



Public Health
England

What we know now 2013

New information collated by the National
End of Life Care Intelligence Network

About Public Health England

Public Health England's mission is to protect and improve the nation's health and to address inequalities through working with national and local government, the NHS, industry and the voluntary and community sector. PHE is an operationally autonomous executive agency of the Department of Health.

The National End of Life Care Intelligence Network

The National End of Life Care Strategy published in 2008 pledged to commission a National End of Life Care Intelligence Network (NEoLCIN) to improve the collection and analysis of national data about end of life care for adults in England. The aim is to support the NHS and its partners to commission and deliver high-quality end of life care in a way that makes the most efficient use of resources and responds to the wishes of dying people and their families. The network was established in May 2010. The NEoLCIN plays a vital role in supporting delivery of the strategy.

On 1 April 2013 the NEoLCIN became part of Public Health England.

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Foreword

The National End of Life Care Intelligence Network (NEoLCIN) has, in just three years, established itself as a leading national and international source of information on where, how and why people die in England, and the services provided to support them.

Three years ago we knew little about people's hopes and fears, their planning for death or the places they died, and what influenced these.

Each year since the network was established there has been a leap in our knowledge and understanding, but this last year has seen exceptional progress and change.

This year's 'What we know now' report covers more topics than before. It has many new sections, illustrating the breadth and depth of knowledge the network has gathered, including on public knowledge and attitudes, specialist palliative care services, ambulance usage, and the roles of primary care, care homes and social care in supporting dying people. Information has been published on the website (www.endoflifecare-intelligence.org.uk), in reports and in scientific literature. Findings have been reported widely in the media in the UK and also as far afield as South Africa.

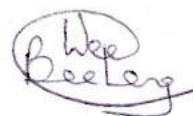
Although it is hard to pick out highlights when all new information adds to our knowledge, two themes have gained prominence where in the past we knew little. These are the care of people with non-cancer conditions and the wide inequalities in end of life care. Both are areas in which improvements in access to and quality of end of life care can be made. Both merit further prioritisation in 2013-14.

We are always seeking to improve the information we deliver. You will find references to the original sources from which the key findings in this report are taken. All authors welcome queries, so please do get in touch. Please also send us feedback so we can continue to make our work as relevant and useful as possible – email neolcin@phe.gov.uk.



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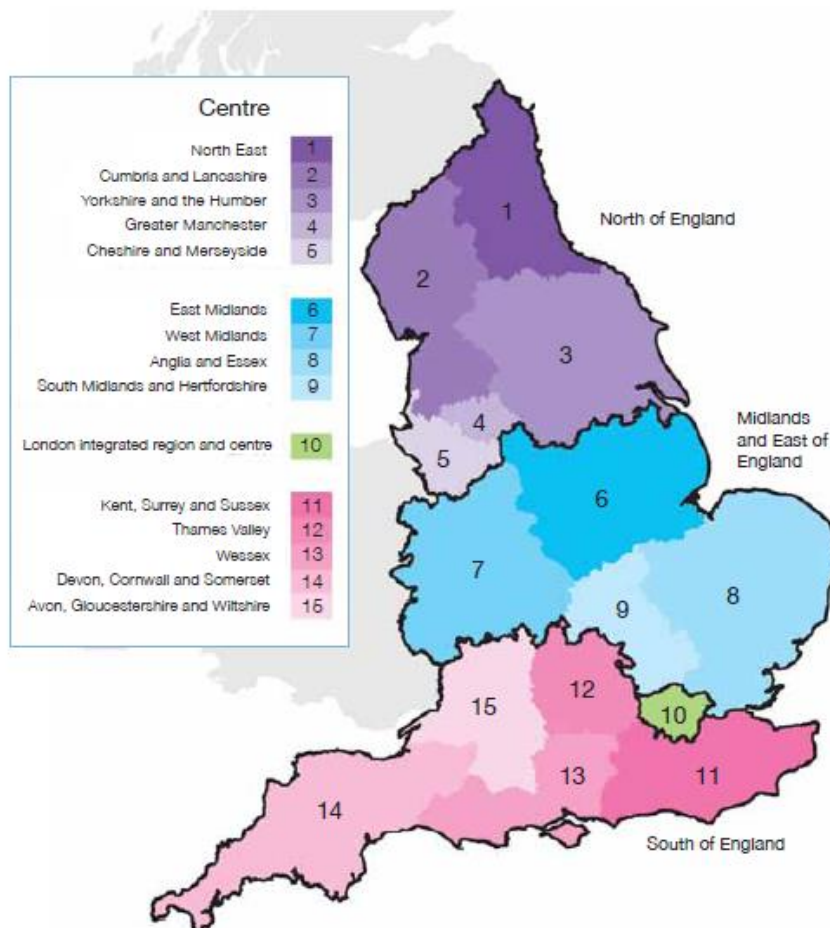
Introduction

What we know now 2013

The NEoLCIN works with partner organisations to collect, analyse and present end of life care intelligence, drawing together data and information from a range of sources. This report builds on 'What do we know now that we didn't know a year ago?', published by the NEoLCIN in May 2012. It provides an update with new information and evidence about end of life care that has been produced by the network and our partners over the past year. We hope the information included in this report will help policy makers, commissioners, providers, researchers and others see the progress being made, identify the gaps and drive improvement.

