



## Local preferences and place of death in regions within England 2010

---

Barbara Gomes, Natalia Calanzani, Irene J Higginson

August 2011

---

Cicely Saunders  
International  
Better care at the end of life

---

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

Comments about this report should be addressed to Barbara Gomes at Cicely Saunders Institute, Bessemer Road, London SE5 9PJ ([barbara.gomes@kcl.ac.uk](mailto:barbara.gomes@kcl.ac.uk)), and copied to the National End of Life Care Intelligence Network at [information@neolcin.nhs.uk](mailto:information@neolcin.nhs.uk).

---

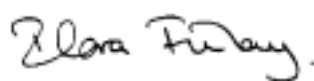
## Foreword

---

This report, published a few days ahead of the End of Life Care Strategy Third Annual Report, represents an important step in improved national intelligence about end of life care across England. It provides us – health care professionals, care managers, policy makers and politicians – with the most updated information aimed at understanding people’s choice on place of death when approaching the end of life. Each year about 460,000 people die in England.

The research team from Cicely Saunders International has been conducting pioneering work on place of death since the very beginnings of this charity, in 2002, when it was founded by Dame Cicely. Reviewed by an international scientific panel of experts, which I am honoured to be part of, the research outputs strive to make a substantial contribution, with rigour and quality. This report is no exception.

Those of us working in palliative care know how important it can be for patients to spend their last days where they want to, often at home with their families. For many people their second choice would be to end their days in a hospice, yet there is still a long way to go until the majority in society live the closing days of their life and die where they wish to. The report provides data on which national and local policies and services can build – showing variations within the country, unveiling the preferences of different groups in our society, quantifying the gap between preferences and reality for place of death. Sensible recommendations are drawn from the data. As a result, I am confident that real improvements in care will follow to support people through better care wherever they want to be at the end of life, now and for generations to come.



Baroness Finlay of Llandaff  
Professor of Palliative Medicine FRCP FRCGP  
Member of the Cicely Saunders International Scientific Expert Panel



# Contents

Page

	Executive summary	5
1	Introduction	6
2	Methodological notes	7
	2.1. Death registration data	7
	2.2. PRISMA survey of preferences	7
	2.3. PRISMA sample in England	8
3	Importance of dying in the preferred place	10
4	Preferences for place of death	11
	4.1. Most preferred place of death	11
	4.2. Least preferred place of death	14
5	Actual place of death	15
6	Limitations and discussion	18
	6.1. Preferences for home and hospices	18
	6.2. Care homes and hospitals	19
	6.3. Older people	20
7	Recommendations	21
8	References	22
	Acknowledgements	23

# Executive summary

This report shows public preferences for place of death in the nine English Government Office Regions (GORs), obtained from a population-based telephone survey in 2010. It compares the results with a similar survey carried out in 2003 to understand how preferences are evolving over time. It goes on to contrast these preferences with actual place of death (as reported for that region) in order to shed light on how people's wishes relate to reality and to aid care planning so that preferences are more frequently met.

## Priorities for end of life care

The proportion for whom dying in the preferred place was either the first or the second most important care-related priority was lowest in London (55%) and highest in the North East (75%).

## Most and least preferred places of death

The majority of participants in all regions said that they would prefer to die at home if circumstances allowed, ranging from 60% in West Midlands to 67% in the North East. Hospice was the second most frequent choice, especially in the South East and the East of England (where about a third of participants chose this). Home and hospices together accounted for the preferences of at least 89% of participants in every region. As age increased, a preference to die at home decreased while a preference to die in a hospice increased (except for the group aged 55-64). Preferences for home death ranged from 45% (for those aged 75+) to 75% (for those aged 25-34).

When compared with 2003 data, a preference to die at home has increased in most regions (except in the West Midlands and

the South East). This increase from 2003 to 2010 was largest in London (49% to 63%) and the North East (55% to 67%) and was evident across all age groups, except the oldest (65+). A preference for hospice death has also increased, except in the North East. This increase was largest in the East of England (rising from 15% in 2003 to 32% in 2010) but there were considerable age variations since a hospice preference decreased amongst the younger sector of the population and increased amongst the oldest sector over these years (except for the 55-64 group).

Hospital was the least preferred place of death in all regions except for the North East, where 34% reported care home as their least preferred place (against 31% for hospital).

## Quantifying gaps between preferences and actual deaths

Comparisons of survey data on preferences with contemporary official statistics on place of death suggest that most people are still likely to see their preferences unmet regardless of where they live. The majority of deaths in 2010 took place in hospitals (53%) and only 21% died at home. Across the country, there is a major gap between the proportion who prefer to die at home and the proportion of actual home deaths – this gap is smaller in the West Midlands (39%) and larger in the North East (46%), but remains wide whichever area is reviewed. The gap between the proportion who prefer to die in a hospice and the proportion of actual hospice deaths is smallest in the North West (20%) and largest in the East of England (27%). For those aged 75+, there is a large gap between a preference to die

in a hospice (41%) and hospice deaths (3%). This age group accounts for 67% of all deaths in the country in 2010.

## Addressing gaps between preferences and reality

It is crucial to address these gaps between preferences and reality. Maximum impact is derived from focusing future investment and service developments in extending and improving care at home and in hospices. This supports the preferences of the large majority of the population. It requires increased collaborations between NHS and non-NHS institutions such as independent, voluntary and social care organisations. Services such as Hospital at Home, for example, expand the provision of palliative care into home settings and have been found to significantly increase people's chances of dying at home.

It is also imperative to understand people's views of care in hospitals and care homes, to define quality standards for end of life care and ensure these are followed, since the majority still die in hospitals and more may die in care homes in the context of an ageing population. Preventing unnecessary hospital admissions while delivering better care at home should, however, remain the priority.

The oldest population (75+) deserves special attention. Greater access to hospice beds needs to be ensured since this group has the highest hospice preference, yet the lowest chance of hospice death than any other adult age group. Policies and benefits should also be considered to enable more older people to die at home as this is still the most frequent preference amongst the aged 75+. ■

# SECTION I

## Introduction

The National Health Service (NHS) End of Life Care Programme (established in 2004) and the End of Life Care Strategy (published in 2008) (1) have been working to increase the number of home deaths based on available evidence that most people prefer to die at home, but also guided by the idea that a “good death” is about being respected, dying with dignity and as comfortable as possible, no matter who one is, where one lives and irrespective of care setting.

From a financial point of view, it is not possible to keep the same high numbers of deaths occurring in hospitals. Moreover, mortality projections from the Office for National Statistics (ONS) predicted a dramatic rise of total numbers of deaths from 2012-16 onwards (3). Projections for place of death alerted for the implications of past trends continuing, and the need to plan ahead for increasing numbers of people in need of end of life care, particularly in older ages (4).

people at the end of life and in care in alternative settings, in particular care homes. In order to guide care planning, it is necessary to understand the preferences of different age groups and how these vary within England.

Population-based studies on preferences for place of death are scarce in England (7). In 2003, a study conducted by Cicely Saunders International and published by the National Council for Palliative Care surveyed 1000 adults (in England, Scotland and Wales) on where they would like to be cared for if they were dying. The study found the majority preferred home (56%), followed by hospice (24%), but there were geographical variations (8). The study also found age differences, with a preference for home falling with increased age although small numbers of participants within the age group of 65+ precluded further analysis.

The present report builds upon this previous work; it describes people’s preferences for place of death in England obtained as part of a cross-national survey in Europe conducted in 2010 (9). It also contrasts people’s wishes with where deaths take place in their region. Furthermore, it compares the preferences in 2010 with those from the 2003 survey. Geographical and age variations are examined. Implications for care, limitations of the study and recommendations are discussed. ■



A previous report from the National End of Life Care Intelligence Network showed that in 2005-2007 most people in England died in hospital but highlighted some regional variations in place of death – hospital deaths ranged from 54% in the South West to 66% in London (2). More investigation was needed to examine whether these variations reflected differences in preferences for where to die.

