emergency admissions throughout the whole last year of life are also important, with almost 90 per cent of people receiving some care in hospital during this final year (Georghiou et al., 2012; Bardsley et al., 2010). However, attempts to establish a similar QIPP indicator for hospital admissions of 8 days or more ending in death and for emergency admissions in the last year of life have proved challenging (Department of Health, 2012). The Information Services Division, Scotland, however, does, as part of its NHS Healthcare Quality Strategy, gather data on ‘percentage of end of life spent at home or in a community setting’. This is gathered at national level, as well as at health board, local authority and community health partnership level. However, where people eventually die is not currently known. For all people dying in Scotland during 2012/13, the percentage of the last six months of life spent at home or in a community setting was 91.2 per cent, increased from 90.4 per cent in 2008/9 (Information Services Division, Scotland, 2014).

Death in usual place of residence remains a key performance indicator in measuring the effectiveness of end of life care. However, it is intended as a proxy measure of good care, reflecting what the majority of, although not all, people say they want. It is not intended to be an aim in and of itself. In particular, Wood and Salter (2013) raise concerns about the

potential over-emphasis on promoting home death, particularly if driven by economic pressures, and they argue for ongoing efforts to ensure high quality care across all settings. This is important since death in usual place of residence may not always be achievable, and may not be a better outcome, for everyone. As Gomes et al. (2013a) note, with regard to research into end of life care, 'it is crucial to ascertain outcomes other than death at home, such as symptom control, quality of life, caregiver distress and satisfaction with care', arguing that these may be as, or potentially more important for patients and families. Other research evidence also emphasises the importance of non-medical factors such as psychological and emotional well-being, dignity, spiritual matters, human touch and affection, spending time with family and friends, having financial and legal affairs in order, having funeral arrangements made and resolving emotional conflicts and other personal matters (Mullick, 2013; Downey et al., 2009).

In this chapter, however, we focus on place of death, because the vast majority of available evidence addresses this outcome. In particular, we consider place of death in relation to:

- diagnosis
- availability of services
- having a spouse/partner
- age
- ethnic background
- living in a care home, and
- geography.

## **Diagnosis**

There are considerable differences in place of death by diagnosis. People with cancer (with the exception of those with haematological cancers) are more likely to die at home or in a hospice than in hospital, reflecting the more predictable disease trajectory and more established community-based services for people with cancer (Howell et al., 2010; National Cancer Intelligence Network, 2014). In analyses of data from the National Survey of Bereaved People in England, 2013, we found that, after controlling for a wide range of factors (age, sex, whether the decedent had a spouse or partner, ethnic background and area deprivation), people with (non-haematological) cancer, when compared to people with other diagnoses, are more likely (at the 99 per cent significance level), to die at home rather than in hospital. In a systematic review of place of death for people with non-cancer diagnoses, Murtagh et al. (2012) found that illnesses with a longer trajectory of functional impairment, even if severe, were also associated with increased home death, possibly because of the increased time this allowed for planning and preparation. People with dementia, on the other hand, are more likely to die in a care home or hospital rather than at home (NEoLCIN, 2010; Handley et al., 2014), a finding that was also confirmed in new analyses of data from the National Survey of Bereaved People in England, 2013, undertaken

for this review, which controlled for age, sex, whether the decedent had a spouse or partner, ethnic background and area deprivation. The condition with the highest proportion of hospital deaths is respiratory disease, with 69 per cent of people with respiratory illness in England dying in hospital (NEoLCIN, 2010).

It is currently unclear what might be acceptable and achievable reductions in rates of hospital death for different conditions. National estimates have, of necessity, been based on extremely broad assumptions, with no separate estimates by diagnosis identified (Balance of Care Group/NAO, 2008). The only indication of at least initial targets thought to be achievable comes from the Whole Systems Partnership (WSP) Cohort Model (NEoLCIN, 2015). This was developed to support local areas in England, but with application to the other countries and nations of the UK, to implement the National End of Life Strategy. As part of its development, three local pilot sites set their own three-year targets for reducing hospital deaths for people with different diagnoses. These targets varied depending on existing rates of hospital deaths for people with these different conditions and local circumstances. For cancer, the three areas aimed to reduce hospital deaths from 39 per cent to 30 per cent, from 45 per cent to 40 per cent and from 39 per cent to 38 per cent respectively. For frailty, including dementia, areas aimed to reduce hospital death rates from 44 per cent to 30 per cent, from 44 per cent to 30 per cent and from 49 per cent to 30 per cent respectively. There were similarly ambitious targets set for reducing hospital death rates associated with organ failure, from 60 per cent to 45 per cent, from 60 per cent to 45 per cent and from 64 per cent to 56 per cent respectively. It is unclear whether, and what, further reductions in the hospital death rate for different conditions might be achievable.

## **Availability of services**

The availability of good quality community-based palliative care services is important in reducing hospital death and increasing rates of death in usual place of residence. While evidence on the impact of generalist palliative care is lacking, there is evidence that people receiving specialist community-based palliative care are less likely to die in hospital. For example, the National Council for Palliative Care (2014a) reports, in the National Survey of Patient Activity Data for Specialist Palliative Care Services: Minimum Data Set for 2012-13 (covering England, Wales and Northern Ireland) that just over 46 per cent of those who received care in the community died at home, while only 18 per cent died in hospital. They compare this with ONS data for all deaths, in which, over the same period, nearly 22 per cent of people died at home and almost 52 per cent died in hospital.

There is an implication here that extending specialist palliative care services would result in more people dying at home. However, such a conclusion does not take account of selection bias, with those referred to specialist palliative care services likely to be those most capable of supporting a home death. However, more robust evidence is available in a recently published Cochrane review. In a meta-analysis of seven trials (five randomised clinical trials

and two controlled clinical trials), Gomes et al. (2013a) found that receiving home-based palliative care more than doubles the odds of dying at home. This result remained statistically significant when the analysis was restricted to the five randomised controlled trials or to the three highest quality randomised controlled trials. However, the majority of participants in all seven trials had cancer, making the generalisability of findings to other diagnoses uncertain, although there were some people with non-cancer diagnoses included in three of the trials. There have also been some high quality evaluations conducted since the Cochrane review by Gomes et al. was published. For example, a recent evaluation by Seow et al. (2014) of 11 community-based specialist palliative care teams in Canada found that, compared with matched controls, they reduced the use of acute care services, reduced hospitalisations by a third, reduced use of emergency departments by a quarter and reduced risk of hospital death by a half in the last two weeks of life. In England, Chitnis et al. (2012), evaluated the Marie Curie Nursing Service, which provides 24-hour hands-on nursing care and emotional support for people in their own homes, as well as discharge support to get people home from hospital quickly, integrated health and social care so that people can be cared for effectively at home, and urgent care to help manage people's symptoms at home. They found that nearly 77 per cent of people receiving the service were able to die at home, while just under 8 per cent died in hospital, compared to a matched control group, where 35 per cent of people died at home and nearly 42 per cent of people died in hospital. Finally, in a systematic review and meta-analysis of ten international studies of community specialist palliative care services that provide home nursing, Lockett et al. (2013), found that, in meta-analysis across all ten studies, these were associated with increased rates of home death, but not when the meta-analysis was limited to the three highest quality studies.

The availability of care homes offering high quality end of life care is also likely to reduce the number of hospital deaths. In comparative international research, based on an analysis of death certificate data for all dementia-related deaths in 2003 of people aged 65 or over, Houttekier et al. (2010), found that the likelihood of dying in a hospital was higher in the three UK countries (England, 36 per cent; Wales, 46.3 per cent; Scotland, 33.9 per cent) than in Belgium (22.7 per cent) or the Netherlands (2.8 per cent). The countries with lower hospital death rates had higher rates of death in care homes, with the proportion of decedents who died in a care home being 59.7 per cent in England, 50.2 per cent in Wales, 60.8 per cent in Scotland, 65.9 per cent in Belgium and 92.3 per cent in the Netherlands. Using multivariate analysis, Houttekier et al. concluded that the much lower hospital death rate in the Netherlands could be explained by the greater availability of nursing home beds, serviced by highly skilled professionals and with advance care planning and effective communication with relatives established as routine. Home death was low in all countries except Belgium, where it was 11.4 per cent.

Perhaps unsurprisingly, people are also more likely to die in an inpatient hospice where there is one close by to their home. For example, in multivariate analyses, undertaken using



378,482 adult cancer death records in England, Wood (2010) found that, once effects attributable to other variables were accounted for, people who live in areas with a high 'accessibility score' (based on drive times to a hospice) were 2.79 times more likely to die in a specialist inpatient hospice than those with a low accessibility score. Similar 'supply-side' effects were noted by Murtagh et al. (2012), who found, in their systematic review of place of death for people with non-malignant conditions, a small but statistically significant association between reduced home deaths and greater hospital bed availability, based on four studies from the US, Canada and Belgium.

### **Having a spouse or partner**

In a systematic review of UK and international literature aimed at understanding place of death for people with non-malignant conditions, Murtagh et al. (2012) found that having a carer was the single most important factor associated with home death, whereas living alone or being unmarried increased the likelihood of a hospital death. Despite a narrowing of difference in life expectancy between men and women, women still tend to outlive male spouses and are more commonly carers for men than men are for women. As a result, more men than women die at home (22 per cent versus 16 per cent) and more women than men die in care homes (21 per cent versus 10 per cent) (NEoLCIN, 2010). We found, in new multivariate analyses of the National Survey of Bereaved People in England, 2013, perhaps unsurprisingly, that decedents without a spouse or partner were less likely (at the 99 per cent significance level) to die at home than in hospital (OR 0.82), with this analysis controlling for age, sex, diagnosis, ethnic background and area deprivation. People without a spouse or partner were, however, more likely (at the 99 per cent significance level) to die in a care home rather than in hospital (OR 1.41).

### **Age**

Older people are more likely to die in hospital than younger adults. In recent data for England, 52.6 per cent of decedents aged under 65 died in hospital, while for people aged 65 to 84, this figure was 59.3 per cent, although for people aged 85 and over the figure was somewhat lower, at 55.3 per cent, reflecting the fact that people in this age group may more often die in a care home (NEoLCIN, 2012). Figures for place of death by age or age band are not available for Wales, Northern Ireland or Scotland.

Other research suggests that the oldest old, those age 85 or over, may be the least likely to die in their preferred place. In a survey, already discussed in earlier chapters, of 1,422 people (response rate 33 per cent) registering a death over a six-month period in two health districts in England, Hunt et al. (2014) found that decedents aged 85 or over were less likely than those under 85 to have known that they were dying, to have their preferences for

place of death recorded, to have died in their preferred place, to die at home or, in the view of respondents, had enough choice about place of death.

In the new multivariate analyses of the National Survey of Bereaved People in England, 2013, that we undertook for this review, it was found that people aged 80 or over, when compared to other adults, were more likely (at the 99 per cent significance level) to die in hospital rather than at home. Specifically, decedents aged 18 to 64 and 65 to 79, compared to those aged 80 or over, were more likely to die at home than in hospital (OR 1.36 and OR 1.33 respectively). However, people aged 80 or over were more likely (at the 99 per cent significance level) to die in a care home rather than in hospital. Specifically, decedents aged 18 to 64 and aged 65 to 79, compared to those 80 or over, were less likely to die in a care home rather than hospital (OR 0.47 and OR 0.52 respectively). These analyses controlled for sex, diagnosis, whether the decedent had a spouse or partner, ethnic background and area deprivation.

## **Ethnic background**

There is some limited evidence that people from BAME groups are more likely to die in hospital, although much of this evidence comes from outside the UK. Authors of these studies have hypothesised, for example, that people from BAME groups may have different preferences or may have possible concerns about receiving equal access to potentially life-extending treatments and that this could account for greater use of hospital care at end of life. However, in practice, few studies have considered place of death in the context of possible differences in attitudes and beliefs, preferences or clinical needs. As a result, evidence in this area has been somewhat inconclusive (Calanzani et al., 2013b; Evans et al., 2012).

However, in a recently published analysis of data for 93,375 decedents who died with cancer in London between 2001 and 2010 and were aged 65 or over, Koffman et al. (2014), found that immigrants (using country of birth as the measure) were significantly more likely to die in hospital and less likely to die at home or in a hospice than those of White ethnicity. Their analysis controlled for age, sex, year of death, marital status and cancer type. The underlying reasons for these results are unclear, and it is also unclear how generalisable they are to immigrants in other areas of the UK. Evidence from the new analyses of the National Survey of Bereaved People in England, 2013, undertaken for this review, suggests that the results are also not necessarily generalisable to British-born BAME people. We found that people from BAME backgrounds were no more or less likely to die in hospital than at home when compared to people of White ethnicity. Although, this analysis was based on a smaller sample than available to Koffman and colleagues, this analysis nevertheless included, in its overall sample of 15,374, 300 people from BAME backgrounds who died in hospital and 109 who died at home. However, we did find that people from BAME backgrounds, compared to people of White ethnicity, were less likely (at the 99 per

cent significance level) to die in a care home rather than hospital (OR 0.57). The reasons for this are not clear, although we know also from our analyses, discussed in the previous chapter, that people from BAME backgrounds report poorer quality of care in care homes. These analyses controlled for age, sex, diagnosis, whether the decedent had a spouse or partner and area deprivation.

