

# Death and dying

Understanding the data

February 2013

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# Foreword

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Improving provision, choice and quality in end of life care represent major challenges for health and social care over the coming decades. Demographic change and ongoing NHS and social care reforms are further challenges, but also provide an opportunity to rethink how we provide services to people in the last year of life.

As the [pressures on hospital-based services grow](#), so the need to look for alternative provision increases. It has long been our goal at Marie Curie Cancer Care for more people to be supported to die in the place of their choice. Our nursing and hospice services support tens of thousands of people and their families each year to do just this.

A number of reports and studies have examined different aspects of end of life care. [The First national VOICES survey of bereaved people](#), Nuffield's latest work on [social care at the end of life](#) and, most recently, on the value of [our community-based nursing service](#), have all stressed the differences and benefits of non-hospital care for both families and the wider health and social care system. We now have a strong basis from which to change the balance of end of life care services; with a move away from hospitals to home and community-based support.

This does not mean an end to end of life care in hospitals; for very many people, hospital is the right place to die because of clinical needs which cannot be met elsewhere. What is needed is a change in the way that hospitals see their role and the way in which they work with other providers locally. This is likely to require significant changes to the way we fund and organise services, but ultimately it will enable us all to deliver better, more integrated and responsive health and social care services for those at the end of life.

We hope that the new [Marie Curie End of Life Care Atlas](#) will help commissioners; those who provide health services and policy makers to improve in end of life care across England. This report identifies differences in provision, experience and outcomes and we hope this information will help focus future interventions, address gaps and increase the provision of home and community-based services for all those who need and want them.

**Dr Jane Collins,**  
Chief Executive,  
Marie Curie Cancer Care

# Introduction

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End of life care in England is currently provided by a range of organisations, including hospitals, hospices, nursing services, families, carers and volunteers. This diversity brings many benefits; providing services which meet the different needs and preferences of people in the last year of life. It also means that people using these services and in different parts of the country will have very different experiences.

As we seek to improve local end of life care services and to ensure that everyone can access the best quality care, it is important that we look at a range of data sources to examine patterns, experiences and outcomes in end of life care across different services and localities.

## The Marie Curie End of Life Care Atlas

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The data presented here is drawn from the [Marie Curie End of Life Care Atlas](#). This tool has been designed to help commissioners, health and social care providers, policy makers and the public across the UK to identify gaps in end of life care in their areas. This report provides headline analysis of the key end of life care data, enabling comparisons for different localities and different health care settings. We hope that it will help commissioners and others to improve the provision and quality of end of life care locally. By clicking on links under the relevant tables and charts in this report you will be able to access [the Atlas](#). To help you use the Atlas, we have produced a simple online guide.

## Data Analysis

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This report provides analysis of a number of external data sources and attempts to identify patterns of service delivery and outcomes in England. Much of the data used in this report has previously been published via the [National End of Life Care Intelligence Network's profiles](#), Department of Health, Office for National Statistics, (VOICES) and local NHS providers. What is new here is the policy analysis and the resulting recommendations. The report offers analysis at Primary Care Trust (PCT) and PCT cluster level, allowing us to identify local trends and variations in the provision of end of life care.

It is not our intention to name and shame any organisation, but rather to identify variations in performance, expenditure and outcomes across all parts of England. It is this variation which emerges as the overarching theme of this report. We hope this will prompt a debate about the cause of local variation and the extent to which it is warranted and encourage commissioners to use the Atlas to address local gaps in services.

## Variation

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There is a considerable literature on the subject of variation in the delivery of health services including ([Appleby and colleagues, 2011](#)). We understand that variation in the delivery of health services, and in this instance in end of life care, is inevitable. As [Appleby and colleagues](#) argue, the important thing is that we 'eradicate avoidable variation'. There is what has been called 'warranted' or 'good' variation and 'unwarranted' or 'bad' variation. 'Good' variation refers to situations for which there are clear factors which explain patterns of performance – for example, where the age profile of an area explains differing patterns of service use in particular localities. 'Bad' variation is not surprisingly, those incidences for which there are no external explanatory factors for variations in service delivery and outcomes.

In analysing the available data we are mindful of the complex factors which can lead to variation in the delivery of health services.

It is important that we are realistic about the task before us. When attempting to address 'variation', [Appleby and colleagues \(2011\)](#) identify four distinct stages:

- I. Collect data
- II. Identify causes of variation
- III. Justify and explain local variation, this may require incentives to encourage action
- IV. Shared decision making to establish right level of variation.

In end of life care we are essentially still at stage one – collecting the right data and ensuring that we are comparing like with like. We have a considerable way to go before we can confidently begin to determine and explain the precise causes of existing variation. In a number of instances, the degree of variation, for example *Declared NHS Spend on Specialist Palliative Care (SPC) per Primary Care Organisation (PCO) death*, is such that the most likely explanation is that localities are collecting different data and reporting on potentially different things. Data collection issues will not explain all variation, however unless we are confident that all localities are collecting and reporting the same things, there is little point spending time and resources determining what else might be going awry. Therefore, the remainder of this report will focus on identifying variation across a number of key measures, rather than attempting to predict the precise reasons for variation in different areas. We have the data, so the first step is complete. The next step is to analyse, then we must develop measures to compare performance across different providers and reflect factors outside their control (such as PROMS or SHMI) it and the final step is to use these measures to do something about it.

## Why now?

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There are two specific factors which mean that now is a good time to focus on and address such variation. First, the current [NHS reforms](#) offer an opportunity to re-prioritise and refocus NHS services to ensure better services for people in the last days and weeks of life. [Appleby and colleagues](#) ask:

**To what extent, for example, will GPs and GP commissioning consortia (GPCC) perhaps be better placed to tackle inequalities in access and implement shared decision-making as a way of establishing a more appropriate level of warranted variation?**

Second, the UK's ageing population means that over the next two decades there will be increasing pressures on NHS resources. [Dilnot's analysis](#) makes clear the growth in the number of older people who are or will be over the age of 80 between 2010 and 2030. This growth is particularly significant because people 'accumulate long-term conditions as they age'; this means that as you grow older the conditions you suffer from increases, as highlighted in a recent [multimorbidity paper](#). Consequently, the more conditions people have the [more hospital care they need](#) and use in the last 12 months of life.

Together, these twin factors underline the importance of providing effective, efficient and appropriate end of life care, for both people and for the wider sustainability of the NHS. We need to ensure that end of life care and the wider health and social care system are ready for these coming pressures.

# 1: Demographics

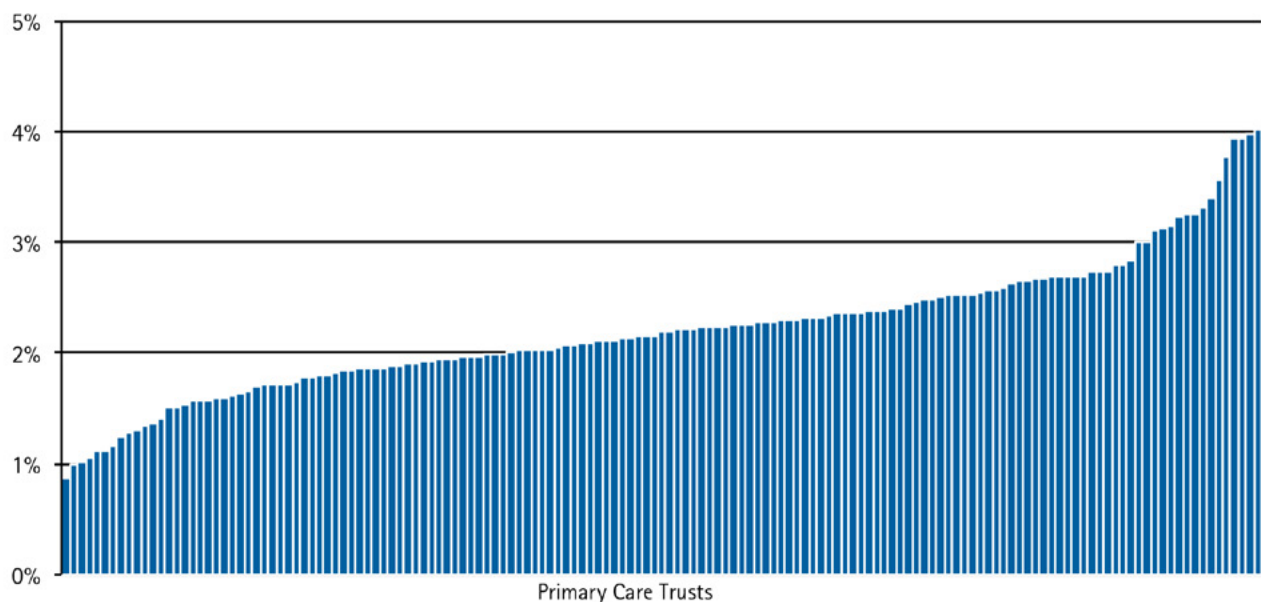
## Population profile

Local demographic profiles are important when planning and delivering end of life care across England. In 2011, 62% of female deaths and 40% of male deaths were of those [over 80 years of age](#). Most obviously, age profiles are crucial because a significant proportion of people who die are drawn from older age groups. This means that those areas with larger older populations are likely to have higher levels of demand for palliative care and other local end of life care services.

There is considerable variation in the local population profiles of Primary Care Trust (PCT) areas across England. This is perhaps most obvious in the differing age profiles of localities and specifically the proportion of people over 85 years of age. Demographics play an important role in shaping the challenges which face different areas. [Analysis](#) of the wider use of hospital-based services shows that hospital bed use increases with age, with those under 65 using one-fifth of a bed day per year, whilst the average for over 85 years is five bed days per annum.

At the extremes, just 0.9% of the population in Tower Hamlets in London is over the age of 85 years, whilst 4% of the population of Hastings and Rother, and Torbay are over 85 years of age. London's younger demographic profile is well established and it is confirmed here; with no area of inner London having an 85+ population of more than 1.9%. Nationally, the average for England is 2.3%.

**Table one: Proportion of PCT population aged 85+**



Data source: Office for National Statistics Mid year population estimates 2010

[Click here to find out how your local area compares](#)

Given existing pressures on the NHS, it is important that we consider what can be done to reduce the levels of bed use by people over 85 years of age. The better identification of people who are in the last days and weeks of life; increased provision of community-based services and greater integration of hospital and community-based services could help reduce both the levels of hospital bed use by older people and the outcomes for those in the last year of life.

The relative age profile is also important in terms of the estimates of dementia prevalence in local areas. With its younger age profile, London has the lowest levels of dementia prevalence, with just 0.6% of the population of Inner North East London. The average for the whole of England is 1.3%, whilst the estimate for Dorset PCT cluster is 2.1%. It is again important that local targets for identifying people with dementia reflect the challenge locally.