In 2008, two-thirds of deaths occurred at ages of 75 and over, and it is known that in England people dying in this age group have fewer chances to die at home (5-6). It is unclear whether this is the result of complex clinical and social circumstances associated with older age or of different preferences amongst older people. Care commissioners are therefore left with the decision of how much to invest in home care for older

## Methodological notes

### 2.1 Death registration data

The mortality data presented in this report on numbers of deaths by GORs and place of death information are provided in aggregated tables by the ONS (10). These statistics derive from death registration records. We report provisional data to those published in the autumn 2011 on all deaths registered in England in 2010. This was kindly provided by the ONS Mortality Statistics team. The nine English GORs are the North East, the North West, Yorkshire & the Humber, East Midlands, West Midlands, East of England, London, the South East, and the South West.

For the purposes of clarity and comparison with survey data, we report place of death in four ONS recently re-designed categories (10): 1) home; 2) hospice (including NHS and non-NHS); 3) hospital (including NHS and non-NHS); and 4) care homes (including local authority and non-local authority). Note that some of these new ONS categories are not directly comparable to categories used in previous years (e.g. many care homes were previously coded as “hospitals and other communal establishments for care of the sick” together with hospitals, but are now coded into a separate category). We do not report the numbers and percentages of deaths taking place in “other communal establishments” (which include “aged persons’ accommodation” and other communal facilities such as “assessment centres”, “schools” and “prisons”) and “elsewhere”. However, we took all ONS categories into account when calculating the proportions of deaths in the four places examined.

### 2.2 PRISMA survey of preferences

The data on preferences for place of death derive from the PRISMA survey - conducted in 2010 by King’s College London in partnership with 11 partner organisations. The work was funded by the European Commission under the Seventh Framework Programme (FP7) as part of the PRISMA project. This was a three-year integrated programme (2008-2011) to coordinate research priorities and practice about end of life care across Europe and Africa (9).

The questionnaire was administered on the telephone to 9,344 participants (aged  $\geq 16$ ) randomly selected in seven European countries, including England. Other regions were Flanders, Germany, Italy, the Netherlands, Portugal and Spain. The survey included only private households (this excluded communal establishments such as hospitals and care homes). The questionnaire included questions on the importance attached to dying in the preferred place compared to other two care-related aspects on information and decision-making (Box 1).

#### Box 1 - PRISMA questions on place of death

In a situation of serious illness like cancer with less than one year to live....

#### Priorities for care

What would matter most to you in the care available?

- A)** Please choose the one you think would matter most to you.
- Having as much information as you want
  - Choosing who makes decisions about your care
  - Dying in the place you want
- B)** And in second place?

#### Preferences for place of death

- A)** Where do you think you would prefer to die if circumstances allowed you to choose?
- In your own home
  - In the home of a relative or friend
  - In a hospice or palliative care unit - places with specialised care and beds for dying patients
  - In hospital - but not in a palliative care unit
  - In a nursing home/residential home
  - Elsewhere
- B)** Which of these do you think you would least prefer if circumstances allowed you to choose?

Participants were also asked where they would most and least prefer to die if they had a serious illness and less than one year to live. In the present report, we abbreviate the categories “hospice or palliative care unit” to hospice and “nursing/residential home” to care home.

We compare PRISMA data on preferences for home death by GOR and age group to the findings from the 2003 survey for England (8). There are three methodological differences: 2003 data are weighted, questions related to place

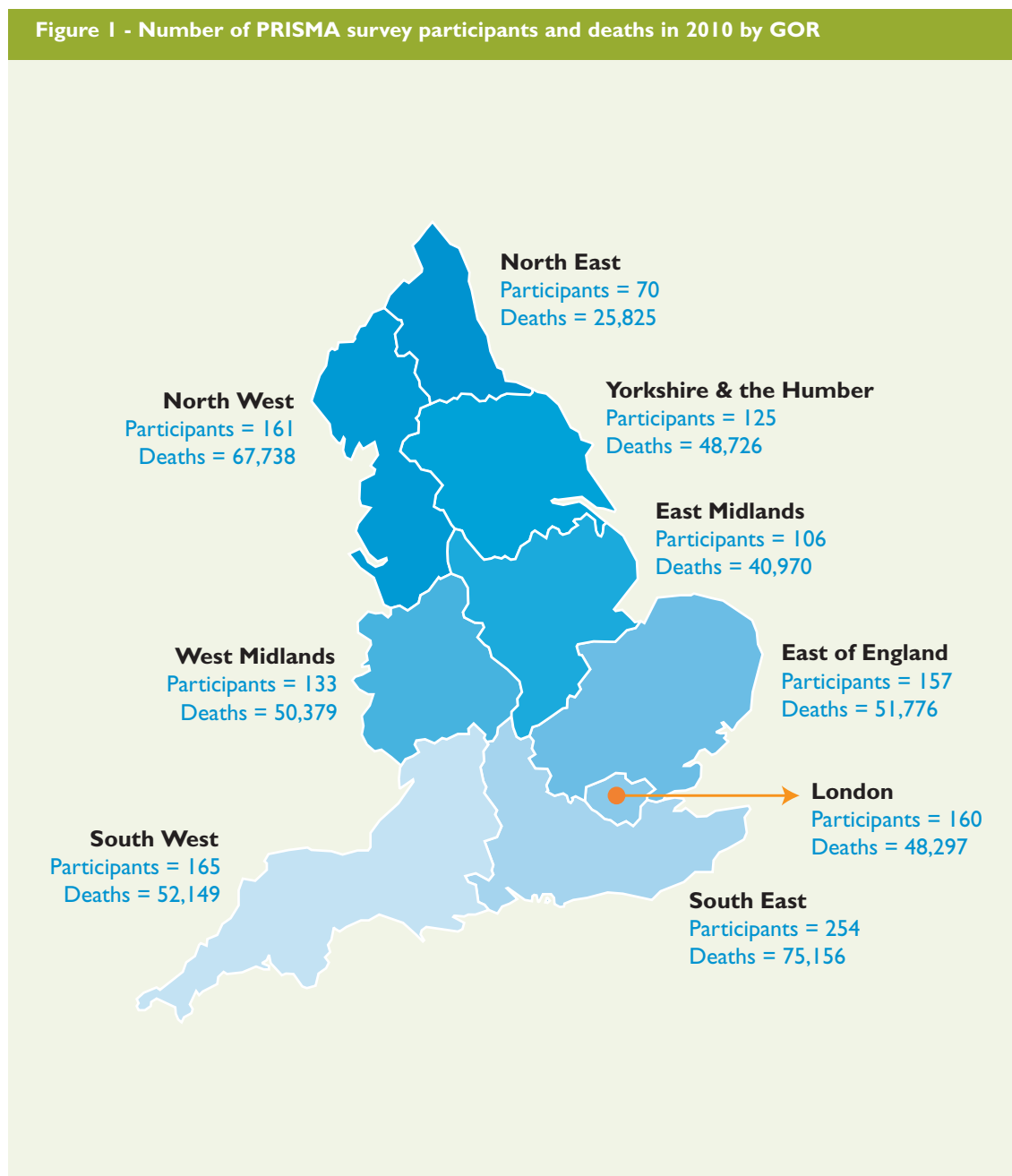
of end of life care rather than place of death and the available options were home, hospice, hospital, nursing/ residential home and other/don't know. In addition, the age group 65+ was further broken down into 65-74 and 75+ in 2010. We contrast people's preferences with actual place of death in their region in 2010 to see the extent of the gap in the different regions and age groups. Quotes regarding place of death included in the report were provided by participants in the PRISMA survey.