## Living in a care home

The National Audit Office (2008), found that the proportion of care home residents who died in hospital varied considerably between different homes, ranging from none to all residents. While these figures did not control for differences in the age of residents or their diagnoses, these findings could suggest that care homes had variable policies as well as variable capacity to care for people at the end of life. It is possible that some care homes were admitting residents to hospital unnecessarily, and that, with appropriate support, many residents could have died in the care home. In other evidence, it was found that, of 93 care home residents dying in an English hospital over six months, as many as 40 per cent died within 24 hours of admission (Ong et al., 2011). Authors such as Kinley et al. (2014) and Sleeman et al. (2014) point to the need to ensure that increased use of care homes as a chosen place of dying is adequately supported by community-based palliative care services.

## Geography

Where people die varies considerably from area to area. For example, death in usual place of residence was found to vary in England from around 27 per cent to around 57 per cent across CCGs, and from around 38 per cent to around 52 per cent across NHS Local Area Teams (PHE, 2013a). Neither death in usual place of residence nor place of death data is available by sub-national geographies, in Wales, Northern Ireland or Scotland. However, in Scotland, we do know that 'the percentage of the last six months of life spent at home or in a community setting' varied across health boards, from between 89 per cent to 93.9 per cent, with this thought to primarily reflect the different use of community hospitals in urban and rural parts of the country.

Area deprivation may be an important underlying factor in geographical variation in place of death. For example, an analysis of ONS mortality data for deaths in England between 2007 and 2009 found that the hospital death rate was highest in the most deprived quintile, with people in these areas being, on average, 29 per cent more likely to die in hospital than those in the least deprived quintile. This relationship remained when looking at different age groups separately (NEoLCIN, 2012). There may be a complex relationship here, with areas with different levels of area deprivation also having different diagnostic profiles. For example, cancer is the most common cause of death in the least deprived areas, accounting for 48 per cent of deaths in the least deprived IMD quintile compared to 29 per cent in the

most deprived IMD quintile. Cardiovascular disease and respiratory disease, however, are more common as a cause of death in the most deprived areas, with around 21 per cent of decedents dying with cardiovascular disease in the most deprived quintile compared to 17 per cent in the least deprived quintile and around 9 per cent of decedents in the most deprived quintile dying of respiratory disease compared to 5 per cent in the least deprived quintile (NEoLCIN, 2012).

However, even after controlling for diagnosis, there appears to be a relationship between area deprivation and place of death. For example, a published analysis of data from the National Survey of Bereaved People in England (ONS, 2013a) found that, after controlling for age, sex and cause of death, those in the least deprived quintile had 48 per cent higher odds of having had enough choice about where they died compared to those in the most deprived quintile. Similarly, Campbell et al. (2010), in a well-controlled study of referrals for people with cancer to a hospice at home service in two areas of Manchester, found that, even though all the patients had the same diagnosis, there were fewer referrals in areas with multiple and income deprivation. The reasons for this were not clear, although the authors hypothesised that people from less deprived areas may be selected for referral because they are considered more likely to be able to manage death at home. In related findings, Murtagh et al. (2012), in a systematic review of literature on place of death for people with non-malignant conditions, found that home deaths are associated with higher household income. They hypothesise that this may be because of a greater ability to manage death at home, for example, by paying for additional care and support or being more able to make one's home a suitable care environment.

New analyses of data from the National Survey of Bereaved People, 2013, confirmed an independent relationship between place of death and area deprivation, with people in the most deprived areas being more likely to die in hospital than at home. Specifically, those living in the most deprived or second most deprived IMD quintiles, compared to those living in the least deprived IMD quintile, were less likely (at the 99 per cent significance level) to die at home rather than in hospital (OR 0.67 and OR 0.82 respectively). These analyses controlled for age, sex, diagnosis, whether the decedent had a spouse or partner and ethnic background. We also found that people from more deprived areas are more likely to die in a hospital than a care home. Specifically, people who live in the most and second most deprived IMD quintile, compared to the least deprived areas, were less likely (at the 99 per cent significance level) to die in a care home rather than in hospital (OR 0.60 and OR 0.77 respectively).

Finally, rurality is also a factor. For example, Audit Scotland (2008), in their review of palliative care services, report that 'Death at home seems more achievable in rural or remote areas where there is no easy option of admitting people to inpatient care, but this can also be construed as lack of choice' (p.36), drawing attention to the fact that place of death in and of itself does not necessarily imply a good quality death.

## **Chapter 8: The costs**

In this chapter, we explore the economic implications of extending the reach of palliative care to those who are currently under-served.

Firstly, in order to better understand the economic case for investment in palliative care services, we consider what is known about the cost-effectiveness of palliative care. We then go on to consider what we know about the possible costs associated with extending palliative care to everyone who would benefit from it but is not currently receiving it. We do not consider the costs associated with addressing other potential inequities discussed in this report because of limitations in the evidence, both concerning the exact nature and extent of inequities and the appropriate measures to address them.

### **Is palliative care cost effective?**

The Economist Intelligence Unit (2010), in a report exploring the quality of end of life care internationally, identifies a range of significant economic challenges that are relevant to the UK and its four constituent countries and nations. These include population ageing, the consequent need for more end-of-life care overall and the challenges of extending palliative care more fully to people with a non-cancer diagnosis, including the increasing number of people with chronic long-term conditions and comorbidities. May et al. (2014a) comment, with reference to the Republic of Ireland but with relevance to the UK, that barriers to investment in palliative care include competition for resources from other, better-established parts of the healthcare sector, challenges in expanding workforce and capacity, and the cross-sectoral nature of palliative care complicating both the delivery and the co-ordination of support for policy. In this challenging context, it is important that decision makers have the best evidence about whether palliative care interventions, overall and also for specific types of intervention or interventions for specific patient groups, are cost-effective so that resources can be allocated effectively (Canadian Hospice Palliative Care Association, 2012; May et al., 2014b).

Cost-effectiveness studies look at the combined costs and outcomes of a course of action, such as employing a palliative care intervention, and compare them with the costs and outcomes of an alternative course of action, generally 'usual care'. Consequently, an intervention can be cost-effective even if it is not cost-saving if the difference in costs is viewed as justifiable because of the difference in outcomes. Palliative care aims to improve quality of life and reduce distress. It is also commonly considered to have the potential to reduce acute care costs near end of life, by reducing unnecessary hospital admissions and acute interventions. Such savings may help to offset the costs of further investment in palliative care services (NAO, 2008; The Economist Intelligence Unit, 2010). Although there is a potentially strong economic case for investment in palliative care, the application of

economic evaluation to palliative care has been slow to develop (Smith et al. 2014; Haycox, 2009).

One important reason for this is lack of useful cost data. SCIE (2013), in their briefing on integrated care to support dying at home, state that ‘the NHS should have a better evidence-based understanding of the relative costs of specialist and generalist care at the end of life, analysed according to place of care delivery’ (p.5). Similarly, the National Audit Office (2008) refers to a ‘lack of robust data on the cost of delivering end of life care to people with conditions other than cancer’. In another example, Cassel (2013) compares the availability of cost data for palliative care services in England with that in Canada and the US, describing the situation in England particularly as ‘stark’. He describes being in England as a US Fulbright Scholar in 2012 and says, ‘while there was much interest in the idea of demonstrating this secondary outcome of better care, I could not find any hospital or commissioning body that had the cost data necessary to prove that specialist palliative care reduces costs for providers (e.g. hospitals) and/or purchasers or funders of healthcare (e.g. commissioning bodies, governments, or insurers)’ (p.103). Hughes-Hallett et al. (2011), in the Palliative Care Funding Review for England, similarly state that ‘There is a stunning lack of good data surrounding costs for palliative care in England’ (p.9). In the same vein, Audit Scotland (2008) report that, ‘NHS boards do not have specific funding to deliver general palliative care and the cost of general palliative care is not collected at a local or national level’ (p.24). This lack of cost data has implications, as we have already implied, not just for effective evaluation, but also for ensuring the most effective and cost-effective investment in palliative care services (Gomes et al., 2009). The National Audit Office, in an analysis of the potential savings associated with reducing reliance on acute care at end of life, states that ‘better data on the cost-effectiveness of interventions are required’ (McBride et al., 2011). In England, attempts are currently being made to address some of these barriers through work to develop a palliative care tariff (NHS England, 2014).

Where economic research is conducted, we find that studies often exhibit a range of methodological limitations or are relatively narrow in their perspective. Costs are generally assessed from the provider perspective, most usually focussed exclusively on acute care costs, while wider health and social care system costs, as well as costs borne by patients and carers are typically not included (SCIE, 2013). Quality of life outcomes are often not measured. A further problem is that palliative care is not consistently defined and, in practice, can include a wide range of different interventions, aimed at different patient populations and delivered across different settings (Hendry et al., 2011). For example, in one literature review of the evidence on hospice at home services, Stosz (2008) found that a wide range of terms were used in the literature to refer to such services (or to key elements of such services), including, for example, palliative home care, out-of-hours palliative care, hospital at home, home care, community palliative care, specialist palliative care, rapid response teams and crisis intervention. The lack of standard service definitions and terminology makes comparisons across interventions challenging and makes it hard to

interpret the literature on the economics of palliative care. Finally, much of the economic literature on palliative care is from the US, with few studies conducted in the UK and its four constituent countries and nations; this is a challenge as economic evidence does not always transfer easily from one country or healthcare system to another.

A number of systematic reviews have been undertaken to better understand the evidence on costs and cost-effectiveness in palliative care. In a recent Cochrane review, Gomes et al. (2013a) assessed the effectiveness and cost-effectiveness of home palliative care services, primarily for people with advanced cancer but also a range of other conditions such as CHF, COPD, acquired immunodeficiency syndrome (AIDS) and multiple sclerosis (MS). This review identified six studies that reported on cost-effectiveness, just one of which was UK-based (Higginson et al., 2009), and reached the view that the evidence on cost-effectiveness was inconclusive. In fact, in all of the studies the intervention was less costly, between 18 per cent and 36 per cent less costly. However, because studies tended to be under-powered (with insufficient sample sizes), the majority of these results failed to be statistically significant. However, based on a meta-analysis, the review did find that receiving home palliative care services more than doubled the odds of dying at home and also that there was strong evidence of reduced symptom burden.

In another recent literature review of international evidence on the costs and cost-effectiveness of palliative care, Smith et al. (2014), considered studies conducted in all settings and deliberately included studies of moderate as well as high quality. They identify 46 relevant studies in their review, two of which are from the UK (Higginson et al., 2009; Douglas et al., 2003). Each of these studies examines the economic implications of a palliative care intervention against a comparator. Only one cost-effectiveness study is identified (Higginson et al., 2009), with the remainder being cost and/or utilisation studies. While the quality of the studies is described as mixed, five of the studies are randomised controlled trials and many of the included cohort studies were considered to have taken reasonable steps to control for potential confounding variables and selection bias. Across the 46 studies, palliative care is most frequently found to be less costly relative to comparators and, in most cases, this difference is found to be statistically significant. Looking just at the randomised controlled trials (RCTs), costs for the palliative care intervention were found to be significantly lower than costs for the comparator in two cases (Gade et al., 2008; Brumley et al., 2007), while differences in the remaining studies were statistically non-significant (which may possibly be because of inadequate sample sizes, a perennial problem in health economic evaluations). The study by Gade et al. focused on an in-patient palliative care team while the study by Brumley et al. focused on a home-based palliative care initiative.

The one UK-based study included in both literature reviews described above is a cost-effectiveness study of a palliative care service in south London for people with multiple sclerosis (Higginson et al., 2009). This study found that total costs of care, including acute

inpatient, ambulatory, other social and community care, and informal care costs were (in 2005 prices) £1,789 lower for the palliative care intervention group than a control group over a 12-week follow-up period. When excluding acute inpatient and informal care from the analysis, mean service costs were £1,195 lower. However, neither of these differences in costs was found to be statistically significant. The second UK-based study in the Smith et al. review looked at palliative day care services and its findings were inconclusive (Douglas et al., 2003).

In another, but less recent, review using Cochrane Review methods, Zimmerman et al. (2008) identified seven randomised controlled trials that assessed the costs associated with specialized palliative care and found that only one US study (Brumley et al., 2007) reported significant cost savings. The only UK study amongst the seven randomised controlled trials found no significant difference in overall costs of care, compared to standard care, for a nurse-led palliative care intervention for people with lung cancer who had completed initial treatment and were expected to survive for at least three months (Moore et al., 2002).

There have been other literature reviews of economic evidence. One that is relevant to the development of UK policy is a technical report on the effects of palliative care on resource utilisation conducted by Hatziandreu et al. (2008), working alongside the National Audit Office, which was undertaken specifically to inform national strategies on end of life care. The authors identified four UK-based studies, three of which were randomised controlled trials (Addington-Hall et al., 1992; Raftery et al., 1996; Grande et al., 2000; Guest et al., 1998). Overall, based on the UK and international literature, Hatziandreu et al. estimated that costs for palliative care patients during the last year of life were, on average, around 30 per cent lower than for other patients. However, the authors acknowledged that this estimate was not based on a formal meta-analysis, and differences in methodologies, context and healthcare system-specific factors were not fully accounted for. The authors also highlighted that, while palliative care was generally associated with savings in acute care costs regardless of condition, the greatest savings were associated with palliative care for people with cancer with, they suggested, this being because palliative care for non-cancer conditions can involve longer periods of care.