The Alzheimer's Society has produced detailed [dementia maps](#). It is important that we properly target resources to meet the needs of different groups and which reflect the very specific end of life care needs of people with dementia.

Finally, age profile also impacts upon the numbers of people who are likely to require palliative care. Inner North East London has just 2,721 people (0.4%) with palliative care needs (Higginson Model), Sussex PCT cluster has 12,883 people (0.8%) and Bournemouth and Poole and Dorset PCT cluster have 6,274 people (0.9%). The national average for England is 0.7%.

## Ethnicity and end of life

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There is increasing academic and clinical interest in patterns and experiences of different ethnic communities of palliative care and end of life care services. In demographic terms, overall ethnic minority communities tend to be younger, which obviously has an impact on the wider age profile of different areas. This is most obviously demonstrated in London, which has the largest ethnic minority populations. Inner North East London has an ethnic minority population of 45%, whilst in North West London it is 33%. This compares with 13% nationally (England) and just 3% in Cumbria PCT and 4% in Cornwall and the Isles of Scilly PCT. This is not to suggest that ethnic minority communities are confined to London. There are substantial ethnic minority populations in Bradford and Airedale PCT (25%) and Birmingham PCT Cluster (29%).

The reality is that the key challenges in relation to ethnicity and end of life will start to impact over the course of the next generation. Ethnic and demographic patterns in the UK reflect wider patterns of post war immigration. Plotting migration patterns shows us that the proportion of dying people who are from a number of non-white British groups will increase significantly over the next two decades. It is important that we lay the foundations for the development of end of life care services which are more responsive to the greater, ethnic diversity of dying people in the 2020s and 2030s, by undertaking modelling of future ethnic profiles across the UK now. Marie Curie Cancer Care is currently working to better understand the differing needs of a range of ethnic communities.

## 2: Variation in experiences

For the first time, the [First national VOICES survey of bereaved people](#) gives us an opportunity to examine the recent experiences of end of life care services locally (PCT cluster level) and nationally. This provides an important piece in the intelligence jigsaw – family experiences of a range of services and health care settings.

The VOICES national bereavement survey was commissioned by the Department of Health and undertaken by the Office for National Statistics in 2011/12. The aim of the survey was to assess experiences of care in the last three months of life for adults who died in England between November 2010 and June 2011.

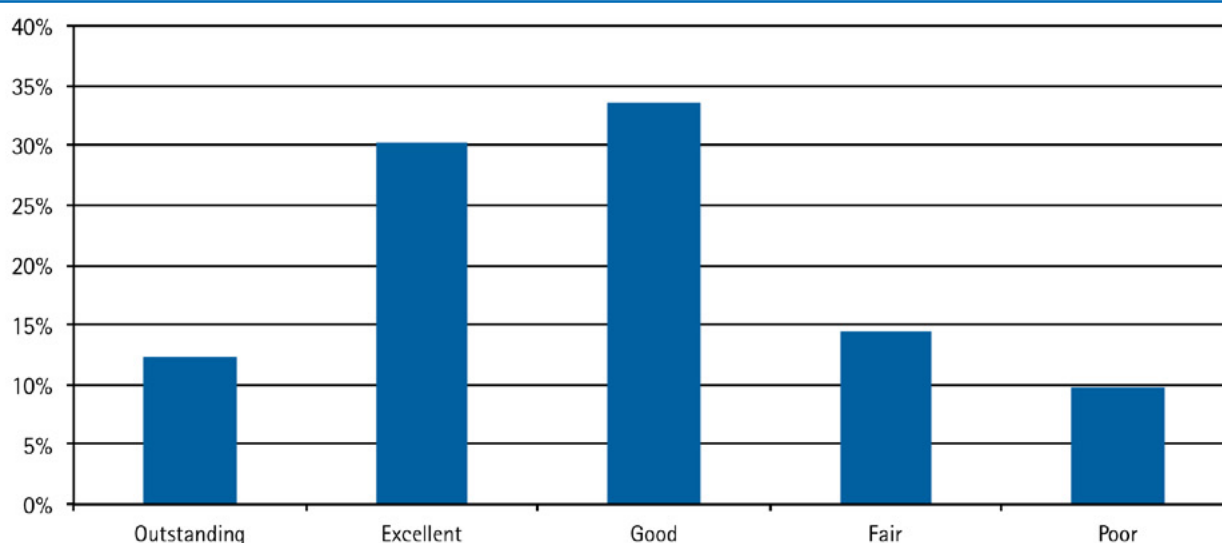
The VOICES Survey sought responses from just under 49,000 bereaved people to questions relating to the quality of care; involvement in decision making; personal choices and preferences and service coordination. It had a response rate of 45.7%, a figure which makes clear that [the English do like talking about death](#). The following section examines the relevant parts of the VOICES survey. Further analysis has been provided by The Office for National Statistics ([general analysis](#), and at [PCT Cluster level data](#)) and the Department of Health's [survey report](#).

Data is presented at a PCT Cluster level. There are 51 PCT Clusters in England, however as the response rate was so low for Inner North East London and numbers so small, this PCT Cluster has been omitted from all charts and analysis.

### 1. Quality of Care

Table two shows the ratings of overall care across all services in the last three months of life. The overall picture is a positive one. In total 76% of respondents felt that the overall care their loved one received in the days and months of life was good, excellent or outstanding.

**Table two: Ratings of overall care across all services in last three months**



Source: Office for National Statistics analysis of the National Bereavement Survey (VOICES)

There is however considerable variation across different settings, most notably between hospitals and other care settings. As table three shows just 32.6% of those whose loved one died in hospital felt that their care was excellent or outstanding, compared to 53.7% (home), 51.3% (care home) and 59.1% (hospice).



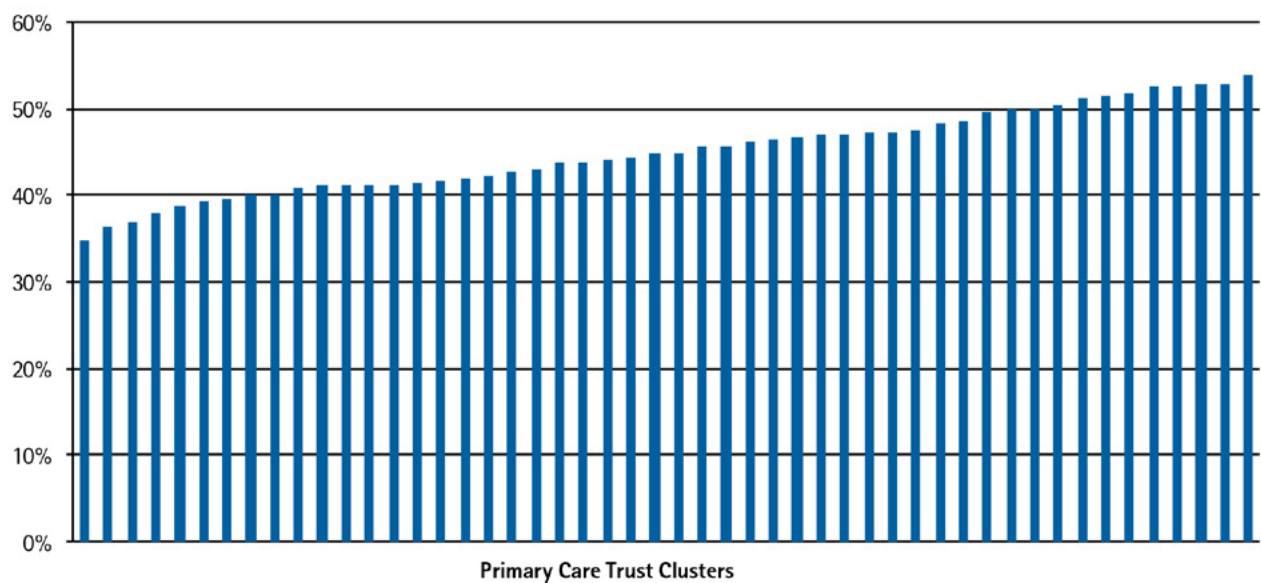
There is also considerable variation in the perceived quality of care across PCT cluster areas. As table four shows, there is a 19.2% difference between the areas with the highest and lowest ratings of quality of care. 14 PCT cluster areas (out of a total of 50) scored less than 40%, whilst just one area scored more than 50% at 50.7%.

**Table three: Ratings of quality of care by location**



The need for improvement is greatest in those areas which scored lowest; however, it is clear that there is considerable scope for improvement in quality of care across England.

**Table four: Quality of care rated outstanding across all services by PCT Cluster**



Source: Office for National Statistics National Bereavement Survey (VOICES), 2011

[Click here to find out how your local area compares](#)

## Coordination of Care

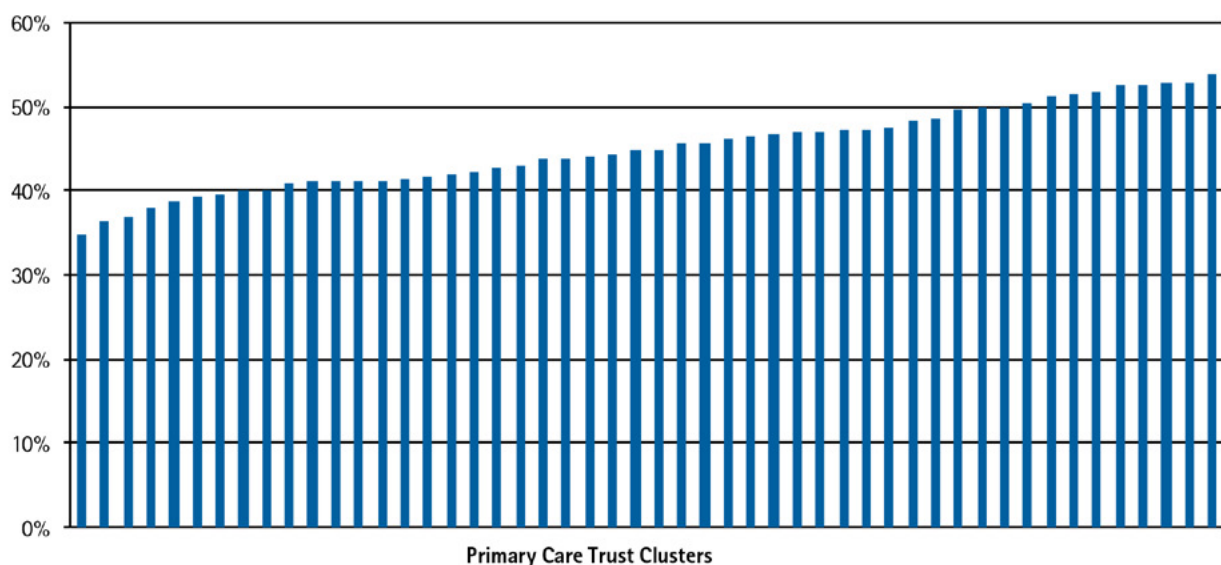
The dominant political theme which currently unites all of the major parties in the UK is integration – the notion that we need a health and social care system which is unified and works together to provide patient-centred care. The glue which holds together an integrated system is coordination – the degree to which health and social care organisations communicate, collaborate, work together and ultimately organise individual care packages. The VOICES Survey includes two interesting measures of local coordination; coordination of care whilst the person was at home and coordination between hospital and community services. It is important to note that the data here reflects those who said 'yes, definitely' and not those who responded 'yes, to some extent', when asked whether all services worked well together.