### 2.3

#### PRISMA sample in England

A total of 1,351 adults (64% female, median age 56) were interviewed in England from May to October 2010 (response rate 21%). Figure 1 shows the number of survey participants in each GOR as well as the number of deaths that took place in the same GOR in 2010. Thirteen percent of participants had been personally diagnosed with a serious illness in the last five

Figure 1 - Number of PRISMA survey participants and deaths in 2010 by GOR





years; 71% had lost a close relative or friend to death and 63% had a close relative or friend diagnosed with a serious illness in the last five years. Fifty one percent of

participants had supported or cared for a close relative or friend in their last months of life. The majority of participants were 45 years or older (Figure 2), with at

least a fifth aged from 55-64 in every region (from 22% in London and the West Midlands to 28% in the East of England, North East and Yorkshire & the Humber). ■

**Figure 2 - Age distribution of PRISMA survey participants by GOR**

<b>GORs</b>	<b>16-24</b>	<b>25-34</b>	<b>35-44</b>	<b>45-54</b>	<b>55-64</b>	<b>65-74</b>	<b>75+</b>
Yorkshire & the Humber	5(4%)	8(7%)	24(20%)	29(24%)	34(28%)	15(12%)	8(7%)
West Midlands	5(4%)	9(7%)	21(16%)	29(22%)	29(22%)	27(20%)	12(9%)
South West	7(4%)	14(8%)	26(14%)	30(16%)	44(24%)	40(22%)	21(12%)
South East	13(5%)	13(5%)	49(20%)	43(17%)	58(23%)	38(15%)	36(14%)
North West	8(5%)	12(8%)	19(12%)	38(24%)	38(24%)	28(18%)	17(11%)
North East	4(6%)	6(9%)	13(19%)	16(23%)	19(28%)	8(12%)	3(4%)
London	10(6%)	18(12%)	24(15%)	26(17%)	35(22%)	24(15%)	19(12%)
East of England	7 (4%)	10(6%)	33(21%)	21(13%)	43(28%)	30(19%)	12(8%)
East Midlands	4 (4%)	13(13%)	15(14%)	16(15%)	24(23%)	23(22%)	9(9%)
All England	63(5%)	103(8%)	224(17%)	248(19%)	324(24%)	233(18%)	137(10%)

*Sums may not always amount to 100% because of rounding. Age distribution did not differ significantly across GORs (Kruskal-Wallis test=9.039, p-value=0.339)*



# SECTION 3

## Importance of dying in the preferred place

“In an ideal world we would like to die in our bed surrounded by our family. To achieve this we need specific care”

67 years old, female resident in the East of England

“I believe that people should be able to die where they want, in terms of location”

42 years old, female resident in the North West

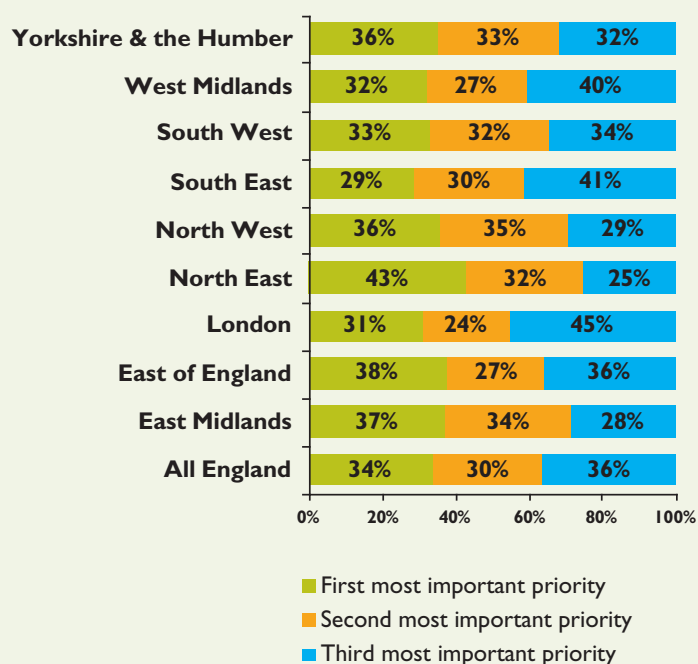
“I think it's very good that there is an opportunity to discuss how we want to die. Hopefully we will be able to choose”

58 years old, female resident in the East Midlands

The proportion for whom dying in the preferred place was either the first or the second most important care-related priority was lowest in London (55%) and highest in the North East (75%), as shown in Figure 3. Between 29% of participants in the South East and 43% in the North East said that dying in the preferred

place was the first most important of the three aspects (when provided with the choice of three options: dying in the preferred place, getting as much information as wanted and choosing who makes decisions about their care). Between 24% in London and 35% in the North West said it was the second most important priority. ■

Figure 3 - Dying in preferred place as first, second and third care-related priority by GOR



There was a trend towards the significance of the geographical differences seen in the graph (Kruskal-Wallis test=15.445; p-value=0.051). Sums may not always amount to 100% because of rounding.

# Preferences for place of death

## 4.1

### Most preferred place of death

More than 60% of participants in all nine GORs would prefer to die in their own home if circumstances allowed them to choose (Figure 4). This proportion was highest in the North East (67%) and lowest in West Midlands (60%). A preference to die in a hospice was the second most frequent in all nine GORs (ranging from 26% in the North East and North West to 32% in the South East and East of England). Altogether, home and hospices accounted for the preferences for place of death of more than 89% of people in all nine GORs (ranging from 89% in Yorkshire & the

Humber to 94% in the South East and East of England). The variation observed in preferred place of death by GORs was not statistically significant.

Those who had cared for a close relative or friend in their last months of life were more likely to prefer to die in a hospice than those who had not had the experience (33% versus 25% respectively;  $\chi^2$  test=9.424;  $p$ -value=0.002). This was the only statistically significant difference on preference for place of death regarding experience of illness, death and dying.

“My father passed away in a hospice last August and it was absolutely excellent. The family were included as much as we wanted to be in everything. The quality of care was superb and I personally wish that everybody had that end of life care and end of life option because it opened my eyes completely”

45 years old, female resident in the West Midlands

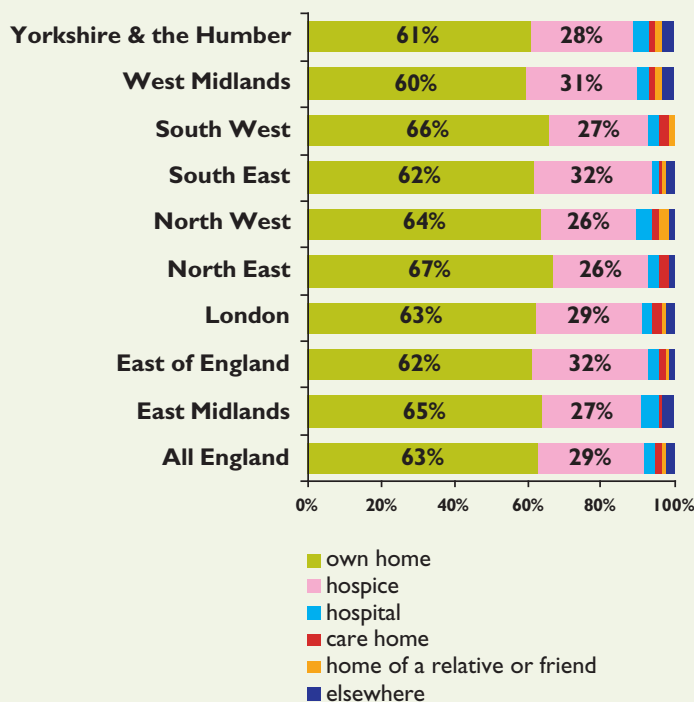
“My dad died on a camp bed at home, and my mum came home and it was so much improved when she died. She had everything she wanted, and we brought her home for five days”

57 years old, female resident in the East of England

“I do firmly believe that people should be given a choice and help to die in their own home if they wish. I do think more help should be given”

57 years old, female resident in the East Midlands

Figure 4 - Most preferred place of death by GOR



There were no significant geographical differences ( $\chi^2$  test=21.123;  $p$ -value=0.994).

Figure 5 shows that a preference to die at home decreased as the age increased (except for the 25-34 and 55-64 age groups, where there was an increase), while the opposite happened to a preference to die in a hospice (except for the latter age group). The youngest age group (16-24) had the lowest proportion of

people who would prefer to die in a hospice.