Two further reviews, based primarily on US evidence, specifically considered hospital-based, specialist palliative care. In a systematic review of international evidence on the costs of treating people with terminal illness, based on six US-based studies and one study from Hong Kong, Simoens et al. (2010) found that palliative care delivered by trained palliative care staff was less costly than the care delivered by generalist or other specialist hospital staff. In another systematic review, May et al. (2014b) considered the economic evidence on specialist palliative care consultation teams, primarily based on studies from the US, and concluded that specialist palliative care consultation teams were associated with cost-savings as well as improvements in the care of those with serious illness. Given the



different healthcare system in the US, it is not clear how generalisable these findings are to any of the constituent countries and nations of the UK.

There have been a number of economic evaluations of UK initiatives. These vary in quality and comprehensiveness but four key UK-based evaluations include an evaluation of the Marie Curie nursing service (Chitnis et al., 2012), an estimate of the relative cost of the Marie Curie Nursing Service (MCNS) to usual care, building on the Chitnis et al. evaluation (Georghiou and Bardsley, 2014), an evaluation of the Marie Curie Delivering Choice programme (Addicott and Dewar, 2008) and an evaluation of the Midhurst Macmillan Specialist Palliative Care Service (Thiel et al., 2012).

The MCNS is a community-based palliative nursing service, which we described in Chapter 5. Chitnis et al. (2012), found that the total hospital costs for people receiving the MCNS, from first contact until death, were £1,140 per person less than for people in a matched control group. These acute care savings were achieved through reduced hospitalisation. The authors acknowledge that, given this was not a randomised study, there was the possibility of selection bias, with MCNS potentially accessed by those who were more able to, and wished to, die at home.

The above study did not include the cost of the MCNS itself and wider impacts on other services. These were explored in a further study by Georghiou and Bardsley (2014), which identified, over the last three months of life, the average cost of the MCNS to be £581 per person, and estimated that the impact on demand for other services to average £10 for primary care, £41 for district nursing and £21 for social care. Georghiou and Bardsley conclude, using conservative estimates, that a person receiving a palliative care nursing service such as MCNS would have lower total care costs than a similar individual in receipt of usual end-of-life care, with average potential savings of around £487 per person over the last three months of life.

The Marie Curie Delivering Choice programme in Lincolnshire, involving a rapid response team and discharge community link nurses to help people who want to be cared for and die at home, was evaluated by Addicott and Dewar (2008). They compared the average overall costs, across both acute and community services, and found no significant cost difference between those using the programme (£5,401) and those in a control group (£5,324). However, the Delivering Choice programme significantly increased the likelihood of dying at home and decreased the proportion of deaths in hospital.

The Midhurst Macmillan Specialist Palliative Care Service, managed by the Sussex Community NHS Trust, is a programme involving early referral and consisting of a multidisciplinary team of specialist palliative care professionals who link with members of the primary healthcare team, community services, social services, care agencies and voluntary organisations to provide proactive specialist palliative care and support. In an evaluation of the programme, Thiel et al. (2012) concluded that the model could, if

reproduced elsewhere, potentially reduce the total cost of care in the last year of life by around 20 per cent.

In summary, then, evidence on the costs and cost-effectiveness of palliative care is hindered by a lack of robust and relevant data on costs and resource use, diversity in the type of services evaluated and lack of consistent service definitions and terminology. There is a particular shortage of evidence in the UK. In this context, existing evidence about whether palliative care interventions are cost-effective is inconclusive, particularly in reviews using the most robust methods (Gomes et al., 2013a; Zimmerman et al., 2008). However, there is promising evidence from well-designed studies of acute care savings, which cover palliative care interventions delivered in all settings and for both people with cancer and non-cancer diagnoses. There is some promising evidence that a palliative approach may be less costly, while at worst, it seems likely that it has the potential to improve outcomes for people with advanced illness or at end of life and their families for little or no more cost.

### **The costs of extending care to those currently not receiving it**

Hughes-Hallett et al. (2011), in the Palliative Care Funding Review for England, estimated the costs associated with extending 'specialist and core' palliative care services to those who would benefit from, but are not currently in receipt of, such services. These services are those that they propose be included in an NHS tariff for palliative care and cover specialist palliative care dedicated in-patient beds, community specialist palliative care, hospice at home services, hospital palliative care support teams, outpatient specialist palliative care review, core palliative care services such as Marie Curie nursing and other dedicated provision, social care specifically related to palliative care and short-term bereavement support (Hughes-Hallett et al., 2011, Annex 6). Using unit costs gathered from pilot sites and activity data from the Minimum Dataset for Specialist Palliative Care Services, the authors of the funding review estimated that it would cost just over £144 million to extend these services to two-thirds of those in need of palliative care but currently not receiving any (on the assumption that the remainder would receive sufficient support from universal or generalist provision alone). This equates to around £2,400 per person. Applying similar cost assumptions in Wales, Northern Ireland and Scotland suggests that, in these countries, it could cost around £9.8 million, £4.6 million and £16.8 million respectively to extend 'specialist and core' palliative care to all of those who would benefit from it. In line with the findings from the economic evaluations described in the preceding section, Hughes-Hallett et al. (2011) argue that these costs can be largely offset by savings associated with fewer people dying avoidably in hospital. They estimate these savings based on the Whole Systems Partnership cohort model, established by the National End of Life Care Programme to support local areas to implement the National End of Life Strategy in England. Assuming improved recognition of palliative care needs as well as optimized provision of services outside of the hospital setting, they estimate that deaths in hospital

could be reduced in England by up to 60,000 a year by 2021. Using the Quality Innovation Productivity and Prevention programme (QIPP) estimate of £3,000 per hospital death, they calculate that this would lead to a potential reduction in hospital costs of £180 million per annum (in 2011 prices). Although this projection is not made for the other UK countries, proportionately we might expect savings in hospital costs of around £12.2 million in Wales, £5.8 million in Northern Ireland and £21 million in Scotland. Hughes-Hallett et al. (2011) state that their figures cover only the costs of the 'specialist and core' palliative care that they propose be included in a palliative care tariff, acknowledging that 'the potential cost saving indicated does not take account of the resources required to provide support to the people who have been shifted to the community.' However, the study by Georghiou and Bardsley (2014), discussed earlier, suggests that difference in these costs between those in receipt and not in receipt of specialist palliative care are unlikely to be substantial.

There is a range of available national cost estimates for an episode ending in death in the community. The report, *Reviewing End of Life Care Costing Information to Inform the QIPP End of Life Care Workstream* (NHS NEOF, 2012a), identifies estimates ranging from £1,200 to £2,800, while the NHS National End of Life Care Information Network (NHS NEOFICIN 2012a) identifies estimates ranging from £1,415 to £2,800, and suggests use of a mid-point figure of £2,107, noting also that there may be a need for additional investment to adequately reflect the potential pump-priming costs likely to be involved in delivering significantly increased levels, and potentially different types, of community-based care. For inpatient costs of an admission ending in death this report proposes a figure of £3,065, arriving at an estimated £958 savings for each death that occurs in the community rather than in hospital. While this figure contains the full estimated costs of community-based healthcare, it only covers the costs for an episode ending in death, roughly the last week of life, whereas the cost estimates in the Palliative Care Funding Review cover the full period over which palliative care is provided. This means we cannot readily combine or compare these figures. However, if we use the potential savings of avoiding a hospital death recommended by the National End of Life Information Network (NHS NEOF, 2012a) of £958 and multiply this by the 60,000 people in England that Hughes-Hallett et al. think could be cared for and die in the community rather than hospital by 2021, this results in an overall savings figure of £57.5 million (in 2012 prices). By extension, this figure would be roughly £3.9 million in Wales, £1.8 million in Northern Ireland and £6.7 million in Scotland. These different estimates provide support to the view that the costs of providing palliative care to those who would benefit from it are likely to be offset, possibly completely, by savings associated with fewer people dying avoidably in hospital.

Furthermore, the cost savings discussed here include only those potential savings associated with fewer people dying avoidably in hospital and not potential cost savings associated with a reduction in emergency hospital admissions (not ending in death) in, say, the last year of life, so these savings estimates may, in any case, be conservative. However, there are also a number of further costs that are not fully accounted for. One of these is the cost of social

care. Hughes-Hallett et al. propose that social care is provided free to people who are eligible on the basis of need but who otherwise would self-fund their social care. However, the costs of this additional care could not be readily calculated and no overall estimate is provided within their report. However, Georghiou and Bardsley (2014), in their analysis of care costs at the end of life, found that those receiving palliative care from Marie Curie nurses incurred very modest additional social care costs compared to those not receiving Marie Curie nurse services, at £21 extra per person over the last three months of life.

The estimates discussed also take no account of the costs of informal (unpaid) care, direct out-of-pocket expenses or indirect financial costs borne by patients and carers. We know that informal care is a significant part of the costs of care for people in advanced illness or at the end of life. McCrone (2009), for example, in a study of costs incurred during the last six-months of life, shows that informal care costs are often considerably higher than formal care costs. Gardiner et al. (2013a), in a systematic review of the literature on the financial impact of caring for family members receiving palliative and end of life care, identify 17 relevant studies that variously report direct and indirect financial costs associated with caregiving and multidimensional caregiver burden (such as delaying studies or medical treatment). In Northern Ireland, in a survey of people registering a cancer death during a five-month period, Fitzgerald et al. (2013) report that 89 per cent of respondents cared for the patient, 17 per cent without any help from other family or friends. Of those that were working, 68 per cent had to stop work or reduce their hours in order to care. While palliative outcomes were better at home, family members and carers experienced higher levels of anxiety. A number of authors also highlight the safety and health issues of caring for someone at end of life at home and the emotional challenges of supporting a loved one at home as they die (Johnston, 2014; Reyniers et al., 2014). Given these potentially significant economic impacts, various authors have raised concerns about the shift to caring for people at the end of life in the community, with this having the potential to transfer costs onto family carers, and potentially also voluntary community service providers, and for this to go unmeasured in economic evaluations (Gott, 2014; SCIE, 2013; Newman, 2013; Smith et al., 2014; Gomes et al., 2009). On the other hand, studies have also identified psycho-social benefits for carers associated with patients avoiding unnecessary hospitalisation and aggressive care at end of life which should also be factored into economic evaluations (Detering et al., 2010; Wright et al., 2008). However, currently, appropriate cost estimates for measuring the economic impact of increased informal care associated with reducing death in hospital are not available. A further challenge in estimating carers' costs also include the fact that distinguishing carers of people at the end of life from carers in general is difficult, because it can be hard to define when an individual is at the end of life (Addicott and Hiley, 2011).

Finally, palliative care aims primarily at quality benefits including reduced distress and suffering, quality of life in the last months and days of life and 'a good death', as well as reducing carer stress and burden. These benefits are not included in the cost and savings

estimates discussed in this chapter. In economic evaluations, it is increasingly common also to use a health-related quality of life measure that can generate estimates of quality-adjusted life years (QALY) (Petrou and Gray, 2011; Gold, 1996; NICE, 2013) allowing comparisons across different clinical areas. However, there are questions about whether QALYs are the appropriate measure for end of life care given the limited anticipated survival benefit from interventions, the inappropriateness of death as an anchor for valuing health states, and the possibility that either quality of life or additional time (with views differing around which is more likely) is valued more highly at the end of life (Zimmerman et al., 2008; Yang and Mahon, 2011). An alternative framework, the Palliative Care Yardstick (or PaLY) has been proposed to replace the QALY (Normand, 2009; Round, 2012; Hughes, 2005; Gomes et al., 2009), although there remains a lack of agreement about the most appropriate measure.

In conclusion, then, the different estimates of the costs and potential savings associated with extending the reach of palliative care that exist are based on varying assumptions. They include and exclude different costs, cover different time periods and cannot be simply brought together or compared. However, these different estimates tend to be in line with the findings of the economic studies discussed earlier. Hence, palliative care services are associated with total healthcare costs at end of life that are thought to be lower or, at worst, similar to those associated with usual care, but with improved outcomes such as a higher likelihood of death in preferred place and better symptom management. Additional support for informal (unpaid) carers, however, is not included in the available estimates, although it is certain that the shifting of care into the community associated with extending palliative care services will place extra demands and costs on carers.

## **Chapter 9: Discussion and conclusions**

It is outside the scope of this review to make any detailed or developed proposals. However, we aim in this chapter to explore the implications of the evidence presented in previous chapters, highlighting issues for further consideration and making a number of broad recommendations.

Some of the areas touched on in this report concern significant strategic challenges in the delivery of high quality end of life care, covering areas such as multi-disciplinary working, service coordination, the interface between generalist and specialist services, investment in community-based services and standards of care in hospitals and care homes. In this short study, we have not been able to give consideration to how these challenges should be addressed, although it is clear that doing so is vital to ensuring the consistent and equitable delivery of palliative and end of life care.

Given the breadth of evidence discussed in this report, the issues highlighted for further consideration and the recommendations set out in this chapter may not be exhaustive. However, they are those that appear to us to be the key issues requiring a response. Although, where available, we draw recommendations and suggestions from the literature, we also base suggestions on own interpretations of the evidence. These are supported, in some cases, by further by evidence and examples, which are intended to be illustrative, rather than to represent an exhaustive exploration of relevant evidence.

We begin by considering the limitations of our review and then go on to discuss the current state of the evidence base and data, and to reflect on research and data needs for the future. We then revisit some of the key findings from the review and draw out implications for policy and practice.