### (i) VOICES Survey: Co-ordination of care – Whilst the Patient was at Home

As table five shows, in the lowest ranked areas, just 34.7% said that they felt care had been well coordinated whilst the patient remained at home. At the other end of the scale, the highest ranked areas scored 53.9%, representing a gap of 19.2%. Just 9 of the 50 PCT cluster areas scored 50% or more.

Coordination of care appears poorest in London, with many of the 25 lowest ranked PCT areas in London. There is a clear difference between urban and more rural areas. The six lowest scoring PCT Clusters are in major cities. By contrast the 9 PCT clusters which scored 50% or more are less urbanised areas.

**Table five: Care 'definitely' well co-ordinated (home) by PCT Cluster**

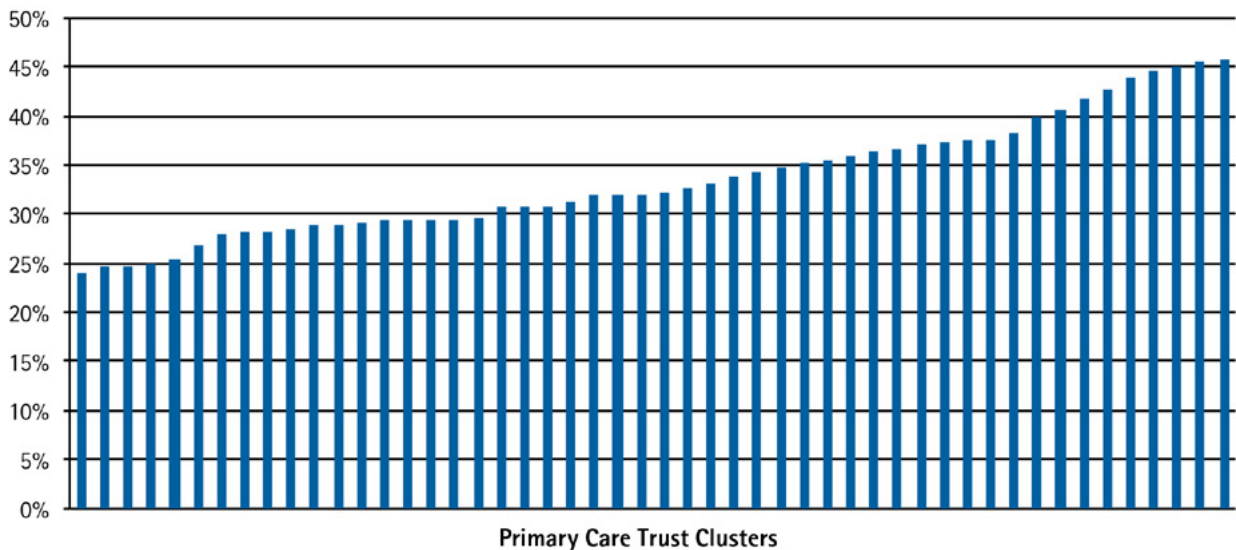


Data source: Office for National Statistics analysis of the National Bereavement Survey (VOICES)

## (ii) Co-ordination: Hospitals worked well with other services

The picture in terms of coordination between hospitals and other services is slightly worse. As table six demonstrates, the lowest scoring area registered 24% and the highest just 45.7%. This means that no area achieved more than 50%.

**Table six: Care 'definitely' well co-ordinated (hospital) by PCT Cluster**



[Click here to find out how your local area compares](#)

Coordination is vital for getting terminally ill patients out of hospital to enable them to die at home, in a hospice or another place of their choice. It is also a potentially contributory factor in the overuse of hospital beds by those who do not have a clinical need. A [National Audit Office report](#) in 2008 found that in one NHS Trust, 40% of those who died in hospital had no medical need to be there.

Coordination will be vital if the NHS is to deal with upcoming demographic and financial pressures. Improving coordination of care would lead to quicker discharge of patients and a considerable freeing up of hospital beds.

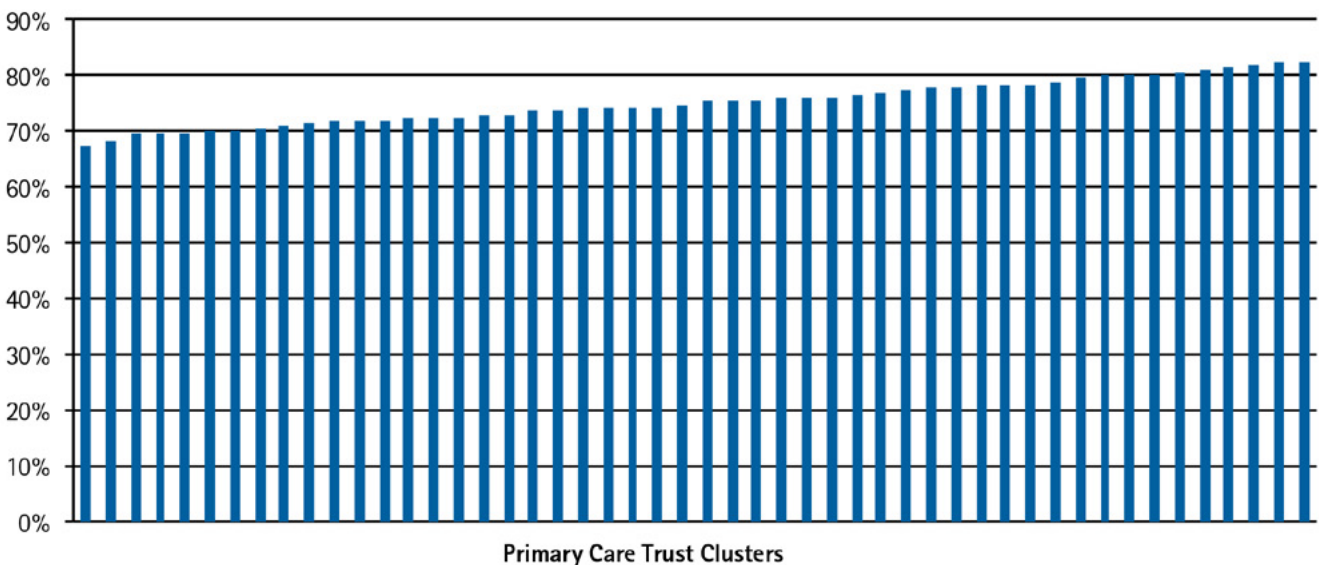
We need to better understand the principles and practices which underpin excellent coordination. Marie Curie's [Delivering Choice Programme](#) (DCP) provides an effective way of ensuring local services are properly aligned and coordinated. It is important that we draw on wider initiatives such as [NESTA's People Powered Health](#) project in order to transfer the best examples of practice to end of life care. It is only by understanding what drives effective coordination that we will be able to deliver the much talked about vision for greater integration.

## Dignity and Respect

Dignity and respect represents one of the most important measures of care at the end of life. Much has been made of the notion that we can measure the state of our society by the way in which we treat dying people. The survey measured perceptions of dignity and respect in the treatment of patients by doctors and nurses, across all settings.

As table seven shows, the highest recorded levels of dignity and respect by doctors in the last two days of life was 82.6%, the lowest was just 67.2%. In half of the PCT cluster areas (25/50) more than 75% of bereaved respondents reported that they felt that their loved one had been treated with dignity and respect.

**Table seven: Dignity and Respect 'always' shown in last two days (Doctors) by PCT Cluster**

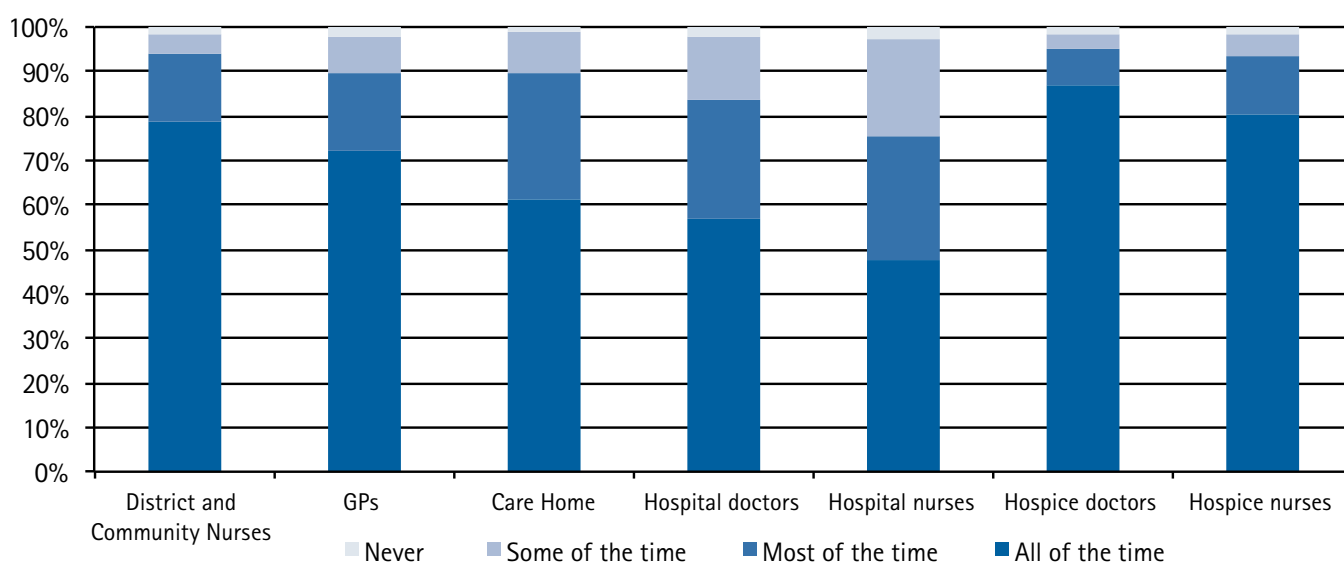


Data source: Office for National Statistics analysis of the National Bereavement Survey (VOICES)

It is vital that we continue to strive to improve services and responses and improve levels of dignity and respect, year on year.