As the NEoLCIN is now part of Public Health England (PHE), some of the data in this report is presented by PHE regions and centres. See the map below.

PHE regions and centres

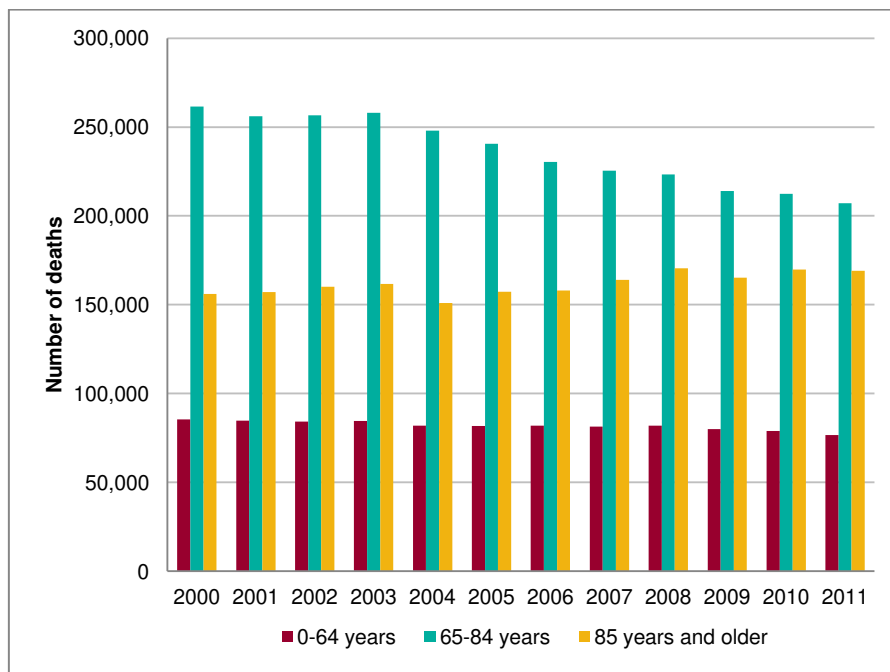


1 What we know about need and trends in deaths

We live in an ageing society and it is important to understand the trends in need in order to plan ahead.

- 1.1 There are changing trends in the age of death, with increasing numbers of deaths in people aged 85 and over and a decreasing trend in people aged 65 to 84. The older age group has a greater likelihood of frailty and multi-morbidities.

Figure 1: Number of deaths in England 2000 to 2011 by age group



Source: Office for National Statistics data analysed by Public Health England (NEoLCIN)

- 1.2 More than eight million people in England are aged 65 or over, representing 16.3% of the population. Of these 56% are female and 44% male.
- 1.3 There is geographical variation. The South of England has the highest percentage of 85s and over in England. By 2033 the Midlands and East of England is predicted have the highest percentage of 85s and over.

- 1.4 36.2% of deaths in England are in the 85 and over age group. Approximately 50% of all female deaths occur in women aged 85 and over, and 30% of all male deaths.
- 1.5 The South of England has the highest percentage of 65s and over in England. London has the lowest. In Devon, Cornwall and Somerset, one in five people are 65 or over compared to almost one in nine in London. The proportion of people aged 65 or over ranges from 7% in Tower Hamlets to 25.1% in Dorset. Urban areas have lower percentages of older people.
- 1.6 Crude death rates range from 0.63% in London to 1.08% in Devon, Cornwall and Somerset. Local authorities in London and the Thames Valley have the lowest crude death rates in England.

Source: Public Health England (NEoLCIN). End of life care profiles summary statistics 2008 to 2010. Forthcoming 2013.

- 1.7 A study that used an expert panel to review existing population-based methods of estimating the need for palliative care concluded that death registration data using both underlying and contributory causes can give reliable estimates without having to draw on symptom or hospital activity data. In high-income countries, 69% to 82% of those who die need palliative care.