In this way we hope that our review may provide a useful framework for considering equity in the provision of palliative care.

### **Strengths and limitations of our review**

The review we undertook was a rapid, rather than systematic review, covering a wide-ranging literature. It cannot, therefore, claim to be definitive. However, we adopted a rigorous approach, using multiple and widely applied strategies for identifying relevant literature, and we drew upon existing systematic reviews and high quality evidence reviews where these existed. In this way, we believe that our review is wide-ranging and comprehensive and that we have identified all the main sources of evidence.

A further limitation of our review is that available research evidence and data are limited in scope and often subject to a range of methodological limitations. These limitations are

discussed in more detail in the next section. However, in order to help address some of these limitations and gaps we additionally undertook new multivariate analyses of the National Survey of Bereaved People, 2013. This dataset is not publicly available. Consequently, these analyses were specified by the review team and undertaken by staff from ONS under our direction. Although, the survey is only conducted in England, the data is recent and based on a large and representative sample of 22,661 informants, representing a response rate of 45.7 per cent. Non-response is associated with the deceased being male, younger, dying at home or in a hospital (rather than a care home), living in a more deprived area and being from a BAME background. Non-response weights (calculated by ONS) were used to minimise the impact of these biases. The survey covers a restricted range of variables, being limited by what data could reasonably be obtained in a large-scale postal survey from the person who registered the death, usually a family member, four to 11 months following the patient's death. Consequently, potentially relevant variables, such as clinical need or functionality, are not included. Nonetheless, a wide range of demographic variables are available in the dataset and our analyses allowed for a fuller exploration of the independent effects of these variables on outcomes than is available in published analyses.

## **Reflecting on the evidence base**

### **The research literature**

There is only a small specific literature addressing equalities or equity issues in palliative care, with other potentially relevant evidence dispersed across a wide range of different studies and reviews. Studies in this area also suffer from a range of common methodological limitations, primarily associated with the limitations of existing data sources and the challenges of conducting primary research with people in advanced illness or at end of life, and with their families. So, for example, studies commonly use retrospective data, such as routinely collected administrative data or medical records. These data sets cover people who have already died, although it is recognised that studies looking at samples of people who have already died may produce very different results from studies based on samples of people who are identified as being likely to die within the next 12 months (Walshe et al., 2009). Potentially important information is also commonly missing from retrospective data, such as attitudes, preferences, beliefs, symptoms, functional status, and the psychological and spiritual concerns of patients. This can make it difficult to distinguish clearly between inequalities, which may well be justified by different needs or preferences, and inequities (Burt, 2012).

Research and data may address only a narrow range of outcomes, focusing on variables that are readily or routinely gathered. For example, while death in usual place of residence remains a key performance indicator, it is not, in and of itself, a measure of a good death. Researchers, therefore, need to engage with a wider set of quality markers, although

identifying and collecting such data is challenging. Where primary research is conducted, randomised controlled studies are rare and controls in non-randomised studies are not always rigorously designed or selected (Luckett et al., 2014). Research in this area is also complicated by the fact that the factors influencing access to, and experiences of, palliative care are multiple, complex and overlapping (Lau and O'Connor, 2012), with few studies employing multivariate analyses in order to effectively identify the independent effects of different factors on outcomes. This can give rise to contradictory and difficult to interpret results. Much of the research literature is also largely descriptive, with causal mechanisms rarely being explored or understood (Walshe et al., 2009). Some of the existing research is also compromised by not being conducted recently and being of moderate or low methodological quality.

Notwithstanding these many limitations, we found a number of high quality studies and systematic and other evidence reviews, including a Cochrane review, although some areas of research are better served with rigorous research than others. For example, there is good evidence on the effectiveness of specialist home-based palliative care services and there has been a fair amount of research conducted on the needs of people with non-cancer diagnoses, although the research needed to develop organisational models of care to better address these needs is still largely lacking (Murtagh et al., 2012; Epiphaniou et al., 2014). With regard to coverage, we also identified a lack of outcome-based studies specific to Wales and Northern Ireland, reflecting their smaller population sizes and research capacity. McIlfatrick et al. (2013), in their review of palliative care research in Northern Ireland, state that, 'whilst there has been a welcome growth in palliative care research across Ireland, this has largely been needs-based and small scale studies. In contrast, international researchers and decision makers recommend the need for more outcomes focused multidisciplinary research'. There is also a lack of relevant research in other key areas, for example, on the contribution of professional social care staff, a role for whom is envisaged in national end of life strategies in all four constituent UK countries (NHS NEoLCP, 2010). Finally, there are also a number of groups that are poorly covered by the literature. These include people in transitional housing, people with mental health problems, people with pre-existing disabilities, people with intellectual disabilities, people living in institutions such as prisons and long-stay hospitals, traveller communities, homeless people and people who identify as lesbian, gay, bisexual or transgender.

### **National data**

The efforts of the National End of Life Care Intelligence Network (NEoLCIN) in England, now part of Public Health England (PHE), have led to a range of improvements in national-level data, including reports, guides to data sources, indicator sets and analyses on end of life care in England. These also include the establishment of the annually conducted National Survey of Bereaved People in England. This is a rich, and potentially evolving, source of



representative data on access to, and experiences of, end of life and palliative care. In our review, it contributed a considerable amount of the available evidence. Unfortunately, no similar survey is currently conducted in Wales, Northern Ireland or Scotland, and so there are consequently gaps in evidence. Jones and Wynne (2014) make a detailed case for extending the survey to Wales and estimate the cost of doing so to be approximately £13,000 annually, with some further costs envisaged for producing the survey in Welsh and if sample sizes needed to be large enough to produce statistically valid results at Health Board level. In Scotland, there was a smaller-scale survey of bereaved relatives conducted in 2007, with topic coverage similar to the survey in England (Audit Scotland, 2008). In common with the survey for England, this was also based on the Views of Informal Carers Experiences of Services (VOICES) approach (Addington-Hall, 1998). It was carried out as part of Audit Scotland's Review of palliative care services in Scotland and covered 997 bereaved relatives in NHS Greater Glasgow and Clyde, NHS Highland, NHS Borders and NHS Fife. No similar study in Scotland has been undertaken since. We are also unaware of any similar survey undertaken in Wales or Northern Ireland. Extending the survey to Wales, Northern Ireland and Scotland would, based on Jones and Wynne's (2014) calculations for Wales, be possible for a relatively low cost and would allow a country-specific perspective on experiences of palliative care as well as inter-country comparisons.

It is also important that the National Survey of Bereaved People in England is fully analysed and continues to be developed and refined methodologically. For example, the new multivariate analyses undertaken specifically for this review identify a strong relationship between having a spouse or partner (using the proxy of a spouse or partner being the person that registered the death and consequently also the survey respondent) and a range of better outcomes. This raises questions about why this relationship exists, which should be further explored. In some cases, such as greater receipt of community-based services, the mechanisms are clear. In this case, it is likely that people with spouses and partners who are prepared to provide informal care are those most able to be cared for and die at home. However, in other cases, such as rating overall quality of care more highly or reporting better pain relief, the mechanisms are less clear. The possibilities include spouses and partners acting as advocates and informal coordinators of care, as well as direct care providers, for example, by administering medications. However, there may also be response effects, with spouses and partners potentially being more likely, perhaps for emotional reasons, to rate the quality of care more highly or consider pain to be better controlled, when compared to other respondents. Currently, there are also no questions in the National Survey of Bereaved People for England, other than for the last two days of life, about the management of symptoms other than pain. Breathlessness, for example, is a common and often severe symptom for a range of non-cancer diagnoses. By focusing solely on pain control, therefore, the survey may exclude measurement of important outcomes for people with non-cancer diagnoses. It may also be useful to measure symptoms such as anxiety and

depression, thereby reflecting the level of emotional and psychological distress experienced by patients.

There is also the Minimum Dataset for Specialist Palliative Care Services, reporting at the level of regional strategic clinical networks in England, as well as at the national level for England, Wales and Northern Ireland. This data is collected from a wide range of specialist providers. The response rate is 66 per cent, although this varies between areas, with the response rate being just 33 per cent in Northern England, for example. Returns, however, commonly contain missing data, with particularly high levels of missing data for the exact diagnoses for people with non-cancer conditions and for ethnic background. However, despite these limitations, the dataset is hugely valuable in mapping the provision of specialist services and understanding who accesses these services, and has been useful in monitoring trends such as increasing access for people with non-cancer diagnoses. Although some data on specialist palliative care services across Scotland was collected by Audit Scotland in 2007, this study has not been repeated and there is currently no parallel dataset to the Minimum Dataset for Specialist Palliative Care Services in Scotland.

Across England, Wales, Northern Ireland and Scotland, there is a lack of data on generalist palliative care, despite this being at the heart of evolving policy on end of life care, and a lack of robust cost and activity data, although this is being addressed with ongoing work on the prospective palliative care tariff (NHS England, 2014). Available data on social care for people at end of life is also currently poor. The National End of Life Information Network made a range of recommendations to inform the development of the Adult Social Care Dataset in England, including the introduction of measures to highlight and monitor the contribution of social care staff to end of life care and to include relatives or carers of people who have died or are too frail to participate as respondents in the Adult Social Care Survey, in order to capture the experiences of people with advanced illness or at the end of life (NEoLCIN/NHS National EoL Care Programme, 2012). In England, PHE and NHS England are continuing to work together to develop improved national data for end of life care. It is important that this includes key data for effective monitoring of equity in the provision of services, and also, more generally, that the momentum achieved by National End of Life Care Information Network is sustained.

## **Themes and issues from the review**

This report has focused on evidence on inequities in palliative care provision. Inevitably, therefore, this has involved a focus on poor care, gaps in care and ongoing challenges. It is important that we recognise that many people receive good quality palliative and end of life care. The National Survey of Bereaved People in England, 2013, for example, found that 13 per cent of respondents thought the overall quality of care received during the last three months of life was 'outstanding', 30 per cent thought it was 'excellent' and a further 33 per cent thought it was at least 'good'.

However, the findings of our review suggest that, despite a wide range of improvements in end of life and palliative care following the publication, in all four UK countries, of national end of life care strategies and their associated programmes, there still remain a range of inequities in provision. These have been discussed in detail throughout this report. In the rest of this chapter, we briefly summarise and discuss the implications of some of the main areas of unequal or inequitable provision identified by our review and, where relevant, highlight considerations and recommendations for addressing these.

### **Addressing unmet need**

A fundamental aspect of inequity identified in this review is overall under-provision of palliative care, with a substantial number of people who would benefit from it thought not to be receiving any palliative care at all. Evidence suggests that others may experience poor quality or poorly coordinated care. There are also specific examples of under-resourcing identified. There is under-provision, against national recommendations, of palliative care teams in a majority of hospitals. There is a need for investment, organisational development and capacity-building in community-based services, particularly in services for people with non-cancer conditions. There is also evidence of insufficient specialist external healthcare support to care home residents. Extending high-quality palliative care services to everyone who can benefit is a central principle in the end of life care strategies in all four UK countries, and addressing current gaps will require additional investment. However, there is consistent evidence suggesting that extending access to palliative care is likely, on balance, to be cost-effective, reducing demand for acute and emergency care and delivering better outcomes for patients and their families.

### **Measuring and monitoring palliative care need**

There is currently very poor data availability on palliative care need. This means that overall estimates of need necessarily rely on broad assumptions. In the Palliative Care Funding Review for England, Hughes-Hallett et al. (2011) estimate that 92,000 people are not receiving the palliative care from which they could benefit. However, the number could be higher or lower, with Hughes-Hallett proposing that it could be anywhere between 46,000 and 138,000 people. The main reason for this imprecision is that data on generalist provision is completely lacking. We also know that, even for those receiving generalist palliative care, there is evidence of poorly coordinated care and gaps in provision. However, we do not know how many people this affects. The evidence also suggests that there are unclear and variable local resourcing decisions, unrelated to assessments of local need, and variability in the extent and type of specialist services available locally. It is important to develop improved data and estimates of need, nationally in England, Wales, Northern Ireland and Scotland, and locally, and to be able to monitor how these needs are being met

in practice.

### **Addressing confusion about roles and responsibilities**

There are many strategic organisational barriers to be addressed. These include poor service coordination and integration and lack of clarity about professional roles and responsibilities. These problems particularly affect people with non-cancer diagnoses, who are less likely to receive the specialist support associated with a cancer diagnosis, and those without a co-resident carer who is able and willing to act as an advocate or informal coordinator of care. Problems of poor coordination and confusion about roles and responsibilities include confusion about the role of the geriatrician in providing palliative and end of life care, the respective roles of care home staff and external health care providers in caring for people living in care homes, the respective roles of different primary care staff such as GPs and nurses and the interface between generalist and specialist providers, in both primary and secondary care settings. Improving clarity about respective roles and responsibilities, and ensuring these are appropriately funded, is important. Other important initiatives that require further development include locality registers, and Electronic Palliative Care Coordination Systems (EPACCS) in England and Wales and Key Information Systems (KIS) in Northern Ireland and Scotland. There is also a need to explore and evaluate alternative organisational models of generalist provision, including developing a better evidence base for existing models of delivering generalist care, such as the Gold Standards Framework or existing approaches to advance care planning, as well as supporting the development and evaluation of new and emerging models of provision.