The largest contrasts are to be found by exploring differences between professionals and across settings. As the VOICES Survey report shows, if one compares the levels of dignity and respect recorded for doctors in different settings, the difference is clear. As table eight illustrates, hospital doctors scored just 56.8% (treated with dignity and respect all of the time), compared to 72% for General Practitioners and 86.7% for hospice doctors. That is a variation of 29.9% between hospices and hospitals. There is a similar pattern for nurses, but interestingly nurses consistently scored lower than doctors in the same settings. District and community nurses scored 78.7%, hospice nurses scored 80.5% and hospital nurses scored just 47.7%.

**Table eight: Proportion who felt patient was treated with dignity and respect in last three months**



Source: Office for National Statistics National Bereavement Survey (VOICES), 2011

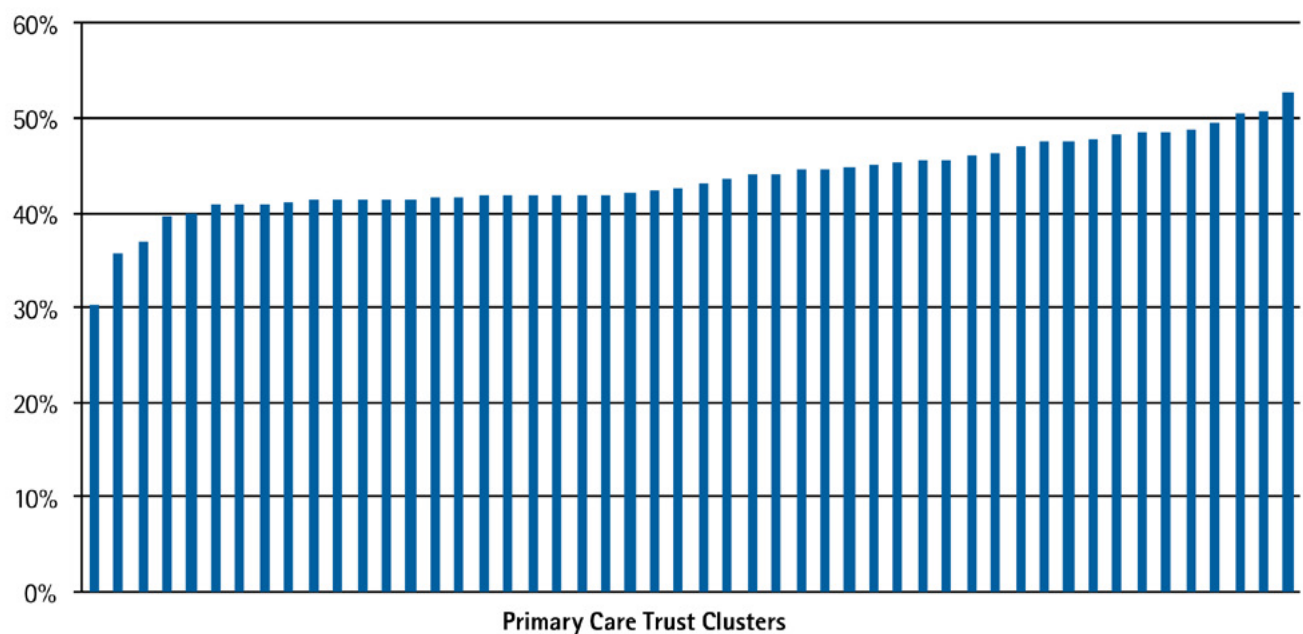
There are a number of explanatory factors at work here. First, hospices and a significant proportion of community-based nurses have end of life care as their core business. Second, hospitals are primarily in the business of making people better. End of life care provides a number of wholly different challenges and requires a different set of staff skills. Third, hospitals are less well set up to provide appropriate end of life care. For example, hospitals have fewer private rooms and those which they do have are often reserved for infection control. This means that more people die on busy, open wards which may affect the perceptions of relatives of dignity and respect. As a footnote, it is important to note that care homes outscore both hospital doctors and nurses in terms of dignity and respect. This runs counter to some prevailing opinions and media coverage of care homes.

## Pain and symptom management

Pain and symptom management is another essential component of excellent end of life care. NICE has produced guidance on pain management. As a recent study showed, the [effective use of opiates](#) makes a huge difference to patients in the last few days and weeks of life and under use can seriously increase levels of [pain and discomfort for dying patients](#).

Respondents offered a highly divergent picture of pain and symptom management across England. Table nine is based on a collation of the data from the different settings (hospital, home, hospice and care home) by PCT cluster area. It records the proportion of respondents who felt that there had been effective pain management 'completely, all of the time' during the last two days of life. The highest recorded response was 52.7%, with the lowest being 30.3%. As table nine demonstrates all but three of the 50 PCT clusters recorded scores less than 50%. This is clearly an area which requires renewed focus.

**Table nine: Effective pain and symptom management 'all of the time' in last two days by PCT Cluster**

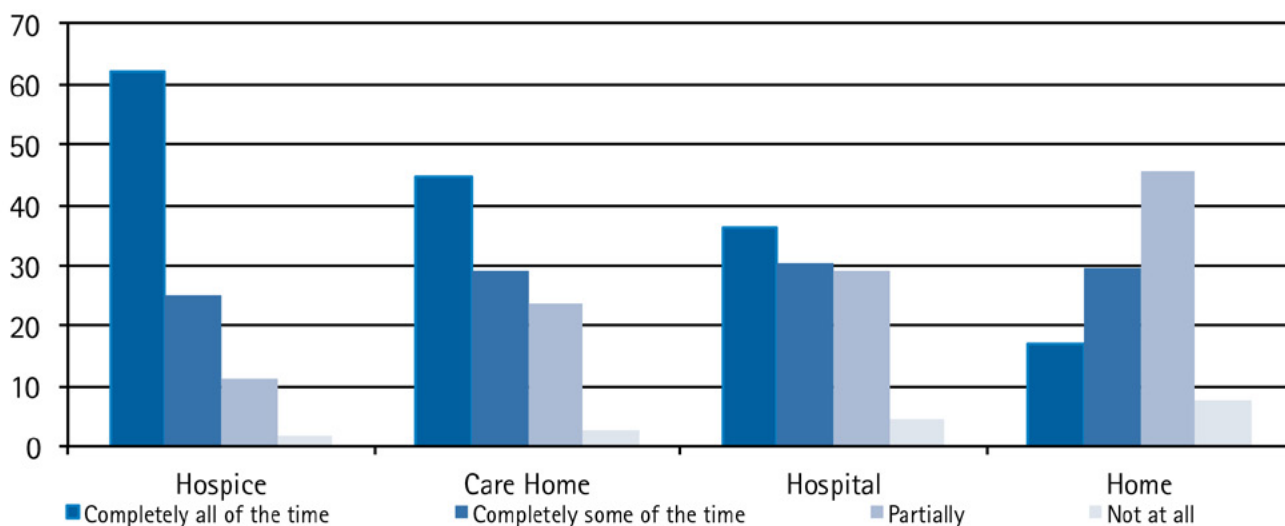


Data source: Office for National Statistics analysis of the National Bereavement Survey (VOICES)

[Click here to find out how your local area compares](#)

Having examined the averaged results across PCT clusters, it is important to return to the VOICES Survey report to explore differences in pain and symptom management across different settings. Table 10 sets out the percentage responses across hospital, hospice, care home and home.

**Table 10: Effective pain and symptom management 'all the time' in the last two days by setting**



Source: Office for National Statistics National Bereavement Survey (VOICES), 2011

There are three particularly noteworthy points to acknowledge here. First is the significant difference between the proportions of respondents who said that they felt that pain had been managed 'completely all of the time' in hospices (62%) compared to other settings, for example hospitals (36.1%). In total, 86.9% of hospice respondents felt that pain had been managed completely all of the time or completely some of the time. This compared to 66.5% for hospitals.

The second noteworthy point is the position of care homes as the setting with the second highest responses for pain and symptom management (completely all of the time) at 44.8%. Again, this runs counter to often repeated perceptions of care homes and delivery care. Third, just 16.8% of respondents felt that pain and symptoms had been managed completely all of the time for patients at home. It has been suggested that this is probably a reaction of the Harold Shipman scandal which had made General Practitioners reluctant to prescribe at home. As [Dr Clare Gerada](#) of the Royal College of General Practitioners (RCGP) noted:

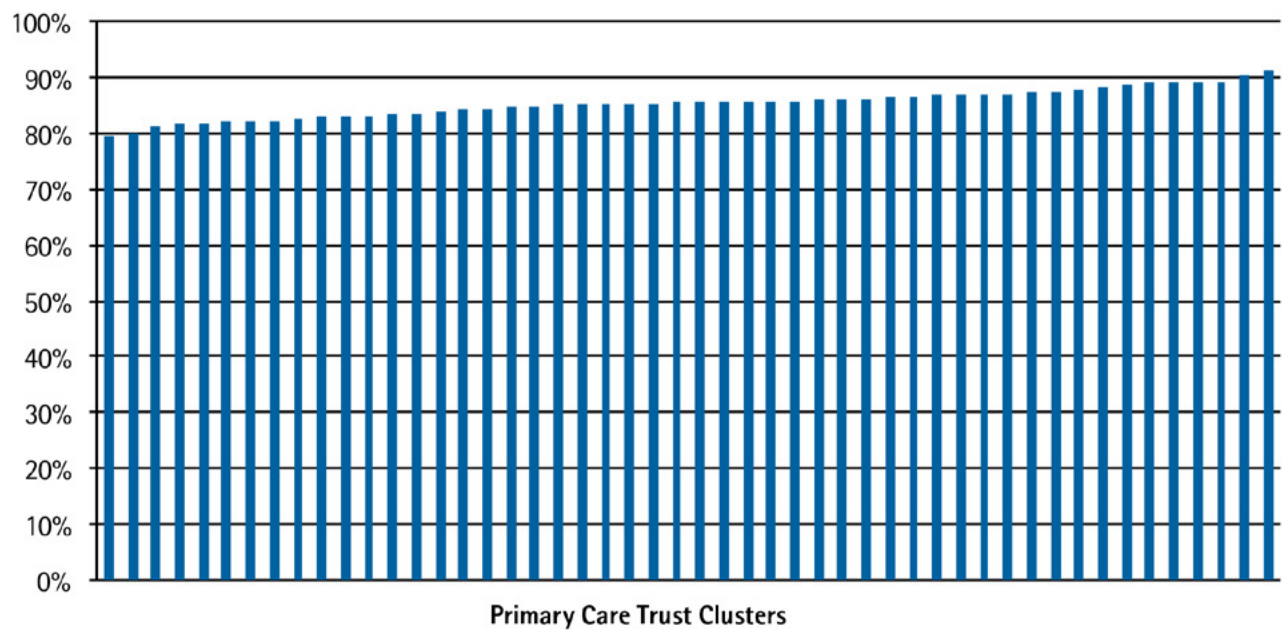
**'One of the problems is an unintended consequence of the Harold Shipman inquiry. GPs are very reluctant to use heavy duty analgesics on their patients generally, and also for things that are not malignant, like osteoporosis. We deal with it very badly.'**

The survey demonstrates that we need to improve pain and symptom management across the board in order to increase the proportion of families who feel that their loved ones experienced pain and symptom management completely all of the time. This can be monitored via future VOICES Surveys, but will also require specific actions in all settings, and the development of guidance and appropriate training for relevant staff. It is suggested that we need to specifically focus on improving pain and symptom management in both hospitals and at home.