When comparing the PRISMA results with the 2003 survey it can be seen that there was an increase in the proportion of people who wish to die at home in most GORs, except in the West Midlands and the South East, where proportions decreased

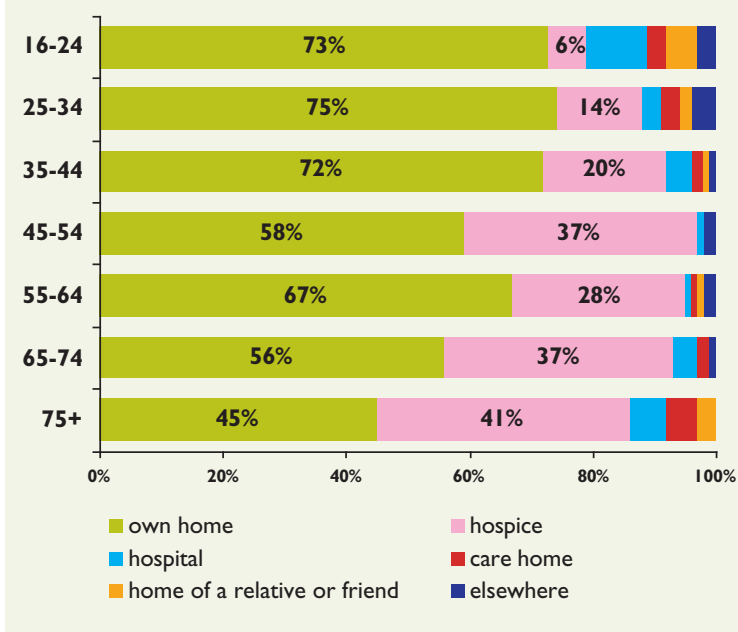
slightly (Figure 6). The increase was most pronounced in London (14%) and the North East (12%). The proportion of people who prefer to die in a hospice increased in most regions (except in the North East where it decreased by 8%), especially in the East of England (17% increase) and the West Midlands (10% increase).

“Ideally people would prefer to die at home. But considering their symptoms they can’t because of breathing problems. People work, and [worry about] being a burden. You can’t do what you want to do”  
53 years old, female resident in the South East

“I hope I don’t die quickly as my mother died in a hospice, and if I had the chance I would die in a hospice as well”  
69 years old, male resident in the North West

“There are very few hospices available and there should be more constructed, as they cost approximately the same as hospitals, but the environment at the hospice is a lot more relaxed and soothing”  
50 years old, male resident in the North East Midlands

Figure 5 - Most preferred place of death by age group



Age differences were statistically significant (Kruskal-Wallis test=43.287; p-value<0.001).

Figure 6 - Preferences for home and hospice by GOR: 2003 and 2010

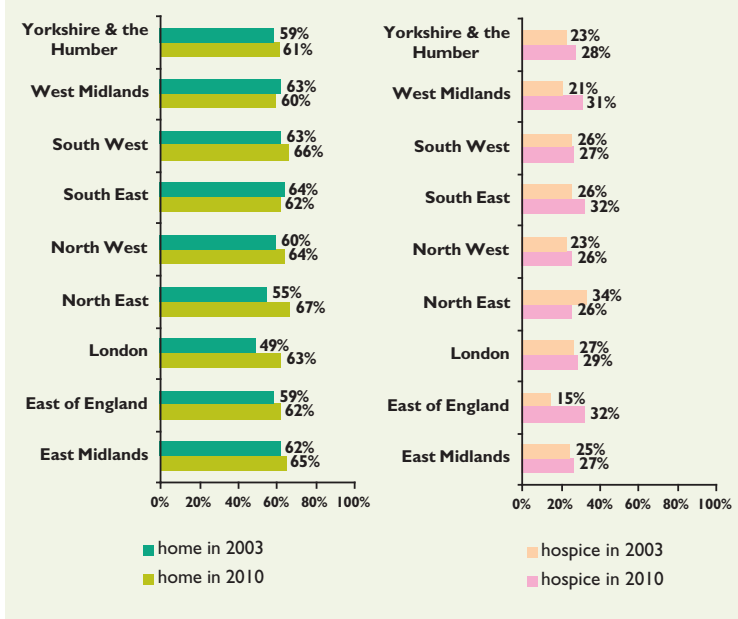
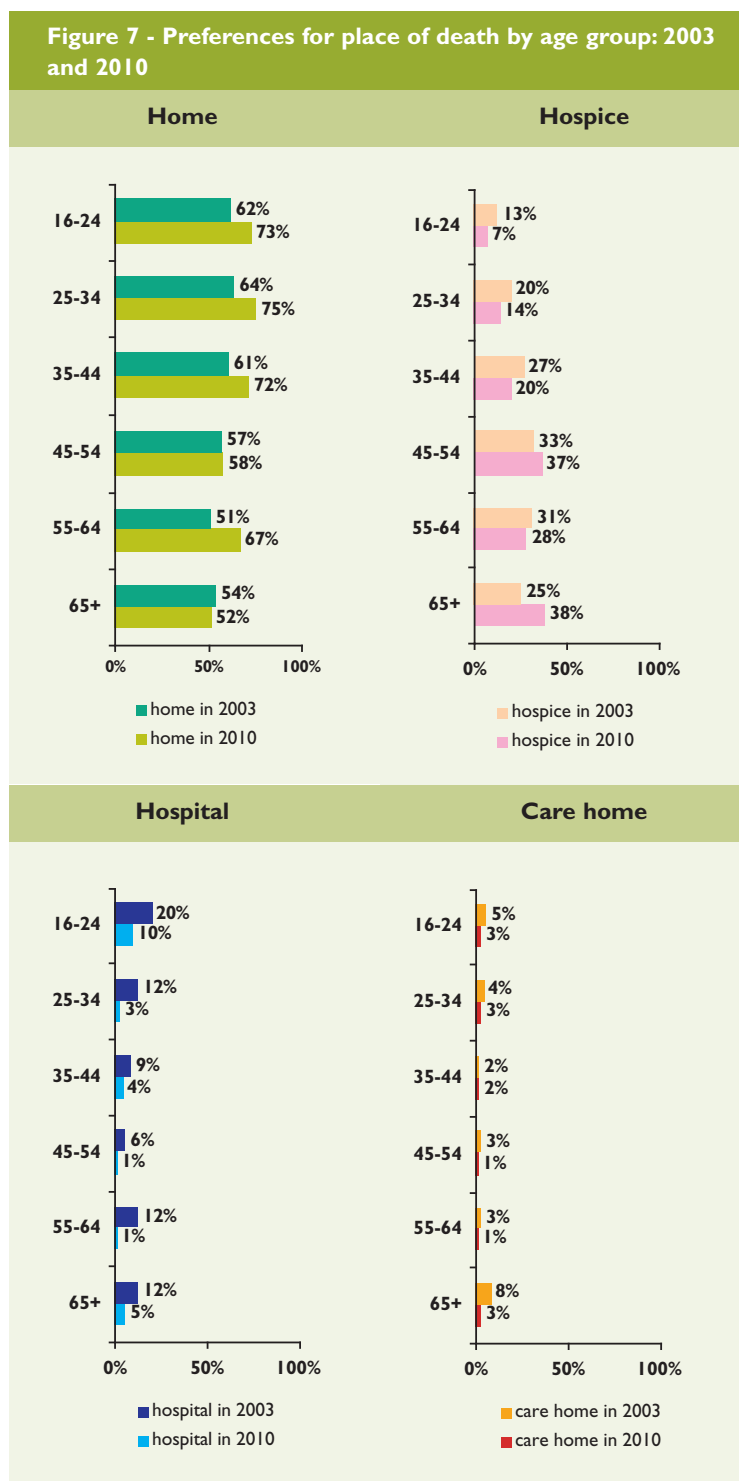


Figure 7 shows that preferences for home increased over time across almost all age groups (except in the aged 65+), particularly amongst the 55-64 age group (from 51% to 67%, an increase of 16%). Preferences for hospice showed a wider variation according to age. The proportion

with a preference for hospice decreased in the younger age groups (up to 44 years), especially in the 16-24 age group (from 13% in 2003 to 7% in 2010). They also decreased in those aged 55-64. In contrast, they increased in the 45-54 age group and in the 65+ (in the latter from 25% in 2003 to

38% in 2010). A preference for dying in hospital decreased in every age group, with the greatest decrease in the 55-64 group (from 12% to 1%). Although the numbers were small, the proportion of those who wished to die in a care home also decreased in all age groups except for the 35-44 group.