### **Improving communication with patients and families**

There is evidence of poor communication between clinicians, in both primary and secondary care settings, and patients and families. This includes failing to initiate discussion about prognosis or end of life care and, in the late stages of illness, failing to initiate conversations about medical interventions such as clinically assisted hydration and nutrition, or informing patients and their families when patients are in the last days and hours of life. Although the need for training in communication skills is commonly referred to in the literature, the contribution of factors such as time and resource pressures, unclear roles and responsibilities, attitudinal barriers, models for referral and forward care, the role of advance care planning, poor multi-disciplinary working and possible perverse organisational or professional incentives remain under-explored.

### **Meeting the needs of people with non-cancer conditions**

There is a need to develop new models of care to address the palliative care needs of people with non-cancer diagnoses. Delivering this care cost-effectively is challenging, given

the potentially longer periods of palliative care needed and the unpredictable disease trajectories associated with most non-cancer diagnoses. There are approaches discussed in the literature for managing these challenges. For example, Stotz (2008) proposes introducing specialist round-the-clock support services that are able to respond quickly to emergencies, rather than a full palliative care service. Zheng et al. (2013) propose a gradual and anticipatory approach, noting that this may anyway be more acceptable to patients, family members and professional carers than the sudden introduction of a palliative approach. Other authors have proposed setting clearer care goals and discharging once these goals are reached (Field and Addington-Hall, 1999; Fisher, 2006).

Timely referral to palliative care services is shown to reduce the use of acute care and to increase death in usual place of residence (Hui et al., 2014; Stosz, 2008; Grande et al., 1999; Grande et al., 2000). For people with non-cancer diagnoses, this may require combining palliative care concurrently with disease-modifying treatments. Gibbins et al. (2009) argue that, instead of asking healthcare professionals to make accurate prognoses or to diagnose dying, an environment needs to be created where teams feel comfortable in actively managing patients alongside consideration of symptom control and planning for possible end-of-life care. To promote this, the literature often calls for the better integration of palliative care specialists and clinical teams, but contains few practical suggestions for how this should be done. The Amber Care Bundle, developed at Guys and St Thomas' Hospital in London, is an approach to managing the care of hospital patients who are being actively treated but are at risk of dying during the next two months. Outcomes from the programme include reduced symptom burden and increased death in usual place of residence, with 70 per cent of those who have died under care of the scheme achieving their preferred place of death. This promising model should be systematically evaluated and developed (Carrow and Higginson, 2013).

Developing models of care for people with dementia also involves very particular challenges, including communication difficulties and concerns about legal and ethical issues. Advance care planning is particularly relevant for people with dementia but also presents various difficulties, such as beginning the process early enough and the challenges of planning for 'a future and unknown self' (Denning et al., 2012). There is a need for practice developments and ongoing evaluation and health economic assessment to ensure the systematic and evidenced development of new models of care for people with non-cancer diagnoses (Gardiner, 2013a; Kinghorn and Coast, 2013). There is also a need for workforce development associated with expanding existing or developing new services. In practice, many specialist skills in symptom management are likely to be transferable across conditions. Specialist training and models of integrated and collaborative working, for example, with nurses with condition-specific expertise, may also help build skills and competence within existing teams (Dharmasena and Forbes, 2001).

### **Improving alternatives where home death is not possible or not preferred**

Although it is generally accepted that everyone should be equally supported to die in their usual place of residence if they want to and can, not everyone will do so. Some groups, such as people aged 80 or over, immigrant BAME groups, people without a spouse or carer, people who live in the most deprived areas and people with non-cancer diagnoses, are more likely to die in hospital than others. There is a need to better understand the reasons for this so that, where appropriate, barriers can be addressed. However, it is also important to ensure high-quality alternative care environments for those unable or preferring not to die in their usual place of residence. Improving standards of end of life care, and access to effective palliative care in hospital is key. Gott (2014) argues that it is important to identify what we value about 'home' and reflect this in how end of life care is provided in hospitals. Other authors have argued that there is a need to develop alternatives to general hospitals for those unable to die at home (Leadbetter and Garber, 2010). Examples in practice, although requiring more development and evaluation, include provision of end of life care in small community hospitals (NHS Evidence: QIPP, 2010) and care delivered to people in dedicated 'bungalows' grouped together with healthcare staff nearby (SCIE, 2013). These and/or similar models of care in 'alternative' settings merit further evaluation and development.

### **Better identification of palliative care needs**

Our review identifies the potential for clinicians to under-estimate pain and distress, particularly for older people, and especially those aged 80 or over, people with dementia and those receiving disease-modifying treatments. There is evidence that use of standardised measures of need rather than professional judgement alone can help to improve effective identification and monitoring of palliative care need (Gardiner, 2013; Gott, 2001; Barclay, 2000). For groups where there is evidence of under-recognition of need, there may be advantage in developing more effective approaches of eliciting information about symptoms and need. Clinical tools for identifying pain and distress in people with dementia should be routinely and effectively employed and, where people are identified as being in pain or with other symptomatic burden, they should receive the most appropriate care. Collecting patient-reported data, where patients portably record, in real-time and into health provider pre-generated templates, any symptoms or concerns they are experiencing has also been proposed as a method of improving the identification of palliative care need (Trotti et al., 2007).

### **Improving non-clinical palliative care**

In the literature covered by our study, palliative care tends to be conceived of in narrow medical terms, even though healthcare inequities are often grounded in wider social

inequalities Gott (2014). We found little evidence on the role of professional social care staff in addressing inequities, although a role for them in end of life care is clearly recognised in each of the national strategies for end of life care and associated programmes in England, Wales, Northern Ireland and Scotland. Social workers and other professional social care staff are experienced at working across health and social care boundaries to help people navigate and access services and address health inequalities. They can also provide practical help and advice on income maintenance, debt counselling and housing, and can provide advocacy and counselling support, both to patients and their families. There is a need to incorporate social work and professional social care into emerging models of care and to fully evaluate this contribution.

### **Ensuring equity in the provision of services for those from BAME groups**

Evidence on inequity in the provision of palliative care for people from BAME backgrounds is equivocal. While they seem to receive similar access to community-based services as people of White ethnicity, more for some services, we do not know about the level of care (for example, the frequency of visits) they receive. They are also less likely to consider care to be of high quality, both overall care in the last three months of life and that received from care homes in particular, even after controlling for factors such as diagnosis, area deprivation and age. The existing literature is comprehensive in mapping the potential barriers to the provision of high quality palliative care to people from BAME backgrounds. The BAME population is much larger in England, and potentially more diverse, than in Wales, Northern Ireland or Scotland, which may result in differences in the barriers or challenges faced.

However, with regard to proposals in the literature for addressing these barriers, Calanzani et al. (2013b) note that there is often no evidence provided that suggested practices are effective or, as they are often based on examples of local initiatives, that they are transferable or generalisable. Similarly, Evans et al. (2012) argue that proposals are often 'reactive and piecemeal'. They also point to frequent recommendations of 'cultural competency' training in the literature, but note there are no evaluations of such training and that it is not clear exactly what such training should involve. There remains a need to understand why people from BAME backgrounds are less likely to experience high quality care in the last three months of life, overall and from care homes in particular. There are significant methodological challenges in researching the needs and experiences of BAME populations, including the lack of available data sources in which ethnic background is consistently recorded, a reliance on small and selective samples, differences between first and later generation BAME groups and the demography of BAME groups being subject to change over time, as well as varying geographically. However, there is a need for renewed attempts to address these methodological weaknesses in future research.

### **Improving outcomes for people living in the most deprived areas**

In new analyses of the National Survey of Bereaved People in England, 2013, it was found that, although people in the most and second most deprived IMD quintiles have similar access to community-based services such as nurses, social workers, hospice at home and rapid response teams when compared to those in the least deprived quintile, they are less likely to feel supported to care for a dying person at home and are more likely to die in hospital. It is important to better understand the reasons for this in order to effectively address barriers. It may be that housing in more deprived areas tends to provide less suitable care environments or that people from more affluent areas are able to pay for additional support that helps them sustain a home death.

However, these outcomes may also reflect differences in wider social support needs that need to be addressed. Alternatively, they may reflect differences in the level or quality of community-based services in more deprived areas. For example, findings from published analyses of the National Survey of Bereaved People in England, 2011, show that people in the most deprived IMD quintile are less likely to consider overall care received in the last three months of life to be 'outstanding' or 'excellent', to be less likely to consider care provided by GPs and care homes to be 'excellent' and to be less likely to feel treated with dignity by nurses and GPs, compared with those in the least deprived quintile (ONS, 2013c). These differences need to be better understood and require an effective policy and/or service response if end of life care is to be delivered equitably and if expectations of reducing increasing death in usual place of residence are to be fulfilled.

### **Making best use of resources**

Finally, as the population ages, there is a need to provide more end of life care and to respond to the challenges of extending palliative care to people with non-cancer diagnoses, chronic long-term conditions and multiple comorbidities. There are also people who would benefit who are currently not receiving any such care, as well as gaps in provision that need to be addressed. This will undoubtedly require investment. It is therefore imperative that resources are allocated efficiently.

Economic evaluation in this area, to inform decision-making about how to best allocate resources, has been slow to develop because of a lack of adequate cost and activity data. In England, work towards developing the palliative care tariff is attempting to address some of these difficulties. However, there is consistent and encouraging evidence in high quality studies and reviews, including a Cochrane review, that palliative care is likely to be cost-effective.

It is not easy to estimate the costs of extending the reach of palliative care to those currently under-served. Estimates of the costs and potential savings associated with extending the reach of palliative care that exist are based on varying assumptions, include



and exclude different costs and cannot be simply brought together or compared. The Palliative Care Funding Review for England (Hughes-Hallett et al., 2011) estimated the costs of extending specialist and dedicated palliative care services to those that would benefit to be around £144 million in England and, proportionately, we might expect these costs to be £9.8 million in Wales, £4.6 million in Northern Ireland and £16.8 million in Scotland. There is likely to also be a need to invest in organisational models of providing generalist palliative care, capacity building and in developing suitable models of care for people with non-cancer conditions. However, these costs are likely to be offset, potentially significantly, by savings associated with reduced need for acute care in the last year of life and reductions in avoidable hospital deaths. These could, based on evidence from our review lead, potentially lead to net savings, potentially of over £30 million in England, £2 million in Wales, £1 million in Northern Ireland and £4 million in Scotland. This investment is also likely to produce improved outcomes such as reduced symptom burden and more people dying in their preferred place.

There is, however, a need to ensure that costs are not shifted to already burdened carers. These include the direct provision of additional informal (unpaid) care, as well as the emotional and psychological burdens of supporting someone to die at home, and carers need to be adequately supported.

## **Appendices**

### **Appendix 1: National Survey of Bereaved People (2013) survey questionnaire**

# **First national VOICES survey of bereaved people: key findings report**

## **Appendix B: Survey questionnaire**

**Appendix B: Copy of questionnaire, reminder letter, information leaflet and reply slips (3 versions)**

Copies of Survey Documentation

Contents

VOICES-SF questionnaire used in this survey, with integral first contact letter

Reminder letter

Information leaflet

Reply Slip used in first mail-out

Reply Slip used in second mail-out

Reply Slip used in final mail-out

[Name]  
[Address Line 1]  
[Address Line 2]  
[Address Line 3]  
[Address Line 4]  
[Address Line 5]  
[Address Line 6]

# VOICES

VIEWS OF INFORMAL CARERS -  
EVALUATION OF SERVICES

Dear [title] [surname]

Invitation to help with the VOICES survey of experiences of care in the last months of life.

If you would like to receive this information in large print please call our Survey Enquiry Line on 0800 298 5313

We are writing to you because you registered the death of [TITLE] [FIRST NAME AND SURNAME OF DECEASED].

We appreciate that this may be a very difficult time but we would like to invite you to take part in the VOICES survey of experiences of care in the last months of life. The results will be used to improve care and services for people and their families at the end of life. The Department of Health is funding this survey which the Office for National Statistics (ONS) is undertaking on their behalf. ONS will not release your personal details to anyone else. Your responses to the survey will be shared with the Department of Health and their approved researchers using only your Study ID Number to ensure that total confidentiality is maintained.

Taking part in the VOICES survey involves completing a questionnaire which asks about experiences in the last months of life, care received from health and social services and whether care needs were fully met. This takes about 30 minutes. If you do not think you are the best person to complete the questionnaire, please pass it on to whoever you feel would be the best person to complete it. If you do not wish to participate you can let us know by completing and returning the reply slip in the pre-paid envelope provided. This will ensure that you do not receive reminder letters.

If you do decide to take part we ask that you complete this questionnaire and return it in the pre-paid envelope to the Office for National Statistics. Alternatively, you can complete the questionnaire online on our secure website at: [www.ons.gov.uk/VOICESonline](http://www.ons.gov.uk/VOICESonline). This facility is available until 31<sup>st</sup> January 2012. After clicking on 'Begin Survey Now', you will be asked to log in using your Study ID Number (see the box at the bottom of the page) and your unique password:

Password: [XXXXXXXXXX]

Your views are important and will help improve future care for patients and families in England. We apologise if this enquiry has caused you any distress and hope this letter does not bring back too many painful memories. We are aware that some local surveys of the bereaved have been undertaken and we apologise if this means you have been approached twice. Thank you for taking the time to read this letter and we very much hope that you feel able to take part in this study.