Involvement in decisions about care

One of the most encouraging messages to emerge from the VOICES Survey is the high degree to which respondents believe that they were involved in decision making about care. All PCT clusters recorded ratings of 79.6% or more, with the highest scoring 91.4%.

Table 11: Proportion that felt deceased was involved in decisions about care as much as they wanted by PCT Cluster



Data source: Office for National Statistics analysis of the National Bereavement Survey (VOICES)

It is clear that we must build on this result and ensure that we continue to drive up standards in terms of patient, carer and family involvement. This will ensure that the lowest performers improve the levels of involvement in decision making to the same levels as those areas which score highest. This will require training and guidance for clinicians and other staff.



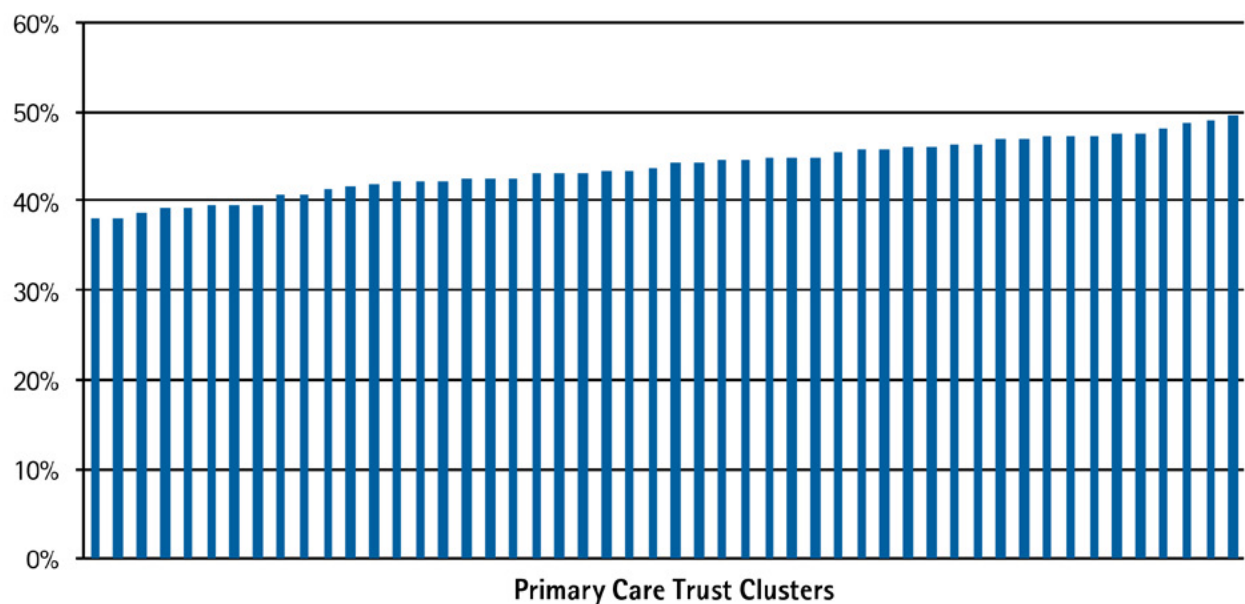
### Expressed a preference about place of death

The survey supports the notion that the majority who do express a preference state that they would prefer to die at home, yet the majority continue to die in hospital. As the survey states:

**For those who expressed a preference, the majority preferred to die at home (71 per cent). However, the most commonly recorded place of death was a hospital (53 per cent).**

At the PCT cluster level, there is significant variation in the proportion of people who had expressed a preference about where they would like to die. The lowest proportion was 38.2%, with the highest being 49.5%.

**Table 12: Proportion of people who expressed preferred place of death by PCT Cluster**



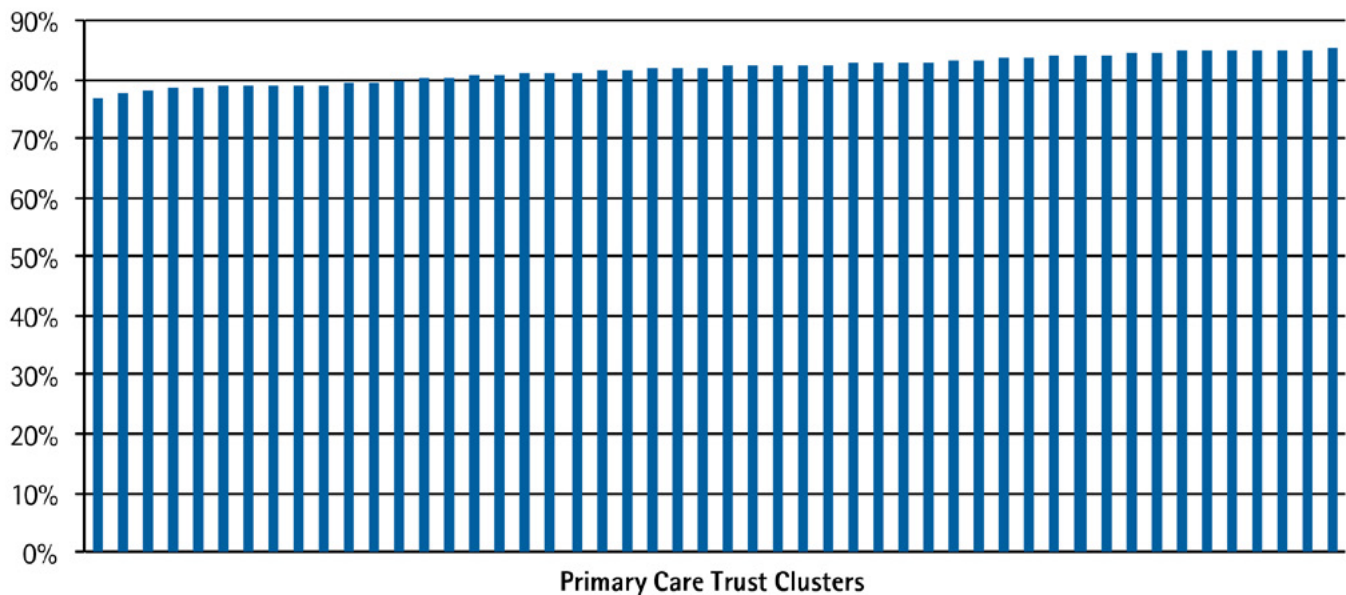
Data source: Office for National Statistics analysis of the National Bereavement Survey (VOICES)

The important question here is whether the relatively low expressions of preference are due to the fact that patients were never asked the question? There is significant literature on the failure or reluctance of a proportion of clinical staff to initiate end of life conversations. This may be a particular issue for generalists who do not routinely initiate such conversations. All health professionals need to be supported to do so. The question of [where someone wishes to die](#) is such an important part of end of life care. Asking the question early could help tailor care and support the needs and preferences of individuals and their families. We need a robust approach to training doctors and nurses – starting with substantial modules in initial medical training and regular refresher sessions throughout one's career.

Preferred Priorities: Respondent considered deceased died in the right place

Closely allied to the question of end of life preference is the question of whether bereaved people felt that their loved one died in the right place. There is little variation across PCT cluster, from 77% to 85.3% – indeed this is the lowest variation level of any question in the survey.

Table 13: Proportion of respondents who thought deceased died in the right place by PCT Cluster



Data source: Office for National Statistics analysis of the National Bereavement Survey (VOICES)

This particular result presents something of a contradiction. As previously noted, a majority of those who expressed a preference, stated that their loved one had expressed a wish to die somewhere other than in hospital. However, as we know the majority of people died in hospital and as table 13 shows, more than 75% felt that their loved one had died in the right place. It is important that we unpick what is happening here. One hypothesis is that individuals had expressed a preference to die at home, but had to be admitted to hospital because their pain could not be adequately controlled at home. We need to understand more about both preferences and perceptions of whether someone died in the right place.

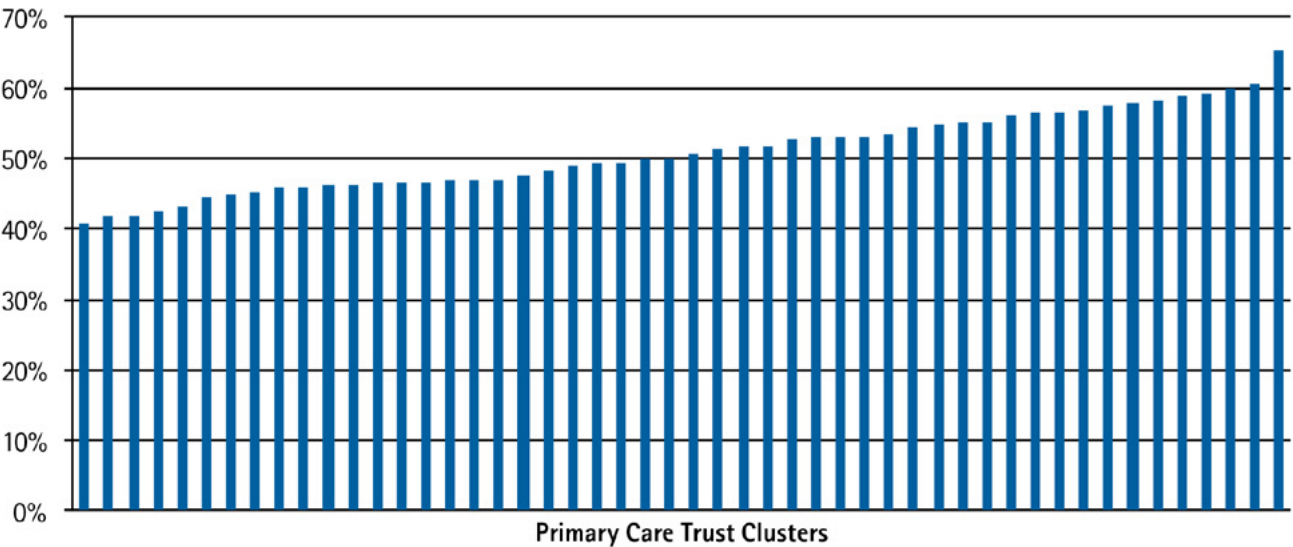
In the interim, it is important that a high proportion of people perceive that their loved ones died in the right place. We must continue to drive up the proportion year on year. It is crucial that we continue to support health professionals to initiate vital conversations about what people want at the earliest points and throughout the period of care.