“Residential places are hard to find for elderly people. If someone was to provide us with better residential places that would be a lot better”  
*60 years old, female resident in the East Midlands*

“I would give great credit to Macmillan nurses. When my husband was to die, the Macmillan nurses came to my husband and asked for his input on how he would like to die. My husband was happy to speak about this but it was more distressing to me than to my husband”  
*75 years old, female resident in the East of England*

## 4.2

### Least preferred place of death

Hospital was the least preferred place of death in all GORs except in the North East (where the least preferred place was a care home for 34% of participants). However, there was variation in the proportions across regions; hospital was the least preferred place of death for 53% in the West Midlands as opposed to 31% in the North East (Figure 8). Care homes (including nursing and residential homes) were the second most

frequent least preferred places of death (lowest in the West Midlands with 21%).

Hospitals and care homes represented at least two thirds of all answers regarding the least preferred place of death in every GOR (ranging from 65% in the North East to 78% in the East Midlands). The home of a relative or friend was the third most frequent answer in all nine GORs, particularly in Yorkshire & the

Humber (19%), London (17%), the South East (17%) and the North East (16%).

The least preferred place of death varied significantly according to age (Figure 9); the percentage of people who chose hospital decreased as age increased (especially in the 75+). People aged 65+ chose home as their least preferred place of death more frequently and hospital less frequently than other age groups. ■

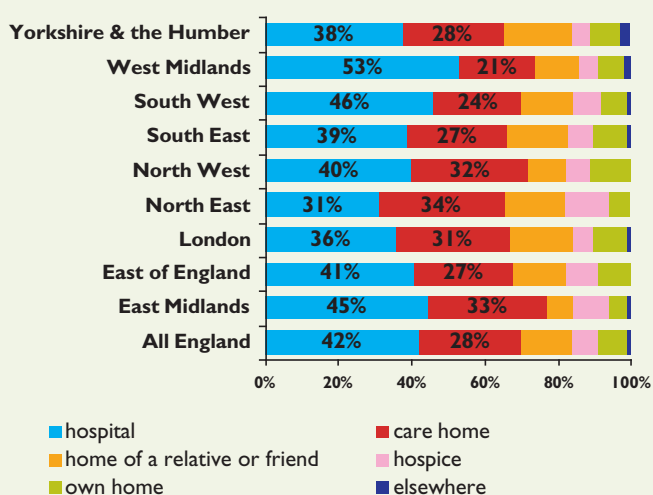
“I see this every day in my work. It's a good thing that you are doing this research. People with a terminal illness should be able to die in a peaceful environment as opposed to a hospital”

36 years old, female resident in the South West

“Round the end of our road there is an old persons' home. It is so old and depressing. I'm a very touch feely person. It would not be just the level of care, it would be the environment too. (...) The chair, the wallpapers. I would never like being in an old persons' home”

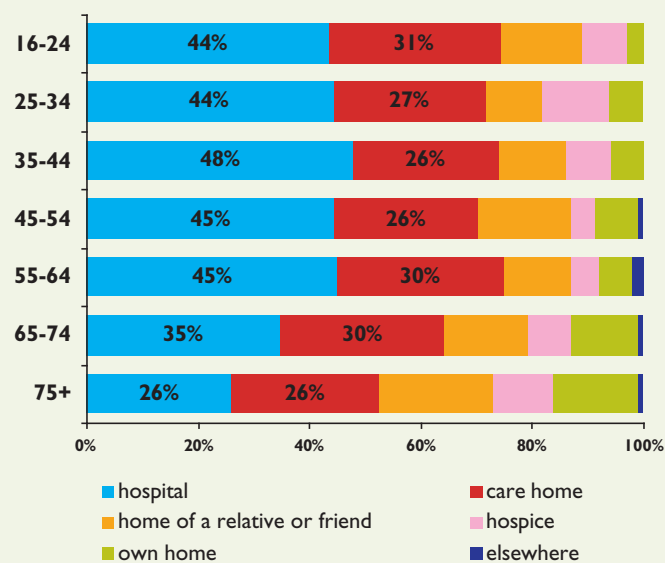
60 years old, female resident in the East Midlands

Figure 8 - Least preferred place by GOR



There were no significant geographical differences ( $\chi^2$  test=45.942;  $p$ -value=0.240).

Figure 9 - Least preferred place by age group



Age differences were statistically significant (Kruskal-Wallis test=24.036;  $p$ -value<0.001).

## Actual place of death

The latest ONS mortality statistics showed that only 21% of all 461,016 deaths in England in 2010 took place at home; this varied from 20% in London, the South East and Yorkshire and the Humber to 22% in the East Midlands and East of England. The majority of people died in hospital (53%) and this varied from 48% in the South West to 59% in London. It is important to note that changes to the coding preclude direct comparisons of these figures with data from previous years. The most comparable of the old categories - hospital and other communal establishment for care

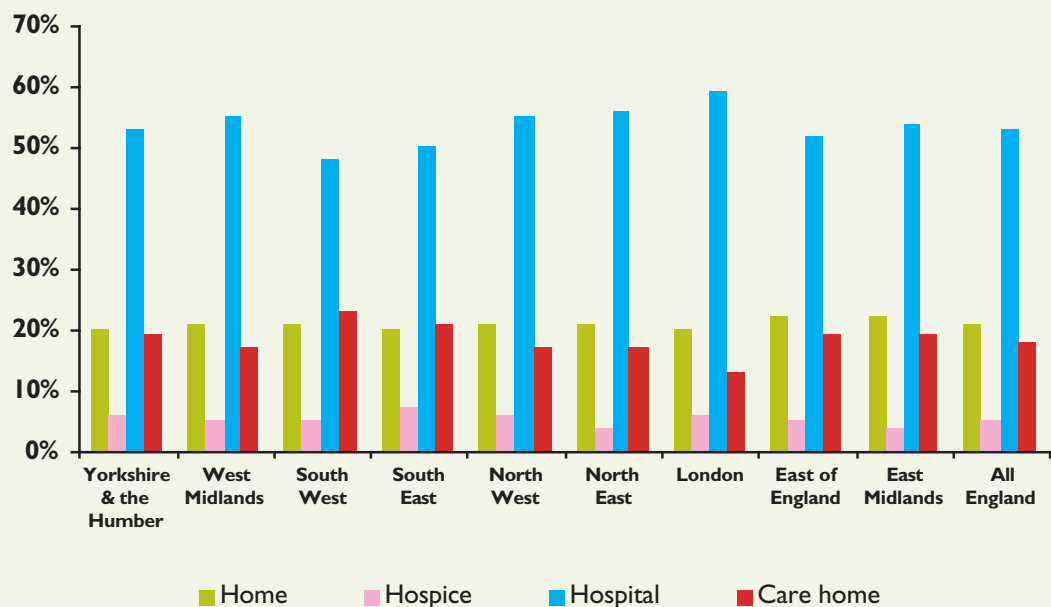
of the sick - included many care homes thus the numbers of deaths were much higher. Coding changes do not impact on the proportion of deaths at home and in hospices, though. A small minority of deaths took place in hospices (5%), varying from 4% in the North East and the East Midlands to 7% in the South East. Eighteen percent of people died in care homes, and this varied from 13% in London to 23% in the South West.

When comparing the proportion of people who would prefer to die at home with the proportion of people who died

at home in each of the regions, the difference (i.e. the gap between local preferences and reality) was of at least 39% (Figure 11 on the next page). This gap was smallest in the West Midlands (39%) and largest in the North East (46%).

When comparing the proportion of people in the population who would prefer to die in a hospice with the proportion of people who died in hospices in each of the regions, the difference was at least 20%. This gap was smallest in the North West (20%) and largest in the East of England (27%).