Yours sincerely



Myer Glickman, Head of Health Analysis, Office for National Statistics

StudyID  
Number

**1** How long had he been ill before he died?

*Tick one only* ✓

- He was not ill - he died suddenly
- Less than 24 hours
- One day or more but less than one week
- One week or more but less than one month
- One month or more but less than six months
- Six months or more but less than one year
- One year or more

If he died suddenly with no illness or time for care, please go to question 37.

Otherwise, please continue with the questions below.

**2** Did he spend any time at home during the last three months of life?

*Tick one only*

- Yes - go to question 3
- No - He was in a care home for the whole 3 months - go to question 12
- No - He was in hospital - go to question 24

## Care at Home

These questions are about care at home - not in a care home

**3** When he was at home in the last three months of life, did he get any help at home from any of the services listed below?

These may be provided by different organisations, such as voluntary organisations, a private agency or social services.

*Tick all that apply*

- A district or community nurse (a nurse in uniform who comes to the house)
- A Macmillan nurse, hospice home care nurse or specialist (a care nurse who visits or telephones to talk and advise on medications and other aspects of care. Not in uniform)
- A Marie Curie nurse (someone who comes to the house for a few hours or overnight to care for the patient)
- Any other nurse at home
- Home care worker, home care aide or home help
- Social worker / support worker
- Counsellor
- Religious leader
- Meals-on-wheels or other home delivered meals
- Hospice at home
- Occupational therapist (OT)
- Rapid response team (team of nurses and home care workers who provide care over the short term to allow someone to remain at home and prevent hospital admission)
- He did not receive any care
- Don't know
- Something else - please write below

**4** When he was at home in the last three months of life, did all these services work well together?

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, they did not work well together
- He did not receive any care
- Don't know

**5** Overall, do you feel that you and your family got as much help and support from health and social services as you needed when caring for him?

*Tick one only*

- Yes, we got as much support as we wanted
- Yes, we got some support but not as much as we wanted
- No, although we tried to get more help
- No, but we did not ask for more help
- We did not need help

**6** During the last three months of his life, while he was at home, how well was his pain relieved?

*Tick one only*

- Does not apply - he did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know

## Urgent Care Provided Out of Hours

**7** In the last three months of life, while he was at home, did he ever need to contact a health professional for something urgent in the evening or at the weekend?

*Tick one only*

- Not at all in the last 3 months - go to question 12
- Once or twice - go to question 8
- Three or four times - go to question 8
- Five times or more - go to question 8
- Don't know - go to question 12

**8** The last time this happened, who did he contact, or who was contacted on his behalf?

*Tick all that apply*

- His GP or the out-of-hours number
- NHS Direct
- District nurses
- Macmillan nurses
- He used his 'lifeline' pendant
- A hospice
- 999
- Something else - please write in the space below

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**9 What happened as a result? Was he...**

*Tick one only*

- Visited by his GP at home
- Visited by another GP at home
- Visited by a nurse at home
- Visited by a hospice doctor at home
- Given medical advice over the phone
- Given another number to ring to get medical advice
- Advised to go to an out-of-hours GP surgery
- Advised to go to the GP surgery when it opened
- Advised to go to an Accident and Emergency Department at a hospital
- Advised to call 999
- Something else - please write below

**10 In your opinion, was this the right thing for them to do?**

*Tick one only*

- Yes
- No
- Not sure

**11 Overall, do you feel that the care he got when he needed care urgently in the evenings or weekends in the last three months of his life was:**

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

## District & Community Nurses

If he had care in the last 3 months from district and community nurses - go to question 12.

If he did not, go to question 15

**12 How often did the district or community nurse visit (at the most frequent time)?**

*Tick one only*

- More than once a day
- Every day
- 2-6 times a week
- Once a week
- 2 - 3 times a month
- Less often
- Don't know

**13 How much of the time was he treated with respect and dignity by the district and community nurses?**

*Tick one only*

- Always
- Most of the time
- Some of the time
- Never
- Don't know

**14 Overall, do you feel that the care he got from the district and community nurses in the last three months of life was:**

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know



## Care from the GP

- 15** In the last three months, how often did he see the GP he preferred to see?

*Tick one only*

- Always or almost always
- A lot of the time
- Some of the time
- Never or almost never
- He didn't try to see a particular GP
- He did not need to see a GP - go to question 20

- 16** How much of the time was he treated with respect and dignity by the GPs?

*Tick one only*

- Always
- Most of the time
- Some of the time
- Never
- Don't know

- 17** Were you able to discuss any worries and fears you may have had about his condition, treatment or tests with the GPs?

*Tick one only*

- I had no worries or fears to discuss
- Yes, I discussed them as much as I wanted
- Yes, I discussed them, but not as much as I wanted
- No, although I tried to discuss them
- No, but I did not try to discuss them

- 18** Overall, if the GP visited him at home in the last three months, how easy or difficult was it to get him / her to visit?

*Tick one only*

- Very easy
- Fairly easy
- Fairly difficult
- Very difficult
- He wanted the GPs to visit but they would not visit
- Does not apply - the GP did not need to visit
- Don't know

- 19** Overall, do you feel that the care he got from the GP in the last three months of life was:

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

Please feel free to make comments in the space below

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# Care Homes

**20** Did he live or stay in a care home at any time during his last three months of life?

*Tick one only*

Yes, he was in a care home - please write the name of the care home in the space below:  
Name:

\_\_\_\_\_

Town:

No - go to question 24

Don't know - go to question 24

**21** How much of the time was he treated with respect and dignity by the staff at the care home?

*Tick one only*

Always

Most of the time

Some of the time

Never

Don't know

**22** During the last three months of his life, while he was in the care home, how well was his pain relieved?

*Tick one only*

Does not apply - he did not have any pain

Completely, all of the time

Completely, some of the time

Partially

Not at all

Don't know

**23** Overall, do you feel that the care he got from the care home in the last three months of his life was:

*Tick one only*

Excellent

Good

Fair

Poor

Don't know

# Last Hospital Admission

**24** Did he stay in hospital at any time during his last three months of life?

*Tick one only*

Yes - please write the name of the last hospital he stayed in below  
Name:

\_\_\_\_\_

Town:

No - go to question 29

Don't know - go to question 29

**25** During his last hospital admission, how much of his time was he treated with respect and dignity by the hospital doctors and nurses?

*Please answer for both doctors and nurses*

Doctors

Nurses

Always

Most of the time

Some of the time

Never

Don't know

**26** During his last hospital admission, how well was his pain relieved?

*Tick one only*

- Does not apply - he did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know

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

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, they did not work well together
- Don't know

**28** Overall, do you feel that the care he got from the staff in the hospital on that admission was:

*Please answer for both doctors and nurses*

- | Doctors                  | Nurses                              |
|--------------------------|-------------------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> Excellent  |
| <input type="checkbox"/> | <input type="checkbox"/> Good       |
| <input type="checkbox"/> | <input type="checkbox"/> Fair       |
| <input type="checkbox"/> | <input type="checkbox"/> Poor       |
| <input type="checkbox"/> | <input type="checkbox"/> Don't know |

## Last Hospice Admission

**29** Did he stay in a hospice at any time during his last three months of life?

*Tick one only*

- Yes - please write the name of the last hospice he stayed in below:  
Name:

\_\_\_\_\_

Town:

- No - go to question 33

- Don't know - go to question 33

**30** How much of the time was he treated with respect and dignity by the hospice doctors and nurses?

*Please answer for both doctors and nurses*

- | Doctors                  | Nurses                                    |
|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> Always           |
| <input type="checkbox"/> | <input type="checkbox"/> Most of the time |
| <input type="checkbox"/> | <input type="checkbox"/> Some of the time |
| <input type="checkbox"/> | <input type="checkbox"/> Never            |
| <input type="checkbox"/> | <input type="checkbox"/> Don't know       |

**31** During the last three months of his life, while he was in the hospice, how well was his pain relieved?

*Tick one only*

- Does not apply - he did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know

**32** Overall, do you feel that the care he got from the staff in the hospice was:

*Tick one only*

- Excellent
- Good
- Fair
- Poor
- Don't know

Please remember to answer the questions by ticking the most appropriate box or boxes like this:



If you make a mistake or wish to change your answer, cross through the answer you do not want.

## Experiences in the last two days of life

**33** During his last two days of life was he:

*Tick one only*

- At home all the time
- In a care home all the time
- In a hospital all the time
- In a hospice all the time
- Other - please write in the space below:  
\_\_\_\_\_

**34** How much of the time was he treated with respect and dignity in the last two days of his life?

*Please answer for both doctors and nurses*

- | Doctors                  | Nurses                                    |
|--------------------------|---|
| <input type="checkbox"/> | <input type="checkbox"/> Always           |
| <input type="checkbox"/> | <input type="checkbox"/> Most of the time |
| <input type="checkbox"/> | <input type="checkbox"/> Some of the time |
| <input type="checkbox"/> | <input type="checkbox"/> Never            |
| <input type="checkbox"/> | <input type="checkbox"/> Don't know       |

**35** Please look at the following statements and tick the answer box that corresponds most with your opinion about the help he received in the last two days of life

*Tick one box for each question (a-c)*

- |   | Strongly Agree           | Agree                    | Neither agree nor disagree | Disagree                 | Strongly disagree        | Does not apply           | Don't know               |
|---|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| (a) There was enough help available to meet his personal care needs (such as toileting needs)                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (b) There was enough help with nursing care, such as giving medicine and helping him find a comfortable position in bed | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (c) The bed area and surrounding environment had adequate privacy for him   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**36** During the last two days, how do you assess the overall level of support given in the following areas from those caring for him?

*Tick one box for each question (a-e)*

	Excellent	Good	Fair	Poor	Does not apply	Don't know
(a) Relief of pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Relief of symptoms other than pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Spiritual support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Emotional support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Support to stay where he wanted to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Circumstances Surrounding His Death

**37** Did he know he was likely to die?

*Tick one only*

- Yes, certainly
- Yes, probably
- Probably not
- No, definitely
- Not sure

**38** In your opinion, did the person who told him he was likely to die break the news to him in a sensitive and caring way?

*Tick one only*

- Yes, definitely
- Yes, to some extent
- No, not at all
- Don't know
- Does not apply - they did not know he was dying
- Does not apply - they did not tell him he was dying

**39** Were you contacted soon enough to give you time to be with him before he died?

*Tick one only*

- Yes
- No
- I was there already
- It was not clear that he was going to die soon
- I couldn't have got there anyway

**40** Where did he die?

*Tick one only*

- In his own home
- In the home of another family member or friend
- In a hospital ward - please write the name of the hospital below  
Name:

Town:

*Continued on page 10*

Please continue with question 40 about 'Where did he die?'

Tick one only

- In a hospital Accident and Emergency Department - please write the name of the hospital below  
Name:

Town:

- In a hospital Intensive Care Unit - please write the name of the hospital below  
Name:

Town:

- In a hospice - please write the name of the hospice below  
Name:

Town:

- In a care home - please write the name of the care home below  
Name:

Town:

- In an ambulance on the way to hospital or hospice

- Somewhere else - please write below

- 41 Did he ever say where he would like to die?

Tick one only

- Yes - go to question 42  
 No - go to question 44  
 Not sure - go to question 44

- 42 Where did he say that he would like to die?

Tick one only

- At home  
 In a hospice  
 In a hospital  
 In a care home  
 He said he did not mind where he died  
 He changed his mind about where he wanted to die  
 Somewhere else - please write below

- 43 Did the health care staff have a record of this?

Tick one only

- Yes  
 No  
 Not sure

- 44 Do you think he had enough choice about where he died?

Tick one only

- Yes  
 No  
 Not sure  
 He died suddenly

**45** On balance, do you think that he died in the right place?

*Tick one only*

- Yes  
 No  
 Not sure

**46** Were you or his family given enough help and support by the healthcare team at the actual time of his death?

*Tick one only*

- Yes, definitely  
 Yes, to some extent  
 No, not at all  
 Don't know

**47** After he died, did staff deal with you or his family in a sensitive manner?

*Tick one only*

- Yes  
 No  
 Don't know  
 Does not apply, I didn't have any contact with the staff

**48** Looking back over the last 3 months of his life, was he involved in decisions about his care as much as he would have wanted?

*Tick one only*

- He was involved as much as he wanted to be  
 He would have liked to be more involved  
 He would have liked to be less involved  
 Don't know

**49** Looking back over the last three months of his life, were you involved in decisions about his care as much as you would have wanted?

*Tick one only*

- I was involved as much as I wanted to be  
 I would have liked to be more involved  
 I would have liked to be less involved  
 Don't know

**50** Were any decisions made about his care that he would not have wanted?

*Tick one only*

- Yes  
 No  
 Don't know

**51** Overall, and taking all services into account, how would you rate his care in the last three months of life?

*Tick one only*

- Outstanding  
 Excellent  
 Good  
 Fair  
 Poor  
 Don't know

**52** Since he died, have you talked to anyone from health and social services, or from a bereavement service, about your feelings about his illness and death?