### Support for carers in the last three months of life for those at home

An often overlooked aspect of care of the dying is the degree of support in place for family and carers whilst the dying person is at home. The role of carers is crucial to ensuring that, where desired, people can remain at home. It is also crucial that carers receive the support that they need to enable people to remain at home.

The survey asked bereaved people whether they felt supported whilst their loved one was at home. This solicited the widest variation in responses. As table 14 shows, there was a variation of 24.7%, with 40.6% at the lower end and 65.3% at the top end of the spectrum.

**Table 14: Proportion of carers by PCT Cluster who felt well supported**



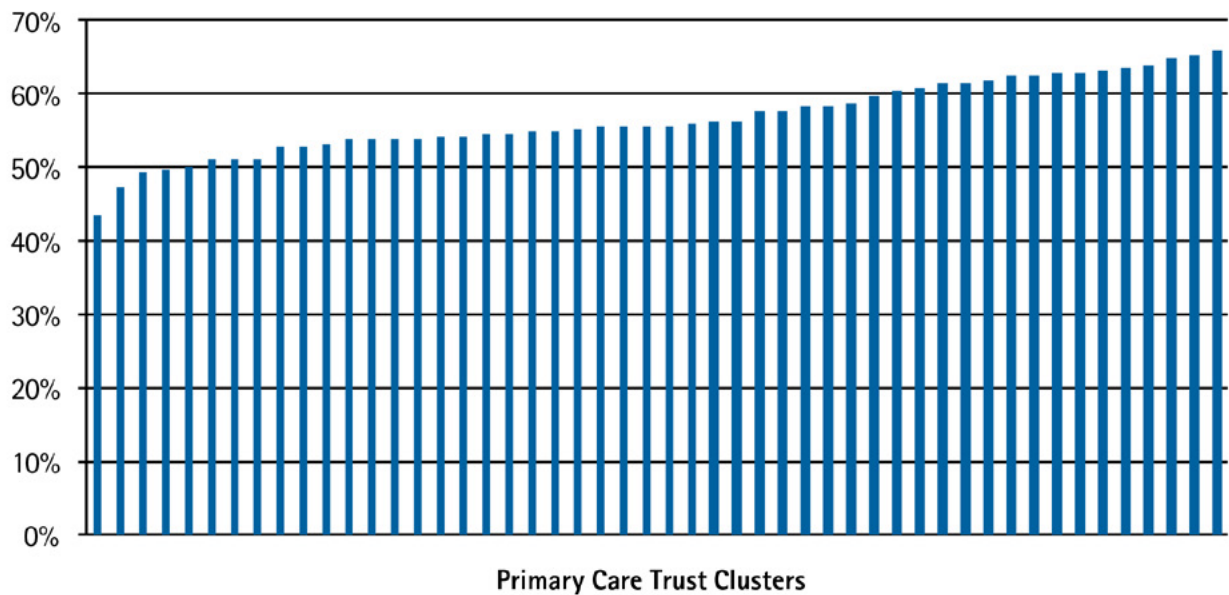
Data source: Office for National Statistics analysis of the National Bereavement Survey (VOICES)

[Click here to find out how your local area compares](#)

## Support for carers: Able to discuss worries or fears with GP

The role of GPs in end of life care is a central one in the support of carers. The degree of variation in responses to the question about whether individuals felt 'able to discuss worries or fears with GP' ranged from 43.3% to 66.1% – a variation of 22.8%. Table 15 illustrates this variation.

**Table 15: Proportion of carers who felt they could discuss worries and fears with GP by PCT Cluster**

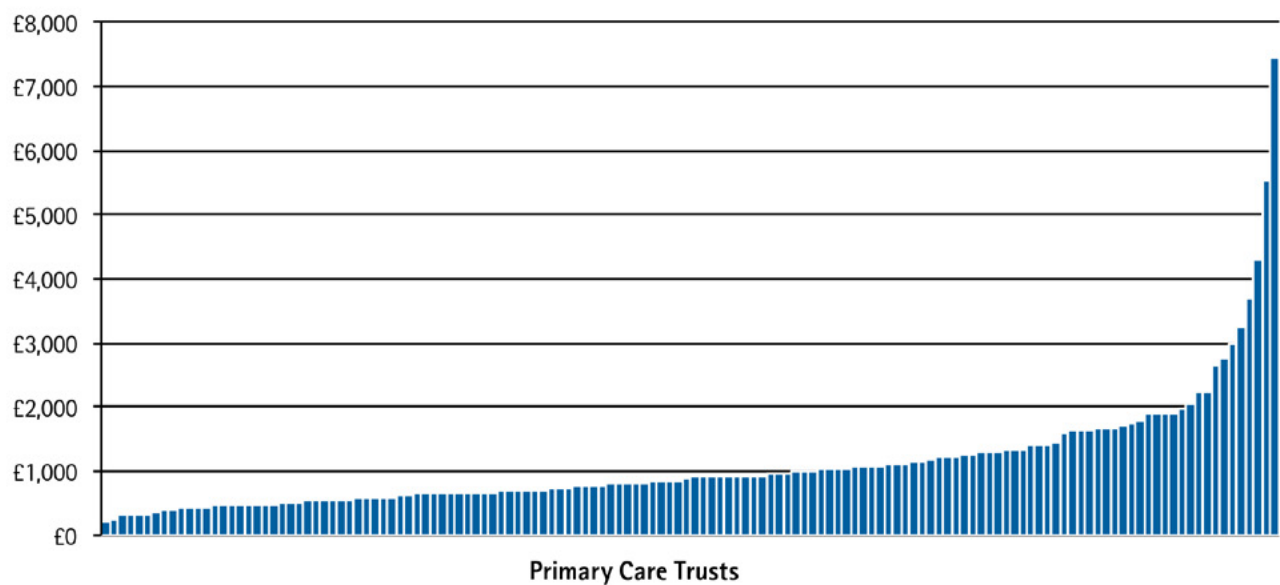


# 3: Variation in spending on end of life care

Spending on end of life care could provide an interesting measure of end of life care. However, the quality of data available means that it is almost impossible to make informed decisions about the impact of end of life care spending and the resulting impact on outcomes for dying people and their families.

The central issue is that the data which providers publish about palliative and end of life care shows such vast variation. This is most starkly illustrated by table 16 which shows that declared NHS spend on specialist palliative care (SPC) per death varies from £193 to £7,445.

**Table 16: Declared NHS spend on specialist palliative care per PCT death**



[Click here to find out how your local area compares](#)

Initial assumptions might lead one to conclude that some authorities were spending very little whilst the others were putting substantial resources into end of life services. However, in some instances high spends might reflect excellent well sourced, multi-team care, whilst in others it may mean that there is an excessive use of hospital-based care.

However, the scale of variation would suggest that there may be other factors at work. The most likely explanation for this considerable variation is that different areas are reporting against very different criteria. Some are likely to be including all NHS spending, including specialist end of life care services, whilst others simply record direct spending on core end of life services (per death).

We need greater consistency in the way in which spending on end of life services is reported. This could be achieved by introducing a standardised formula for reported end of life spending, such as that which exists for spending for cancer. These were introduced following [similar concerns about variation in cancer spend reporting in 2008-09](#).

This new end of life spending reporting mechanism should be supported by detailed guidance to assist administrators in accurately calculating and reporting spending.

If we are to have an open and honest debate about spending on end of life care, and to determine whether there is an optimum figure per death, then our first step must be to ensure that we have accurate and reliable data. The Palliative Care Funding Pilots are currently collecting data which, it is proposed, will form the basis of a future end of life care tariff.

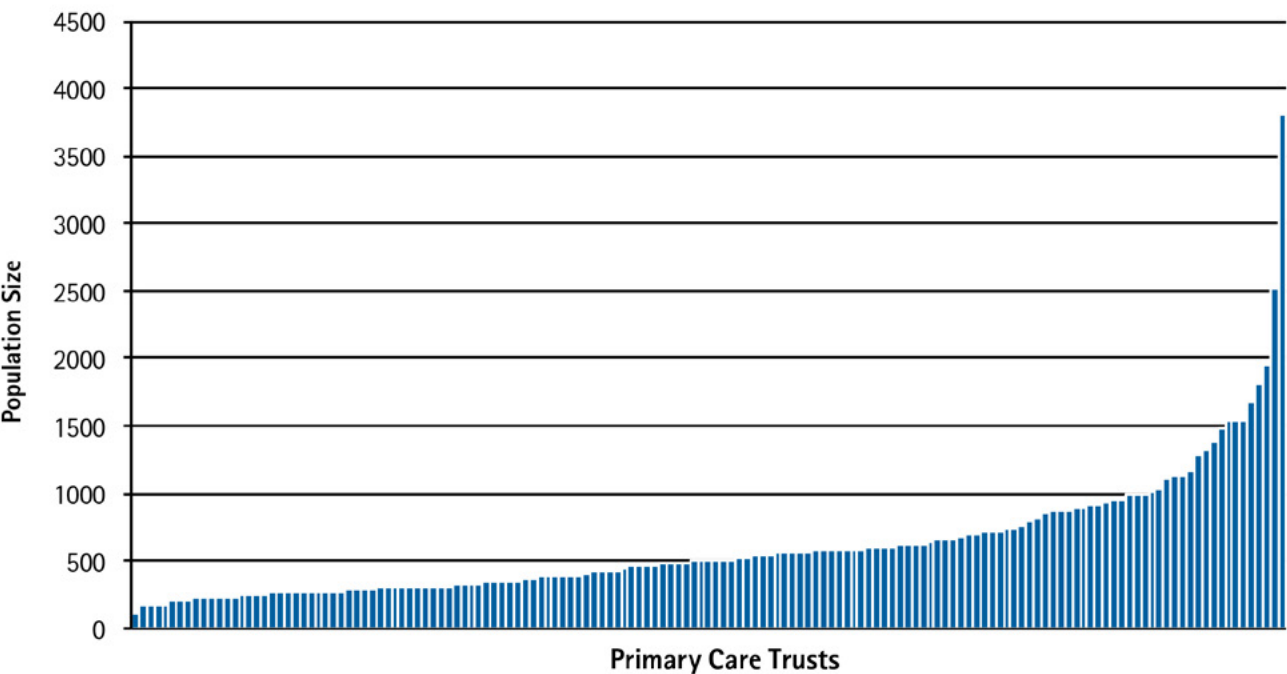
# 4: Variation in the recognition of end of life care

Identifying when someone requires palliative care, and latterly end of life care is an important part of the care process. Palliative Care Registers (PCR) play a key role in enabling people to access excellent end of life care. Their use should mean that individuals can be signposted into relevant and appropriate services.

There are three ways to measure the effectiveness of PCR use. The first is to simply count the number of people on QOF Palliative Care Registers.