Figure 10 - Place of death by GOR 2010



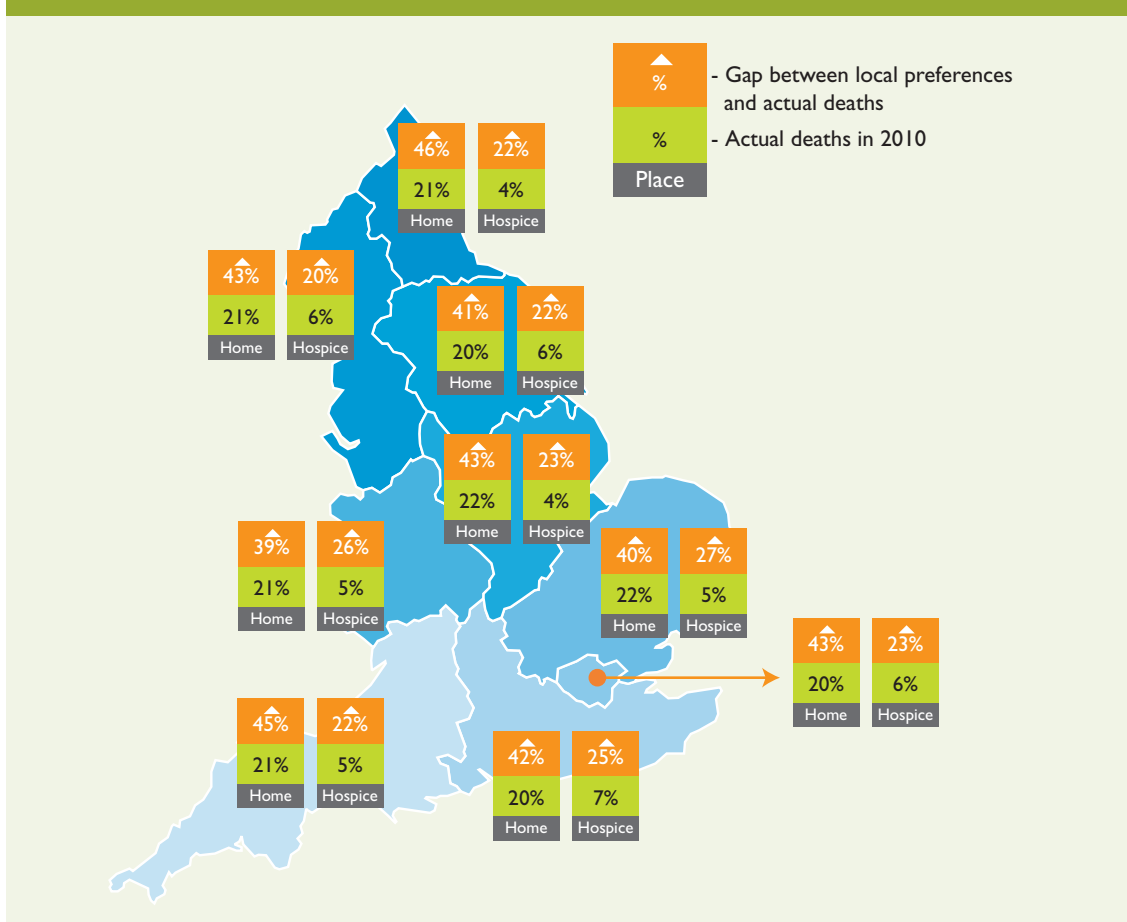
The gap between preferences and actual place of death in terms of hospital and care homes was different as the proportion of deaths in these places was much higher than the expressed preferences of the population to die there. The gap in hospital

deaths ranged from 45% in the South West to 56% in London. The gap in care home deaths ranged from 10% in London to 20% in the South West.

The gap between preferences and reality applied across all age groups and was widest in

relation to hospital deaths, followed by hospice deaths in the 75+. Although 41% of this age group wished to die in a hospice (the group who wanted it the most), only 3% of all deaths at ages of 75+ took place in hospices in 2010 (Figure 12). ■

**Figure 11 - Preferred versus actual place of death by GOR: home and hospice**



The gap between local preferences and actual deaths represents the percentage for preferences minus the percentage of actual deaths, for home and hospices separately.

**Figure 12 - Preferred vs. actual place of death by age group**

Place of death	45-64		65-74		75+	
	Preferred	Actual Deaths	Preferred	Actual Deaths	Preferred	Actual Deaths
Home	63%	32%	56%	28%	45%	17%
Hospice	32%	11%	37%	9%	41%	3%
Hospital	1%	50%	4%	54%	6%	54%
Care home	1%	3%	2%	7%	5%	25%

The three age groups selected for the table represented 96% of all deaths in 2010 (45-64 represented 13%, 65-74 represented 16% and 75+ represented 67% of all deaths).



## Box 2 - Summary points

- ▶ Most people are likely to see their preferences for place of death unmet regardless which GOR they live in England.
- ▶ Fifty-three per cent of deaths in all GORs in 2010 occurred in hospitals, the least preferred place of death in all but one region (North East). London had the highest proportion of hospital deaths (59%), despite seeing the largest increase in preferences to die at home (from 49% in 2003 to 63% in 2010).
- ▶ Although preferences to die at home and hospices seem to have increased from 2003 to 2010, in which year together they covered the preferences of at least 89% in every English region with no significant variation across the nine GORs, only 26% of all deaths in 2010 took place in these places (21% at home and 5% in hospices).
- ▶ Regions where local preferences are likely to be more often met are the West Midlands (for those wishing to die at home) and the North West (for those wishing to die in a hospice); however, even in these regions there is still a large gap between preferences and reality.
- ▶ The largest gap between local preferences and place of death is in the North East for those wishing to die at home, in the East of England for those wishing to die in a hospice, and for people aged 75+ wishing to die in a hospice.



# SECTION 6

## Limitations and discussion

This report provides health care professionals, managers and care commissioners with the latest intelligence on local preferences and place of death. The data suggest that there is still a long way to go until the majority in society have their preferences for where to die fulfilled. To support this process and the work championed by the National End of Life Care Programme and Strategy, we have provided local baseline information to monitor the impact of future changes, we have identified variations within the country (flagged regional nuances to explore reasons why they exist), and we have unveiled some concerns that groups within the society have about certain places of care and death.

### Four main limitations:

- ▶ Using a telephone survey approach to surveying preferences resulted in a relatively low response rate (typical of telephone surveys) and selection biases towards women and older people (i.e. groups that are often at home when calls are made). Knowing where the gender and age differences lie, we are likely to have underestimated the overall home preference and overestimated the hospice preference. The age bias, however, enabled a better examination of the views of those who are potentially closer to reaching the end of life. Since older people are likely to be more aware of their mortality through illness, their views may be more accurately reflective than those of younger people. Selection biases apply to all GORs and do not affect regional and age group comparisons.

- ▶ Comparisons of 2010 and 2003 data on preferences and 2010 data on place of death are limited by the differences detailed in the methodological notes. Moreover, these are indirect comparisons; although the data report to the same regions, it relates to different groups of people. A longitudinal study would allow testing whether preferences change over the years for individuals until death. This report is concerned with societal preferences and reality at a given point in time.

- ▶ We did not survey the preferences of terminally ill patients and the findings reflect largely the views of healthy people; however, the sample included 13% who had been diagnosed with a serious illness in the last five years and their preferences did not significantly differ from those without a serious illness. Still, individual preferences may change as people become unwell and approach the end of life. It is also important to note that having cared for a close relative or friend in their last months of life affected significantly a hospice preference (increasing it), which suggests that knowledge and experience of services may inform choices. None of the other aspects on experience of serious illness, death and dying influenced preferences.

- ▶ In the PRISMA 2010 survey we surveyed private households; care homes residents were therefore not included. Therefore we do not know the views of people who have moved into care homes. Further research with this population group is much needed, as one in every four deaths of people aged 75 years and over take place in care homes.

### 6.1 Preferences for home and hospices

By studying the evolution of preferences from 2003 to 2010 we saw that both preferences to die at home and in hospices seem to have increased, that these two places accounted for at least 89% of preferences in all regions in 2010 and that despite this, only 26% of all deaths take place at home and in hospices taken together, with no significant variation across the nine GORs. Since there were no significant differences in the age distribution of participants in the PRISMA survey across GORs, it is unlikely that age masked any important variations in preferences across GORs. This indicates that in order to narrow the gap between preferences and reality for place of death at both national and local levels, maximum impact is derived from focusing future investment and service developments in extending and improving care at home and in hospices. This supports choice for a large majority (at the same time addressing variations in experiences of care at home), and maximises the impact of new service developments on meeting preferences for place of death for populations.