*Tick one only*

- Yes
- No, but I would have liked to
- No, but I did not want to anyway
- Not sure

If you feel that you would like to talk about your feelings or discuss painful memories brought back by completing this questionnaire, please call:

Cruse Bereavement Care  
0844 477 9400

or by email on:  
helpline@cruse.org.uk

## Information About You Both

**53** What was your relationship to him? Were you his:

*Tick one only*

- Wife / Partner
- Son / Daughter
- Brother / Sister
- Son-in-law / Daughter-in-law
- Parent
- Other relative
- Friend
- Neighbour
- Staff in care home
- Warden (sheltered accommodation)
- Other official
- Someone else - please write below
- \_\_\_\_\_
- \_\_\_\_\_

**54** What is your age?

- 18-19
- 20 -29
- 30 - 39
- 40 - 49
- 50 - 59
- 60 - 69
- 70 - 79
- 80 - 89
- 90 +

**55** Are you:

- Male
- Female



**56** Please could you indicate which ethnic group you belong to:

*Tick one only*

**White**

English / Welsh / Scottish / Northern Irish / British

Irish

Gypsy or Irish Traveller

Any other white background

**Mixed / Multiple ethnic group**

White and Black Caribbean

White and Black African

White and Asian

Any other mixed background

**Asian / Asian British**

Indian

Pakistani

Bangladeshi

Chinese

Any other Asian background

**Black / African / Caribbean / Black British**

African

Caribbean

Any other Black / African / Caribbean background

**Other ethnic group**

Arab

Any other ethnic group

**57** Please could you indicate which ethnic group in your opinion he belonged to:

*Tick one only*

**White**

English / Welsh / Scottish / Northern Irish / British

Irish

Gypsy or Irish Traveller

Any other white background

**Mixed / Multiple ethnic group**

White and Black Caribbean

White and Black African

White and Asian

Any other mixed background

**Asian / Asian British**

Indian

Pakistani

Bangladeshi

Chinese

Any other Asian background

**Black / African / Caribbean / Black British**

African

Caribbean

Any other Black / African / Caribbean background

**Other ethnic group**

Arab

Any other ethnic group

**58** What was his age when he died?

- 18-19
- 20-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- 90 +

**59** What was his religion?

- No religion
- Christian (all denominations)
- Buddhist
- Hindu
- Jewish
- Muslim
- Sikh
- Any other religion: please write below

Thank you for taking the time to complete this questionnaire

We would be grateful if you could return it to us in the  
pre-paid envelope provided  
If you require a replacement envelope  
or if you have any other questions  
please phone the Survey Enquiry Line  
on 0800 298 5313

Please use the space below if there is anything you would like to say about the care provided. What, if anything was good about the care? What, if anything, was bad about the care?

Please indicate if you are willing for us to share these comments with local care organisations and providers. (Your name and address will not be shared with them)

Yes

No

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[FirstName Surname]  
[Address Line 1]  
[Address Line 2]  
[Address Line 3]  
[Address Line 4]  
[Address Line 5]  
[Post Code]

Dear [firstname(s)] [surname]

Invitation to help with the VOICES survey of experiences of care in the  
last months of life.

You may remember that we wrote to you a few weeks ago asking for your help with a survey we are currently conducting on behalf of the Department of Health. As our records show that we have not heard back from you, we are writing again to check whether or not you are willing to take part in this study.

**If you have responded recently, please accept our apologies for having bothered you. Some reply slips were returned without the Study ID number entered in the box and we were unable to remove these respondents from the mailing list. We have made every effort to remove everyone who has responded from the list.**

We would be grateful if you could complete the questionnaire and return it to the Office for National Statistics in the pre-paid envelope provided. If you do not feel you are the best person to complete the questionnaire, please pass it on to whoever you think may be the best person to take part. If you require another copy of the questionnaire please phone the Survey Enquiry Line on the number below.

Your views are important and will help improve future care for patients and families in England. We apologise if this enquiry has caused you any distress and hope this letter does not bring back too many painful memories.

You can complete the questionnaire online if you would prefer. To do this, go to our secure website at: [www.ons.gov.uk/ons/index.html](http://www.ons.gov.uk/ons/index.html). Click on the 'About ONS' tab, then select 'A-Z of Surveys' and go to the letter N for 'National Bereavement Survey'. After clicking on 'Begin Survey Now', you will be asked to log in using

your Study ID Number (username) [XXXXXXXXXX]

your unique password: [XXXXXXXXXX]

If you do not wish to take part in this study please complete the 'REPLY SLIP' and return it in the pre-paid envelope provided. This will ensure that you do not receive any further reminder letters from us. It is important to enter your Study ID number on the slip so that we can remove you from our mailing list.

Thank you for taking the time to read this letter and we very much hope that you feel able to take part in this study.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Myer Glickman', with a long, sweeping flourish extending to the right.

Myer Glickman, Head of Health Analysis, Office for National Statistics

If you would like to receive this information in large print please call our  
Survey Enquiry Line on 0800 298 5313

# VOICES Survey

## Experiences of care in the last months of life

### INFORMATION LEAFLET

You are being invited to take part in a questionnaire-based research study called The VOICES Survey (Views Of Informal Carers - Evaluation of Services). Before you decide to participate, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

**If you would like more information or you have any questions, please phone our Survey Enquiry number on 0800 298 5313 (Monday to Thursday - 9 am to 9 pm; Friday - 9 am to 8 pm and Saturday - 9 am to 1 pm).**

#### What is the purpose of the VOICES Survey?

VOICES is a survey of bereaved carers who provided support and care to a relative, partner or friend. It covers experiences in the last months of life and will be used nationally to monitor and improve services provided. Although participation in VOICES will not help you directly, we hope that the information you give us will enable us to improve people's experiences of care at the end of their lives and improve services provided to bereaved relatives and friends.

#### Why have I been chosen?

You have been chosen to take part because you registered a death in the past year. The Office for National Statistics will not share any personal information about you with anyone else. Your survey responses will be shared with the Department of Health but only identified by an anonymous ID number. This ensures that the information you provide is totally confidential, in accordance with the Data Protection Act.

#### What will taking part involve?

We would like you to fill in a questionnaire which will take around 30 minutes. It asks about the care and support both you and your relative / friend received in the last months of their life and whether your relative / friend's needs were fully met. Your experiences are very important, so please feel free to be completely open and honest. If you do not think that you are the best person to complete the questionnaire, please pass it on to whoever you feel would be the best person to complete it.

Most of the questions can be answered by simply ticking the most appropriate box. If you would prefer not to answer a question, please go on to the next one. We would be very grateful for any additional comments that you would like to make in the spaces provided.

To return the completed questionnaire, simply use the enclosed pre-paid envelope. You can request a replacement envelope by phoning the Survey Enquiry Line number 0800 298 5313.

If you prefer, you can complete the questionnaire online (until 31<sup>st</sup> January 2012) on our secure website at: [www.ons.gov.uk/ons/index.html](http://www.ons.gov.uk/ons/index.html). Click on the 'About ONS' tab, then select 'A-Z of Surveys' and go to the letter N for 'National Bereavement Survey'. After clicking on 'Begin Survey Now', you will be asked to log in using your Study ID Number (see the box at the bottom of the questionnaire page) and your unique password:

## **Do I have to take part?**

Taking part is completely voluntary. If you do decide to take part you may change your mind or choose not to continue in the research at any time, without having to give a reason for doing so. However, if you decide not to complete the questionnaire, please return the reply slip so that the Office for National Statistics does not contact you again about this survey.

## **What are the possible disadvantages of taking part?**

Some people find it distressing to think about the care that their loved ones or close friends received during the last year of their lives. Answering questions about care at the end of life can bring back painful memories. If you find it distressing, you can stop completing the questionnaire at any time and choose not to continue.

We are working with Cruse Bereavement Care services, a charitable organisation that provides help and support to those who have lost loved ones. If you feel that you would like to talk about your feelings or discuss painful memories brought back by completing this questionnaire, please call Cruse Bereavement Care on 0844 477 9400 or by email at [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

## **How will the information I give be kept confidential?**

The Office for National Statistics (ONS) will not give personal information which identifies you to anyone else. Your survey responses will only be identified by an anonymous ID number. All the information collected will be kept strictly confidential within the approved researchers and secured against unauthorised access. We would also like to make absolutely clear that no information that could identify you will be used in any reports or journal articles we write. If you add comments at the end of the questionnaire, you are asked for additional consent to share these comments in full with local care organisations and providers. You will *not* be asked to include your name (or the name of your relative, partner or friend) on the questionnaire.

The information collected will be retained and securely stored for 10 years and will then be disposed of securely.

## **Who is organising and funding the study?**

The VOICES study is funded by the Department of Health and run by the Office for National Statistics.

## **What will happen to the results of the study?**

Information obtained from the questionnaire will be entered into a database and analysed by the Office for National Statistics, the Department of Health and their approved researchers. At the end of the project, the findings will be written up into a report that will be submitted to the Department of Health. The results will be available to the public. The information we get from this project will help improve the quality of end of life care provided in England.

If you have further questions about the study, or if English is not your first language and you would like interpreter services, you can call our Survey Enquiry Line on 0800 298 5313 which is open Monday to Thursday - 9 am to 9 pm; Friday - 9 am to 8 pm and Saturday - 9 am to 1 pm.

**We understand that coping with the loss of a loved one is not easy and we really appreciate you taking the time to read this information. We are confident that this study will make a difference to improving the way that care is delivered to people at the end of their lives.**

**Many thanks again.**



# VOICES Survey

## Views Of Informal Carers - Evaluation of Services

### REPLY SLIP

Please enter your Study ID number (you can find it in the box at the bottom of the questionnaire pages)

Study ID Number:

If you would prefer NOT to take part in the VOICES study, please return this form in the pre-paid envelope, so that the Office for National Statistics does not contact you again about this survey.

(Please tick)

You do not have to give a reason, but if you feel able to tell us why, it will help us to understand why some people choose not to take part in this type of research.

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**Thank you for taking the time to complete and return this form**

**Please return in the pre-paid envelope**

# VOICES Survey

Views Of Informal Carers - Evaluation of Services

## REPLY SLIP

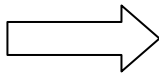
If you would prefer NOT to take part in the VOICES study,  
please return this form in the pre-paid envelope.

This will ensure the Office for National Statistics does not contact you again about this survey.

Please enter your Study ID number so that we can remove  
you from the mailing list

(you can find the Study ID number on the second page of the letter)

Fill in Study ID Number  
here:



You do not have to give a reason, but if you feel able to tell us why, it will help us to understand why some people choose not to take part in this type of research.

.....

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.....

**Thank you for taking the time to complete and return this form**

**Please return in the pre-paid envelope**

# VOICES Survey

Views Of Informal Carers - Evaluation of Services

## REPLY SLIP

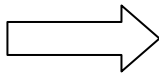
If you would prefer NOT to take part in the VOICES study,  
please return this form in the pre-paid envelope.

Please note that the Office for National Statistics will not contact you again about this survey.

Please enter your Study ID number

(you can find the Study ID number on the questionnaire, in the box at the bottom of the page)

Fill in Study ID Number  
here:



You do not have to give a reason, but if you feel able to tell us why, it will help us to understand why some people choose not to take part in this type of research.

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.....

**Thank you for taking the time to complete and return this form**

Please return in the pre-paid envelope

## Appendix 2: National Survey of Bereaved People (2013) sample characteristics

The National Survey of Bereaved People, 2013 (Voices, Views of Informal Carers – Evaluation of Services) was commissioned by NHS England and is administered by the Office of National Statistics (ONS). The sample for the 2013 survey was selected from the 168,719 adult deaths registered between 1st January 2013 and 30th April 2013, which were extracted from the death registration database held by ONS. Approximately 150,000 deaths were eligible and from these a stratified sample of 49,607 was drawn. Informants were contacted between four and 11 months following the death. The survey was completed by 22,661 informants, representing a response rate of 45.7 per cent. Non-response was associated with the deceased being male, younger age, dying at home or in a hospital (rather than care home or other location) and area deprivation (of place of residence). The response rate was also poor for non-White decedents. Forty-four per cent of the deceased were male and 34 per cent died before the age of 80. Forty-four per cent died at home. Cancer was the most frequent cause of death. Survey respondents were most frequently the son or daughter of the deceased (59.8 per cent) or their spouse or partner (24.5 per cent). Sixty per cent of respondents were female. Table 1 provides demographic data on the sample.

Table 1: Sample characteristics

Characteristic	Number	Percentage <sup>1</sup>
<i>Deceased sex</i>		
Female	12,701	56.0
Male	9,960	44.0
<i>Deceased age</i>		
18 to 59	1,146	5.1
60 to 69	2,208	9.7
70 to 79	4,363	19.3
80 to 89	8,726	38.5
90 and over	6,218	27.4
<i>Place of death</i>		
Home	4,523	20.0
Hospital	10,851	47.9
Care home	6,013	26.5
Hospice	1,274	56.2
<i>Deprivation (IMD 2010)</i>		
1 (most deprived)	3,488	15.4
2	4,310	19.0
3	4,947	21.8
4	5,038	22.2
5 (least deprived)	4,878	21.5
<i>Relationship of respondent to deceased</i>		
Spouse/Partner	5,455	24.5
Son/Daughter	13,292	59.8
Brother/Sister	485	2.2
Son-in-law/Daughter-in-law	977	4.4
Parent	304	1.4
Other	1,707	7.7
<i>Sex of respondent</i>		
Female	12,845	60.0
Male	8,543	40.0
<i>Age of respondent</i>		
18 to 59	9,408	42.0
60 to 69	7,966	35.6
70 to 79	3,464	15.5
80 to 89	1,405	6.3
90 and over	134	0.6
<i>Ethnic background of respondent</i>		
White	21,630	97.6
Mixed	74	0.3
Asian/Asian British	284	1.3
Black/African/Caribbean/Black British	143	0.6
Other	25	0.1

### Appendix 3: Results tables for analyses of data from the National Survey of Bereaved People (2013)

Results from multivariate analyses of data from the National Survey of Bereaved People, 2013, specified by the authors of this report and undertaken by staff at ONS are set out in the following tables. Odds ratios and 99 per cent confidence intervals are provided for each statistically significant term in each logistic regression model. All models include, as independent variables, age at death, sex of the deceased, cause of death, area deprivation (based on IMD quintile) of the decedent's place of residence, whether respondent was the spouse or partner of the decedent (taken as a proxy for decedent having a spouse or partner) and ethnic background of the decedent. The tables are arranged by the chapter in which results are discussed.