The total number of people on [QOF Palliative Care Registers in England](#) in 2010-11 was 93,000. This is a point in time estimate dating from March 2011. However, use of PCRs varies considerably across the country, with the lowest ranked PCT having just 115 individuals recorded on the local PCR. This compares to 3,817 people in the highest 'performing' PCT area.

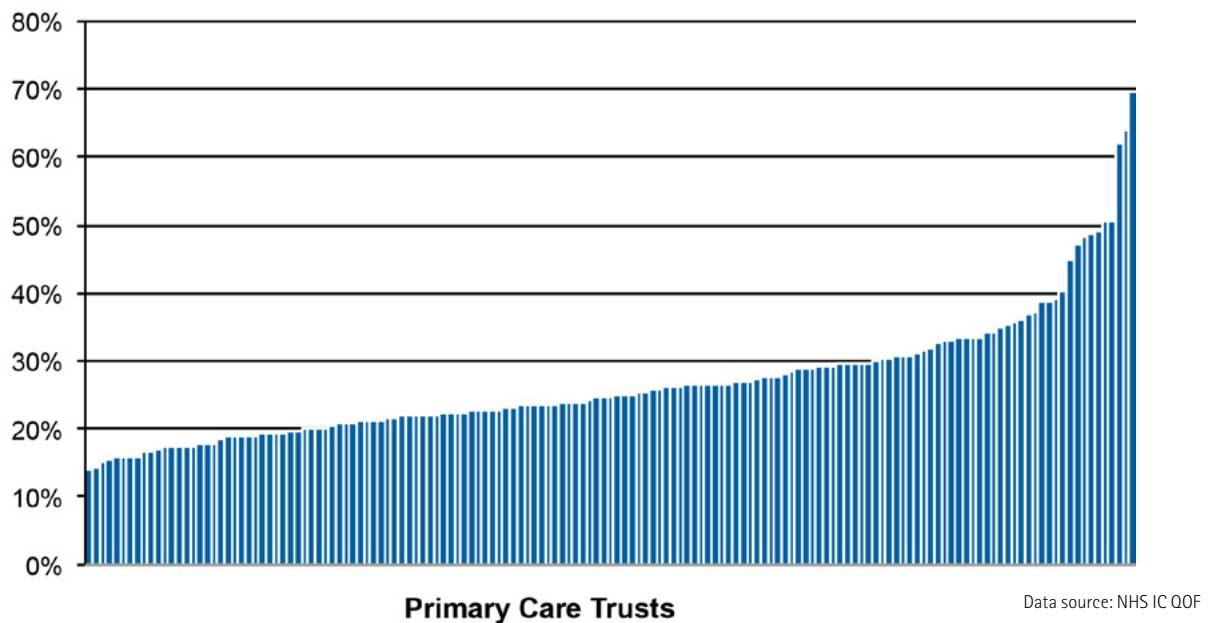
**Table 17: Number of PCT population on QOF Palliative Care Register**



Data Source: Quality and Outcomes Framework 2010/2011, NHS Information Centre

The second measure is to look at estimates for the percentage of [deaths of people with palliative care needs](#) who were on the Palliative Care Register. Nationally, 26% of deaths with palliative care needs were on the Palliative Care Register. Local variation is again considerable, ranging from 14% to 70% – a variation of 56%. Of greater concern, just five PCTs scored more than 50%. Table 18 sets out the national picture.

**Table 18: Estimated percentage of people per PCT with palliative care need on a Palliative Care Register**



[Click here to find out how your local area compares](#)

The final measure of the effectiveness of Palliative Care Registers is to look at the estimated percentage of all deaths that were listed on Palliative Care Registers. The variation is again huge, ranging from 11% to 53%. Just 12 PCTs scored 30% or more.

The three measures together underline that we have a significant problem – that in the vast bulk of the country we are simply not identifying sufficient numbers of people with palliative care needs, prior to their deaths.

We need to reemphasise the use of Palliative Care Registers and ensure that we increase the number of people that we identify at the earliest possible stage. To help increase the local use of Palliative Care Registers, it is important that we try to learn from those areas in which there is evidence that the local approach to end of life care is leading to increased use of PCRs and the better identification of those with palliative care needs. Some of the stronger performers appear to have prioritised end of life care more generally, developing local strategies and producing detailed guidance materials for local health professionals. This appears to have ensured a wider focus on end of life care locally.

Whilst it is important that we identify people with palliative care needs at the earliest possible stage, this should merely be the first step. We should also see increased support for people who are terminally ill so that they can exercise choice about their care and ultimately about where they want to die.

There is emerging evidence from an independent evaluation of Marie Curie Cancer Care's Somerset [Delivering Choice Programme](#) that higher PCR performance can translate into lower hospital death rates or higher scores for local service quality. We need stronger performance measures which gauge quality of care and delivery of excellent quality of care. Rewarding GPs for QOF palliative care registration may be the wrong measure.

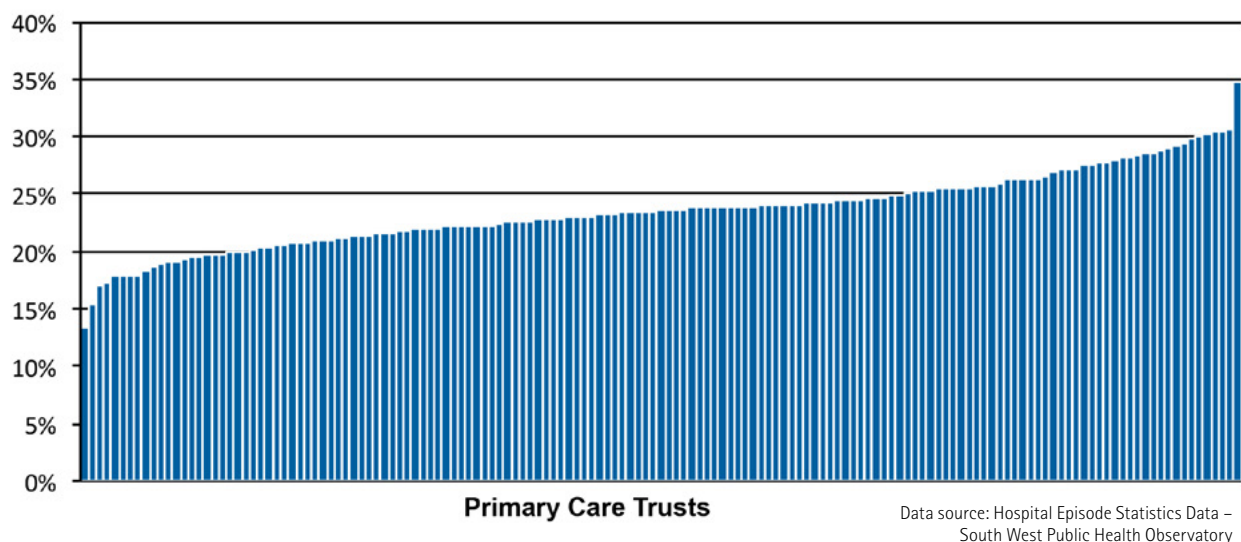


# 5: Variation in hospital use prior to death

As we saw in chapter two, hospitals are consistently rated by bereaved relatives as providing poorer care and lower levels of dignity and respect for people in the last hours and days of life. It is therefore interesting to look at the differences in hospital use at the end of life.

The most obvious measure is the length of time that individuals spend in hospital prior to their death. Table 19 shows the proportion of all deaths in an area that are preceded by a hospital admission of eight days or more. The average for England is 24%; with the highest proportion being 35% and the lowest 13%.

**Table 19: Eight+ day terminal admissions as a percentage of all deaths per PCT**



[Click here to find out how your local area compares](#)

It is not possible to determine the principal reasons for such variation, but it is assumed that those areas with lower rates are more effective at moving patients into more appropriate settings, or preventing them from being admitted to hospital in the first place. Table 19 also demonstrates that a number of areas have much lower numbers of people who are spending prolonged periods in hospital prior to death.

A crucial factor in determining one's likelihood of dying in hospital is geography and specifically whether you live in a rural or urban area. The King's Fund has noted a clear [urban/rural divide](#) in terms of general hospital bed use. It notes that the PCTs with the lowest levels of bed use are almost exclusively rural, whilst seven of the 10 trusts with the highest bed use are urban.

The conclusion is that 'populations closer to services such as Accident and Emergency (A&E) are more likely to use them' (King's Fund). Analysis of data regarding end of life care appears to affirm this pattern. A far greater proportion of people die in hospital in urban areas than rural ones. Table 20 shows that there is an almost 10% difference between hospital death rates across England, with the differentiation clearest between outer London (London Cosmopolitan and London Suburbs) and elsewhere.