Such strategy requires increased investment but also close cooperation of NHS and non-NHS institutions such as independent, voluntary and social care organisations. Hospital at Home services, for example, extend the reach of palliative care into home settings and are found to significantly increase patients' chances of dying at home (11). Other case study

examples, such as the Royal Marsden Hospital2Home service, aiming to support patients and families in a choice to be cared for at home can be found at the National End of Life Care Programme website ([www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)).

We flag the case of London. Bearing in mind the region's unique challenges (e.g. densely populated, significant population growth due to births and migration and an extremely ethnically diverse population) (12), this GOR has seen the largest increase in home preferences (from 49% in 2003 to 63% in 2010) and yet, despite efforts and an array of service provision, London continues to have the lowest proportion of home deaths (20%, along with the South East and Yorkshire and the Humber). This is partially shaped by being an urban/suburban area and what is known to be one of the strongest determinants of death at home (proximity to hospital beds) (13), but it is important to find out what else is shaping the mismatch between preferences and reality in London (e.g. ethnicity, cultural and social issues may play a role). A large-scale study (called the QUALYCARE study), funded by Cicely Saunders International and supported by the Department of Health and local NHS authorities, is now examining variations within London (14). The region accounts for 15% of the 51 million people who live in England and for 10% of all deaths (10). A better understanding of London will benefit other urban/suburban regions in England (where 80% of people live) (15).

## 6.2 Care homes and hospitals

Although the data support a focus on home and hospices, it is important to investigate further some geographical variations.

► Whilst the sample was small in the North East, the findings suggest that the importance

attached to dying in the preferred place and a preference to die at home (67%) is currently highest in this region than elsewhere. Because the proportion of home deaths is not greatly different from other regions, the North East has the largest gap between preferences and home death. It does not seem that hospice preferences are particularly high in the region (in fact, the proportion is the lowest of all GORs at 26% along with the North West) but it is of concern that care homes are the least preferred place of death in the North East (for 34%), when in all other regions it is hospital.

► The West Midlands is a case of interest for different reasons. Here, a preference to die at home decreased since 2003 (to 60% in 2010, the lowest of all nine GORs); this might be partially explained by the relatively high preference for hospice (31%) but it is worth noting that the region had the highest percentage of people who would least prefer to die in a hospital (53%).

Issues related to care homes and hospitals as settings of end of life care and where death takes place are also present in the quotes from survey participants, where aspects related to the level of care, environment and peacefulness transpire. It is therefore imperative to better understand people's views as they may underlie preferences (both hypothetical and real) and explain how important it is for people to choose where they die. Despite the fact that altogether care homes and hospitals are the least preferred places of death for at least two thirds of people in all regions, improving end of life care in these two settings remains very important.

► In the context of a rapidly ageing population with increasing numbers of people living alone towards the end of life with a complex condition and co-morbidities, more may need to be cared for in care homes (16). It is therefore urgent to understand

why people do not wish to die in these places to identify if and what improvements need to be made (e.g. the development of a home and hospice-like environment within care homes). Until such investigation is done, caution is recommended if and when considering care homes as equivalent to people's own home (the first being the second least preferred place of death and the second being the most preferred place of death).

► Hospitals are still the most common place of death; at least 48% of the population die in hospital in every English GOR and despite the fact that for many people the last hospital admission before death may have been preventable, for others it is inevitable and appropriate (17). Alongside policy changes and service developments to help prevent undesired hospital admissions (often via Emergency Departments), it is crucial to secure good palliative care for the large number of people who die in hospitals. Mobile hospital palliative care teams are key champions of good practices and care across hospital wards, helping to identify people who need palliative care and to ensure a safe return home if they wish (18). Concerns with the lack of peacefulness in hospital can in part be addressed by the existence of wards of dedicated palliative care in quieter and family-friendly areas within hospitals. In this analysis we were not able to separate community hospitals from acute hospitals, which might usefully be examined in the future.

Considering our data alongside recent reports of abuse and neglect of people towards the end of life in care homes and hospitals (19;20), indicating that there are some issues to be tackled in these settings, the definition and monitoring of quality standards for end of life care in these settings and the work of the Care Quality Commission and the NHS Commissioning Board become even more important.



### 6.3 Older people

---

Although home is the most frequent preference for place of death in all age groups, it is important to consider separately the group of older people for three reasons:

- ▶ Aligned with previous results (8), we found that a home preference decreases with age (except for the 25-34 and 55-64 age groups) as a hospice preference increases, particularly in the 75+. Reasons for this difference are not fully known, but might be related with the fear of being a severe burden to others when reaching older age (21), although this needs to be further investigated.
- ▶ Despite being the age group with the highest hospice preference (41%), people aged 75+ have fewer chances of dying in hospice (3% versus 9-11% in other age groups).
- ▶ The gap between preferences and reality is widest for the 75+ wishing to die in hospice than for any other age group and preference.

It is important to remember that the aged 75+ account for 67% of all deaths (53% of all cancer deaths) (10) and that this percentage is

projected to increase rapidly and dramatically in the future (4). Despite being focal to end of life care and wanting to die in hospices more than any other age group, the aged 75+ account for less than half (41%) of all hospice deaths (92% of which are caused by cancer) (10). Ensuring greater access of older people to hospice beds is therefore vital to narrow the gap between preferences and reality for them and for all. National and local action is needed.

Ensuring assessment of need and referrals of older people from community services and hospitals to hospices may help to tackle the issue. Data on hospice referrals, users and number of deaths by age group can be investigated by hospices to help identify barriers, differences and solutions. Other measures such as advanced training so that hospice staff develop further competencies to care for the specific needs of older patients may be considered. Greater access of older people to hospice beds goes hand in hand with greater hospice provision in non-malignant conditions such as dementia which are increasing causes of death for older people. Persisting age and cancer/non-cancer differences suggest inequities (4) that are urgent to tackle (i.e. older people and non-cancer patients are less likely to die at home).

It is important to note that a preference to die at home is still the most common among older people, slightly more than a preference to die in hospice. Since 1974, older people have always had fewer chances to die at home than any other adult age groups (4). This may reflect their complex clinical situations, often longstanding and with trajectories that are hard to predict, as well as a lack of social support. However, it is neither a universal nor an inevitable fact that older people die less often at home. Older age has been found to be associated with increased odds of dying at home for those diagnosed with cancer in New York but decreased odds of dying at home in London (22). The difference was maintained when adjusting for other factors, and was not easily explained by symptom profiles or family structures. Cancer diagnoses and the proportions of persons living alone were similar and New York had more acute beds than London. It is possible that the increased odds of older people dying at home in the USA may reflect the intensive home care support provided by the Medicare hospice program (mainly provided at home) to people aged 65+. Policies or benefits targeting older people may be considered to enable more older people to die at home in England. ■

## Recommendations

We hope our findings and discussion aid care planning to ensure that future developments in end of life care are based on people's health needs and preferences. This report by no means exhausts the topic, but we hope that the data shown can help put in place more responsive end of life care. Box 3 summarises our key recommendations.

Through this work, we know more about the commonalities and differences between regions in

relation to preferences and place of death. The findings are feeding into the work of the National End of Life Care Programme and the Strategy to help ensure each region and their specificities are taken into account when appraising local needs and services and to help find new ways of improving end of life care for all people in need in England.