#### Chapter 4: Access to palliative care

<b>Sufficient support to family from health and social services when caring for decedent at home ('Yes, we got as much support as we wanted') (Q5)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
Ages 18 to 64 (compared to age 80 or above)	0.67	0.56 to 0.80
Ages 65 to 79 (compared to age 80 or above)	0.81	0.71 to 0.91
<i>Sex</i>		
Male (compared to female)	0.76	0.69 to 0.85
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancers)	0.68	0.60 to 0.78
Haematological cancer (compared to non-haematological cancers)	0.71	0.53 to 0.95
Neurological condition (compared to non-haematological cancers)	0.72	0.59 to 0.88
Respiratory illness (compared to non-haematological cancers)	0.72	0.61 to 0.86
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.65	0.56 to 0.76
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Most deprived (compared to least deprived)	0.75	0.64 to 0.89
Second most deprived (compared to least deprived)	0.79	0.67 to 0.92
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.48	0.42 to 0.54

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

<b>Receipt of Marie Curie nurse services (Q3)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancer)	0.11	0.08 to 0.15
Haematological cancer (compared to non-haematological cancer)	0.62	0.39 to 0.99
Neurological condition (compared to non-haematological cancer)	0.09	0.05 to 0.14
Respiratory illness (compared to non-haematological cancer)	0.13	0.08 to 0.21
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.11	0.07 to 0.16
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.75	0.60 to 0.94

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

<b>Receipt of other nursing services – including district, community, Macmillan, hospice home care, specialist or other nurse or occupational therapist (Q3)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
65 to 79 (compared to 80 or over)	1.17	1.06 to 1.30
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancer)	0.19	0.17 to 0.21
Haematological cancer (compared to non-haematological cancer)	0.46	0.36 to 0.59
Neurological condition (compared to non-haematological cancer)	0.13	0.11 to 0.15
Respiratory illness (compared to non-haematological cancer)	0.32	0.28 to 0.37
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.22	0.20 to 0.25
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Third least deprived (compared to least deprived)	0.86	0.76 to 0.97
<i>Ethnic background</i>		
Non-White (compared to White)	1.39	1.06 to 1.82

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

<b>Receipt of support from a social worker or support worker (Q3)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Cause of death</i>		
Haematological cancer (compared to non-haematological cancer)	0.51	0.29 to 0.88
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Second most deprived (compared to least deprived)	1.23	1.00 to 1.51

<b>Receipt of home help/meals-on-wheels – including home care worker, home care aide, home help, meals-on-wheels or other home delivered meals (Q3)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
18 to 64 (compared to 80 or over)	0.45	0.37 to 0.54
65 to 79 (compared to 80 or over)	0.70	0.63 to 0.78
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancer)	0.72	0.64 to 0.81
Haematological cancer (compared to non-haematological cancer)	0.73	0.55 to 0.98
Neurological condition (compared to non-haematological cancer)	0.51	0.43 to 0.59
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.80	0.70 to 0.91
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	1.33	1.18 to 1.50
<i>Ethnic background</i>		
Non-White (compared to White)	1.40	1.07 to 1.84

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.



<b>Receipt of religious/emotional support services – from counsellor or religious leader (Q3)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
65 to 79 (compared to 80 or over)	0.80	0.64 to 0.99
<i>Sex</i>		
Male (compared to female)	0.83	0.70 to .99
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancer)	0.40	0.32 to 0.50
Neurological condition (compared to non-haematological cancer)	0.28	0.20 to 0.59
Respiratory illness (compared to non-haematological cancer)	0.43	0.31 to 0.60
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.42	0.32 to 0.55
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Most deprived (compared to least deprived)	0.65	0.49 to 0.87
Second most deprived (compared to least deprived)	0.63	0.49 to 0.83
Third most deprived (compared to least deprived)	0.73	0.58 to 0.94
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.53	0.43 to 0.66
<i>Ethnic background</i>		
Non-White (compared to White)	2.31	1.46 to 3.64

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

<b>Receipt of hospice at home services (Q3)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
65 to 79 (compared to 80 or over)	1.32	1.02 to 1.71
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancer)	0.09	0.06 to 0.14
Haematological cancer (compared to non-haematological cancer)	0.51	0.30 to 0.85
Neurological condition (compared to non-haematological cancer)	0.15	0.09 to 0.25
Respiratory illness (compared to non-haematological cancer)	0.14	0.08 to 0.24
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.08	0.05 to 0.14
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.54	0.42 to 0.69

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

<b>Receipt of rapid response team services (Q3)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
18 to 64 (compared to 80 or over)	0.48	0.35 to 0.66
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancer)	0.41	0.34 to 0.50
Neurological condition (compared to non-haematological cancer)	0.27	0.20 to 0.37
Respiratory illness (compared to non-haematological cancer)	0.64	0.50 to 0.81
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.50	0.40 to 0.62
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.73	0.61 to 0.87

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

## Chapter 5: Pain and symptom control

<b>Pain managed 'completely, all of the time' while at home (Q6)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
Ages 18 to 64 (compared to age 80 or above)	0.74	0.58 to 0.95
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancers)	0.47	0.38 to 0.59
Respiratory illness (compared to non-haematological cancers)	0.62	0.48 to 0.81
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.49	0.39 to 0.62
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.57	0.48 to 0.67

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

<b>Pain managed 'completely, all of the time' while in a care home (Q22)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
Ages 65 to 79 (compared to age 80 or above)	0.76	0.60 to 0.97
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.64	0.49 to 0.85

<b>Pain managed 'completely, all the time' while in hospital (Q26)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Cause of death</i>		
Neurological condition (compared to non-haematological cancers)	1.46	1.20 to 1.79
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	1.22	1.04 to 1.43
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Most deprived (compared to least deprived)	1.21	1.01 to 1.44
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.78	0.68 to 0.90

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

## Chapter 6: Quality and experience of care

<b>Overall care 'excellent' or 'outstanding' (Q51)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age</i>		
Ages 65 to 79 (compared to age 80 or above)	0.87	0.79 to 0.96
<i>Sex</i>		
Male (compared to female)	0.82	0.76 to 0.89
<i>Cause of death</i>		
Cardiovascular illness (compared to non-haematological cancer)	0.62	0.55 to 0.69
Respiratory illness (compared to non-haematological cancer)	0.64	0.56 to 0.74
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.60	0.53 to 0.67
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Most deprived (compared to least deprived)	0.81	0.71 to 0.92
Second most deprived (compared to least deprived)	0.88	0.78 to 0.99
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.65	0.59 to 0.72
<i>Ethnic background</i>		
Non-White (compared to White)	0.74	0.57 to 0.97

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

<b>Overall care 'excellent' or 'outstanding' (Q51), for sub-sample of people who spent some of last three months of life being cared for in hospital (Q2)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Sex</i>		
Male (compared to female)	0.89	0.81 to 0.98
<i>Cause of death</i>		
Cardiovascular illness (compared to non-haematological cancer)	0.69	0.60 to 0.79
Neurological condition (compared to non-haematological cancer)	0.77	0.65 to 0.92
Respiratory illness (compared to non-haematological cancer)	0.64	0.54 to 0.76
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.63	0.55 to 0.73
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.64	0.57 to 0.73

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

<b>Overall care 'excellent' or 'outstanding' (Q51), for sub-sample of people who spent some of last three months of life being cared for at home (Q2)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Sex</i>		
Male (compared to female)	0.87	0.79 to 0.96
<i>Cause of death</i>		
Cardiovascular illness (compared to non-haematological cancer)	0.55	0.48 to 0.62
Neurological condition (compared to non-haematological cancer)	0.74	0.60 to 0.91
Respiratory illness (compared to non-haematological cancer)	0.55	0.46 to 0.65
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.54	0.46 to 0.62
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Most deprived (compared to least deprived)	0.82	0.70 to 0.97
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.59	0.52 to 0.66

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

<b>Overall care 'excellent' or 'outstanding' (Q51), for sub-sample of people who spent some of last three months of life being cared for in a care home (Q20)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Sex</i>		
Male (compared to female)	0.81	0.71 to 0.93
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Most deprived (compared to least deprived)	0.80	0.65 to 1.00
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.66	0.53 to 0.83
<i>Ethnic background</i>		
Non-White (compared to White)	0.45	0.25 to 0.84

<b>Overall care 'excellent' or 'outstanding' (Q51), for sub-sample of people who spent some of last three months of life being cared for in a hospice (Q29)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Cause of death</i>		
'Other' <sup>1</sup> cause (compared to cancer)	0.28	0.21 to 0.36
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Most deprived (compared to least deprived)	0.59	0.40 to 86
Second most deprived (compared to least deprived)	0.69	0.48 to 0.99
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.70	0.54 to 0.91
<i>Ethnic background</i>		
Non-White (compared to White)	0.50	0.27 to 0.92

<sup>1</sup> Other than cancer or cardiovascular disease

<b>Care provided by care home 'excellent' (Q23)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
65 to 79 (compared to 80 or over)	0.79	0.65 to 0.97
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancer)	0.75	0.61 to 0.93
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Most deprived (compared to least deprived)	0.80	0.64 to 0.98
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.80	0.64 to 0.99
<i>Ethnic background</i>		
Non-White (compared to White)	0.48	0.27 to 0.88

<b>Care provided by GP 'Excellent' (Q19)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
65 to 79 (compared to 80 or over)	0.87	0.77 to 0.97
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancer)	0.72	0.63 to 0.82
Neurological condition (compared to non-haematological cancer)	0.74	0.63 to 0.86
Respiratory illness (compared to non-haematological cancer)	0.77	0.66 to 0.91
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.63	0.55 to 0.73
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Most deprived (compared to least deprived)	0.72	0.61 to 0.83
Second most deprived (compared to least deprived)	0.79	0.69 to 0.91
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.55	0.49 to 0.62

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

<b>Care provided by out-of-hours services 'Excellent' (Q11)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
Ages 18 to 64 (compared to age 80 or above)	0.78	0.62 to 0.98
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancers)	0.75	0.63 to 0.90
Respiratory illness (compared to non-haematological cancers)	0.80	0.64 to 0.99
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.70	0.57 to 0.84
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.57	0.49 to 0.67

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

## Chapter 7: Place of death

<b>Death at home (compared to death in a hospital) (Q40)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
Ages 18 to 64 (compared to age 80 or above)	1.36	1.14 to 1.63
Ages 65 to 79 (compared to age 80 or above)	1.33	1.18 to 1.50
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancers)	0.44	0.41 to 0.47
Haematological cancer (compared to non-haematological cancers)	0.46	0.34 to 0.63
Neurological condition (compared to non-haematological cancers)	0.35	0.29 to 0.41
Respiratory illness (compared to non-haematological cancers)	0.28	0.24 to 0.33
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.22	0.19 to 0.24
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Most deprived (compared to least deprived)	0.67	0.57 to 0.79
Second most deprived (compared to least deprived)	0.82	0.70 to 0.95
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	0.82	0.72 to 0.92

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.



<b>Death in a care home (compared to death in a hospital) (Q40)</b>		
<b>Effect</b>	<b>Odds ratio</b>	<b>99% confidence interval</b>
<i>Age at death</i>		
Ages 18 to 64 (compared to age 80 or above)	0.47	0.40 to 0.56
Ages 65 to 79 (compared to age 80 or above)	0.52	0.46 to 0.58
<i>Sex</i>		
Male (compared to female)	0.66	0.60 to 0.72
<i>Cause of death</i>		
Cardiovascular disease (compared to non-haematological cancers)	0.27	0.25 to 0.29
Haematological cancer (compared to non-haematological cancers)	0.47	0.34 to 0.64
Neurological condition (compared to non-haematological cancers)	1.51	1.35 to 1.69
Respiratory illness (compared to non-haematological cancers)	0.30	0.27 to 0.35
'Other' causes <sup>1</sup> (compared to non-haematological cancers)	0.26	0.24 to 0.29
<i>Level of deprivation of area of residence (IMD quintile)</i>		
Most deprived (compared to least deprived)	0.60	0.52 to 0.69
Second most deprived (compared to least deprived)	0.77	0.67 to 0.89
<i>Relationship of respondent</i>		
Child/friend/other (compared to spouse or partner)	1.41	1.25 to 1.60
<i>Ethnic background</i>		
Non-White (compared to White)	0.57	0.41 to 0.79

<sup>1</sup> Other than cancer, cardiovascular disease, neurological conditions, renal failure or respiratory illness.

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