**Table 20: Hospital death rate by English area type**

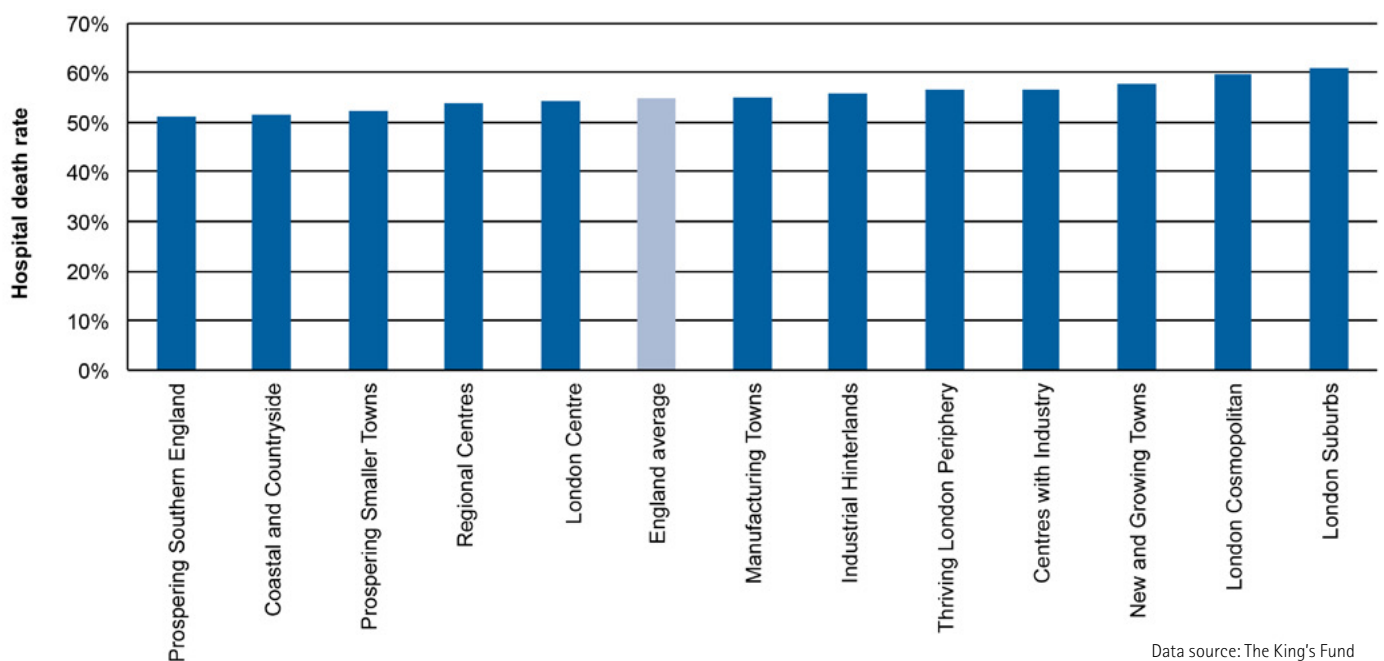
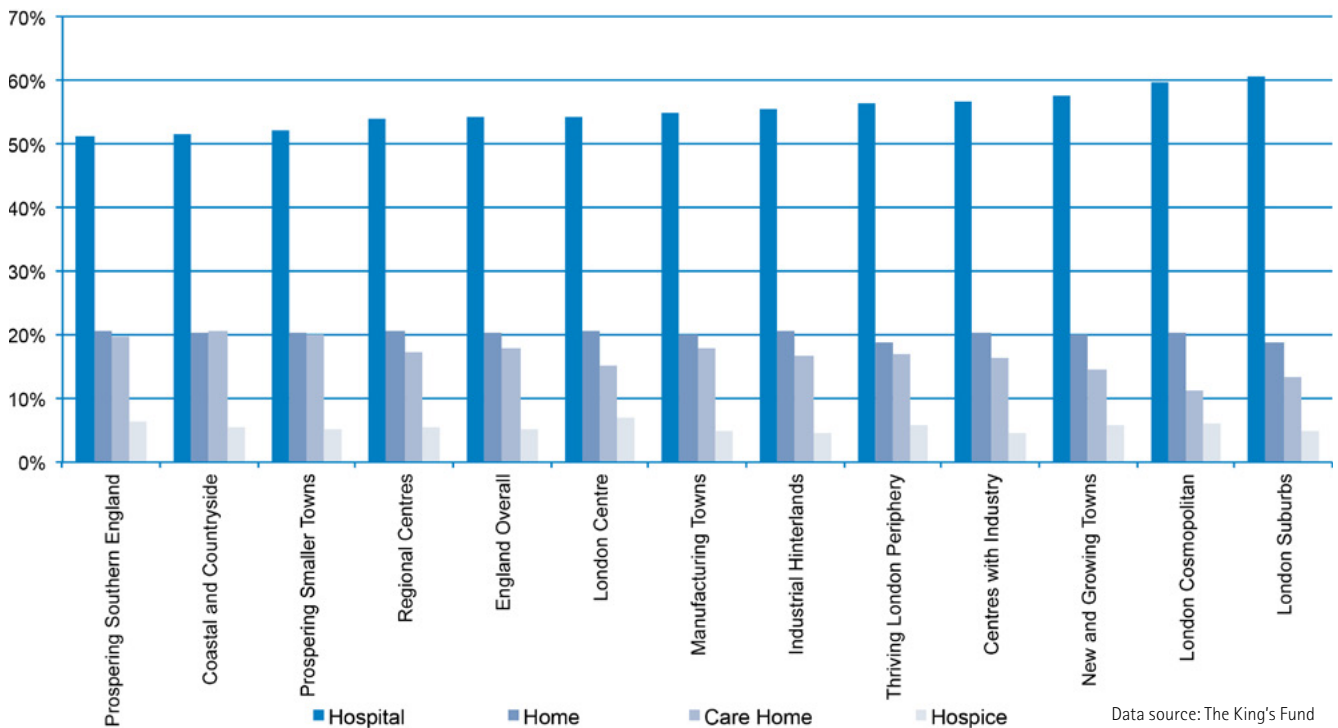


Table 21 sets out place of death (setting) by location type. In those areas which can loosely be labelled less urbanised, a greater proportion of people are dying at home or in care homes, with a slightly higher proportion dying in hospices.

It is important that as we seek to improve end of life care nationally, we reflect the differences between rural and urban areas. We must ensure that everyone has access to excellent end of life care and can exercise real choice which enables them to spend their final days of life properly supported, surrounded by their loved ones and comfortable, regardless of where they live.

**Table 21: Place of death by English area type**



# 6: Conclusions

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No matter whether one looks at experiences, perceptions, expenditure or outcomes, it is clear that there is significant variation in experiences for people at the end of life across England.

Within a unified health system such as the NHS it is important that we strive to ensure that we minimise such 'bad' or 'avoidable' variation so that people can access the same high standards of care, regardless of where they live, their age, diagnosis and the type of services they use.

The bottom line is that 'avoidable' variation in all facets of end of life care can result in the inefficient use of scarce resources.

## Chapter one

Explores the significance of demography for end of life care. Differing demographic patterns underline the importance of designing and commissioning services which reflect local populations, patterns of disease and current provision.

**Recommendation: Clinical Commissioning Groups and Local Area Teams should follow [NICE Quality Standard QS13](#) for end of life care. Commissioners should use the Marie Curie End of Life Care Atlas so that they can commission services and adjust targets to reflect local need.**

## Chapter two

Examines experiences of care, as seen through the eyes of those who had lost a loved one in the previous year. The VOICES Survey provides an invaluable source of data and a fresh perspective. It is important that the survey becomes an annual occurrence and is valid at CCG level.

The clear message to emerge is that hospitals score worst for most measures of care, coordination and support, with higher ratings for hospices, home and residential care homes. This supports a fundamental shift away from hospitals to home and community-based services.

However, we must acknowledge that any such shift would take time and that it is important that we improve end of life care in hospitals. Equally we must focus on improving pain management for those who are cared for at home.

**Recommendation: Marie Curie Cancer Care should work with the Royal Colleges to improve initial and continuous end of life care training for doctors and nurses and improve prescribing and pain management for patients at home.**

### Chapter three

Demonstrates the very clear variation in local spending on end of life care. We quickly concluded that a radical overhaul of reporting on end of life care spending in England is needed.

**Recommendation: The National Commissioning Board should adopt a standardised approach to reporting spending on end of life care, such as that used for cancer spending.**

### Chapter four

Illustrates the divergent levels of recognition of palliative care needs and use of Palliative Care Registers across England. It is clear that this variation is not simply explained by demographic differences, but rather reflects wider differences in local priorities.

The recognition of palliative care needs should be the first step in setting in motion a series of interventions which support the person through to death. It is important that we move toward more outcomes-focused measures of performance.

**Recommendation: The National Commissioning Board should develop outcomes-based Key Performance Indicators (KPIs).**

### Chapter five

Shows that where you live has a significant impact on where you die. It illustrates the very real differences in hospital death rates and the length of time people spend in hospital prior to death across England. The most striking differences are to be found between urban and rural areas.

It is important that we explore how we can reduce the number of people who find themselves in hospital in the last few weeks and days of life, who do not want to be there.

**Recommendation: As a first step, the coalition government should immediately introduce free social care funding for those in the last six months of life. In the longer term, commissioners must grasp the nettle and shift the balance from hospital to community-based care. This will require a fundamental shift in thinking and ultimately in the ways services are funded.**

# 7: What does this mean for policy and practice?

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Having explored the available evidence, it is important to think about what all this means for national and local policy and service delivery.

It is clear that the current models of end of life care, which rely disproportionately on hospital-based services, no longer provide the best model of care for people at the end of life, or represent the most effective use of resources.

It is also important to remind ourselves that we face two major challenges over the coming decades. First, our ageing population and second, the ongoing constraints on public service spending. These will require us to deliver better quality services for more people and with less money. In addition, the current NHS reforms mean that health and social care services are undergoing unprecedented change.

We can either see this as a daunting challenge, or a unique opportunity. Demographics, finances and structural changes conspire to provide us with the chance to fundamentally change the way in which we organise and deliver health and social services. End of life care represents an excellent case study which can demonstrate just how this might be done.

We know from asking terminally ill people what type of services they want at the end of life; that they prioritise being surrounded by their loved ones; being comfortable (pain free) and for the majority to die in a place other than in hospital. We also already know that a significant proportion of those who die in hospital have [no medical need](#) to be there. A National Audit Office report of one area of the country in 2008 found that:

**'40 per cent of patients who died in hospital in October 2007 did not have medical needs which required them to be treated in hospital, and nearly a quarter of these had been in hospital for over a month.'**

If this is being replicated across the country then we are in a position whereby people neither want or need to be in hospital in the final days and weeks of life. This neither serves the interests of patients or the wider healthcare system.

Modelling work undertaken by King's College London for the [Palliative Care Funding Review](#) projected:

**'that delivering improved recognition of palliative care needs, as well as optimised provision of services outside the hospital setting, could potentially reduce deaths in hospital by up to 60,000 a year by 2021. Using the QIPP estimate of £3,000 per hospital death, this would translate to a potential reduction in hospital costs of £180m per annum.'**

This is further supported by the latest work by the Nuffield Trust examining [the impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life](#). This demonstrates that excellent community-based nursing services can not only provide more personalised services, but can also prevent accident and emergency use and hospital admissions at the end of life. Providing the right support for people in their own home (including in residential care homes) is better for patients and their families, but also better for the NHS.

The [Francis report](#) has further underlined important issues relating to the quality of hospital-based care. We should be looking beyond hospitals to other settings to provide more, excellent quality end of life care. The overarching conclusion is that many people are dying in hospital when they could be better supported to die in other settings.

A fundamental reorganisation of the way end of life care services are organised and delivered will require health and social care commissioners to take the bold decision to shift a proportion of current funding for acute services into community-based and collaborative services. As a first step, they should provide additional funding for early discharge schemes and increased at home support. For many, the reality is that too many people find themselves stuck in hospital because of the inability to secure funding for health and social care locally. For many, the current system is too slow. This issue could be solved by the coalition government enacting free social care for all those in the last six months of life.

The fundamental reorganisation of the NHS, which is currently underway, represents the perfect opportunity to redesign and rebalance end of life care. Starting with the National Commissioning Board, working through Clinical Commissioning Groups and local NHS Trusts and on to General Practitioners and nurses in localities across England, the most important thing is that we ensure a strong focus on end of life care. We must seize the opportunity afforded us and ensure that people in the last year of life get the services they require; in the place of their choice, being pain free and surrounded by the people they love. This report demonstrates that we have the evidence, what we need now is the political will to affect the fundamental changes which will ensure better quality care for dying people, even against the background of massive demographic change and shrinking finances.

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Marie Curie Cancer Care provides high quality nursing, totally free, to give people with terminal cancer and other illnesses the choice of dying at home, supported by their families.

**[mariecurie.org.uk](http://mariecurie.org.uk)**