As the understanding of preferences and factors influencing place of death matures and as

important decisions are made about the allocation of resources, intelligence on the conditions in which people die in different places needs to grow. It is clear that the majority of people prefer to die at home. It is now important to find out whether the conditions in which people die at home are better than in hospitals, hospices and care homes, and what improves health outcomes for patients and families in each of these settings of care. ■

### Box 3 - Recommendations to narrow the gap between preferences and place of death in England

- ▶ Maximum impact to meet preferences for place of death is derived from focusing future investment and service developments in extending and improving care at home and in hospices both at national and local levels.
- ▶ A strategy focused on home and hospice care needs to be supported by a close collaboration of NHS and non-NHS institutions such as independent, voluntary and social care organisations; Hospital at Home services, for example, expand provision of palliative care into home settings and have been found to significantly increase people's chances of dying at home.
- ▶ Issues related to dying in care homes and hospitals stress the importance of defining and monitoring quality standards for end of life care; steps need to be taken to improve the quality of care in these settings.
- ▶ Mobile hospital palliative care teams and the existence of wards of dedicated palliative care in quieter and family-friendly areas within hospitals (acute and community) can help promote better practices of end of life care in hospitals and safe returns home if wished.
- ▶ Greater access of older people (75+) to hospices is needed; assessment of need and referrals from community care and hospitals, monitoring hospice referrals, users and deaths by age group, developing advanced competencies and groups specialised in caring for older people may be considered to ensure this.
- ▶ Policies and benefits targeting older people aged 65+ are required to help those who wish to die at home.

# SECTION 8

## References

- 1 Department of Health.  
**End of Life Care Strategy - Promoting high quality care of all adults at the end of life.**  
*Department of Health; 2008.*
- 2 Ruth K, Pring A, Verne J.  
**Variations in place of death in England.**  
*National End of Life Care Intelligence Network; 2010.*
- 3 Office for National Statistics.  
**2008-based National Population Projections.**  
*Office for National Statistics; 2009.*
- 4 Gomes B, Higginson IJ.  
**Where people die (1974-2030): past trends, future projections and implications for care.**  
*Palliative Medicine 2008;22(1):33-41.*
- 5 Ruth K, Verne J.  
**Deaths in older adults in England.**  
*National End of Life Care Intelligence Network; 2010.*
- 6 Lock A, Higginson IJ.  
**Patterns and predictors of place of cancer death for the oldest old.**  
*BMC Palliative Care 2005;4:6.*
- 7 Higginson IJ, Sen-Gupta GJ.  
**Place of care in advanced cancer: a qualitative systematic literature review of patient preferences.**  
*Journal of Palliative Medicine 2000; 3(3):287-300.*
- 8 Higginson IJ.  
**Priorities and preferences for end of life care in England, Wales and Scotland.**  
*The Cicely Saunders Foundation, Scottish Partnership for Palliative Care and the National Council for Hospice and Specialist Palliative Care Services; 2003.*
- 9 Harding R, Higginson IJ, PRISMA.  
**PRISMA: a pan-European co-ordinating action to advance the science in end-of-life cancer care.**  
*European Journal of Cancer 2010;46(9):1493-1501.*
- 10 Office for National Statistics.  
**Mortality Statistics - Deaths registered in 2010.**  
*[unpublished provisional data to these published by the ONS in the autumn 2011]. Office for National Statistics; 2011.*
- 11 Shepperd S, Wee B, Straus SE.  
**Hospital at home: home-based end of life care.**  
*Cochrane Database of Systematic Reviews 2011, Issue 7. Art. No.: CD009231.*
- 12 Office for National Statistics.  
**Focus on London 2007.**  
*Palgrave Macmillan; 2007.*
- 13 Gomes B, Higginson IJ.  
**Factors influencing death at home in terminally ill patients with cancer: systematic review.**  
*BMJ 2006;332(7540):515-521.*
- 14 Gomes B, McCrone P, Hall S, Koffman J, Higginson IJ.  
**Variations in the quality and costs of end-of-life care, preferences and palliative outcomes for cancer patients by place of death: the QUALYCARE study.**  
*BMC Cancer 2010;10:400.*
- 15 Office for National Statistics.  
**The UK's major urban areas.**  
*Palgrave Macmillan; 2005.*
- 16 World Health Organization.  
**Palliative care for older people: best practices.**  
*World Health Organization; 2011.*
- 17 Beynon T, Gomes B, Murtagh FE, Glucksman E, Parfitt A, Burman R, et al.  
**How common are palliative care needs among older people who die in the emergency department?**  
*Emergency Medicine Journal 2011;28(6):491-495.*
- 18 Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AG, et al.  
**Do hospital-based palliative teams improve care for patients or families at the end of life?**  
*Journal of Pain & Symptom Management 2002;23(2):96-106.*
- 19 Health Service Ombudsman.  
**Care and compassion? Report of the Health Service Ombudsman on ten investigations into NHS care of older people. Fourth report of the Health Service Commissioner for England - Session 2010-2011.**  
*London: The Stationery Office; 2011.*
- 20 Devlin K.  
**Almost 50,000 patients a year 'die in hospital while suffering from malnutrition'.**  
*Telegraph 2010 Feb 26.*
- 21 Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S.  
**Older people's views about home as a place of care at the end of life.**  
*Palliative Medicine 2004;18(5):460-467.*
- 22 Decker SL, Higginson IJ.  
**A tale of two cities: factors affecting place of cancer death in London and New York.**  
*European Journal of Public Health 2007;17(3):285-290.*

# Acknowledgements

---

We are most grateful to all the participants in the PRISMA survey and to the ONS Mortality Statistics team (Claudia Wells and colleagues) for providing the data on actual place of death. We thank the National End of Life Care Intelligence Network and the National End of Life Care Programme for making this report possible, and the European Commission for the financial support needed to undertake the PRISMA survey. This report reflects only the authors' views. Neither the National End of Life Care Intelligence Network nor the European Commission are liable for any use that may be made of the information contained therein.

Barbara Gomes and Natalia Calanzani are researchers of Cicely Saunders International, working at the Cicely Saunders Institute, King's College London. Professor Irene J Higginson is Scientific Director of Cicely Saunders International, Director of the Cicely Saunders Institute, Professor of Palliative Care & Policy at King's College London and Senior NIHR Investigator.

PRISMA was funded by the European Commission's Seventh

Framework Programme (contract number: Health-F2-2008-201655) with the overall aim to co-ordinate high-quality international research into end-of-life cancer care. PRISMA aimed to provide evidence and guidance on best practice to ensure that research can measure and improve outcomes for patients and families. PRISMA activities aimed to reflect the preferences and cultural diversities of citizens, the clinical priorities of clinicians, and appropriately measure multidimensional outcomes across settings where end of life care is delivered. Principal Investigator: Richard Harding. Scientific Director: Irene J Higginson.

We thank all our colleagues from PRISMA: Gwenda Albers, Barbara Antunes, Ana Barros Pinto, Claudia Bausewein, Dorothee Bechinger-English, Hamid Benalia, Emma Bennett, Lucy Bradley, Lucas Ceulemans, Barbara A Daveson, Luc Deliens, Noël Derycke, Martine de Vlieger, Let Dillen, Julia Downing, Michael Ehteld, Susie Edwards, Natalie Evans, Dagny Faksvåg Haugen, Nancy Gikaara, Marjolein Gysels, Sue Hall, Richard Harding, Stein Kaasa, Jonathan

Koffman, Pedro Lopes Ferreira, Arantza Menaca, Johan Menten, Fliss Murtagh, Bregje Onwuteaka-Philipsen, Roeline Pasman, Francesca Pettenati, Robert Pool, Richard A. Powell, Miel Ribbe, Katrin Sigurdardottir, Steffen Simon, Franco Toscani, Bart Van den Eynden, Paul Vanden Berghe, Trudie van Iersel. We also thank BMG Research and Zentrum für Evaluation und Methoden (ZEM) for assistance in survey administration and data collection for the 2010 survey; Joachim Cohen for his advice and support; Gao Wei, Joana Cadima and Vicky Simms for statistical advice. The invaluable work of Ron Irwin, Sian Best and Mike Gover at King's College London and Brenda Ferns at Cicely Saunders International is also highly appreciated.

We thank Lukas Radbruch for the photograph on page 6, Alex Dionysiou for his design work with the report and Susan Chandler for proofreading. Finally, we thank Katie Lindsay, Claire Henry, Katherine Sleeman, Barbara Daveson, Claudia Bausewein, Fliss Murtagh and Kirstie Newson for their comments and discussion. ■



Cicely Saunders  
International  
Better care at the end of life