Source: Murtagh FEM, Bausewein C, Verne J, Groeneveld EI. How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliat Med*
<http://pmj.sagepub.com/content/early/2013/05/20/0269216313489367.abstract>

2 What we know about public attitudes

The National End of Life Care Strategy (2008) recognised that death is a taboo subject for the majority of people in England. In 2009, the National Council for Palliative Care (NCPC) set up the Dying Matters Coalition to promote public awareness of dying, death and bereavement.

2.1 Commissioned by Dying Matters, NatCen Social Research interviewed 2,145 adults in Britain on their attitudes to dying as part of the 2012 British Social Attitudes survey. The survey found:

- Although 70% of the public say they are comfortable talking about death, most haven't discussed their end of life wishes or put plans in place
- Only 35% of respondents said they have a will. This is down from 39% in 2009. Economic pressures is a possible cause of this decline
- Fewer than a third (28%) have registered as an organ donor or have a donor card – although the number of organ donations after death has risen by 50% since 2008. More than 1,000 people on the transplant waiting list die each year (NHS Blood and Transplant figures)
- Only 11% have written their funeral wishes or made a funeral plan
- 5% say they have set out how they would want to be cared for at the end of life if they couldn't make decisions themselves
- 7% say they would prefer to die in hospital, compared to two-thirds (67%) who would prefer to die at home

Source: British Social Attitudes survey published May 2013
www.dyingmatters.org/sites/default/files/BSA30_Full_Report.pdf

2.2 Public concerns about death and dying have remained relatively constant over the past 20 years. These include being in pain, leaving families behind, fear of the unknown, being alone, wanting to know about the prognosis, care options available and likely symptoms, wanting to be involved in decisions about care, not wanting to be kept alive at all costs, and the importance of quality of life over length of life where there was no hope of recovery from a serious illness. Concerns about being a 'burden to others' were also present in a number of studies, such as the PRISMA survey of 9,344 adults across seven European countries, including England.

Source: Bausewein C et al on behalf of PRISMA, 'Burden to others' as a public concern in advanced cancer: a comparative survey in seven European countries. BMC Cancer 2013; 13(1):105

3 What we know about preferences for place of care and place of death

Meeting people's preferences for place of care and place of death is an important measure of the quality of end of life care. The End of Life Care Strategy aims to support more people to die in their preferred place. Surveys and research indicate that home is the preferred place for many people.

3.1 A systematic review of the literature that analysed 210 studies reporting the preferences of just over 100,000 people from 33 countries, including 34,021 patients, 19,514 caregivers and 29,926 general public members, found:

- Home is the preferred place of care and death for the majority of people and most do not change this preference. However, a substantial minority do not make home their first choice or change their minds
- Among high-quality studies and excluding outliers, estimates of a preference for dying at home ranged 31% to 87% for patients (nine studies), 25% to 64% for caregivers (five studies), 49% to 70% for the public (four studies)
- 20% of patients in the ten studies that examined preferences over time changed their preference for place of care or death as their illness progressed

Source: Gomes et al. Heterogeneity and changes in preferences for dying at home: a systematic review, *BMC Palliative Care* 2013, 12(1):7

3.2 The PRISMA survey across seven European countries determined people's preferences for place of death if faced with a serious illness such as cancer, had less than one year to live, and circumstances allowed them to choose. At least two thirds would prefer to die at home (69% across the seven countries, 64% in England). Hospices and palliative care units are the second most common preference (20% across the seven countries. 29% in England).

Source: Gomes B et al on behalf of PRISMA. Preferences for place of death if faced with advanced cancer: A population survey in England, Flanders, Italy, Germany, the Netherlands, Portugal and Spain. *Annals of Oncology* 2012; 23(8):2006-15

3.3 Another systematic review that focused on non-cancer and included 290 studies confirmed variation in preferences between people with cancer and non-cancer conditions:

- Just under half of people with advanced non-malignant conditions report a preference for a home death (this is notably lower than among people with cancer)

Source: Murtagh FEM, et al. Understanding place of death for patients with non-malignant conditions: a systematic literature review, National Institute for Health Research, Service Delivery and Organisation Programme, September 2012

3.4 The first national VOICES survey of the bereaved provides valuable insight into place of death preferences:

- According to relatives, only 44% of people had expressed a preference of where they wanted to die. For those who expressed a preference, the majority (71%) preferred to die at home
- Sufficient choice in place of death varied by cause of death: two-thirds of relatives of people who died from cancer felt the person had enough choice (65%) compared with about 40% of non-cancer deaths
- Sufficient choice in place of death varied by the recorded place of death: most relatives of people who died at home or in a hospice considered they had enough choice about where they might die (88% at home and 70% in a hospice). This compared with about half of those dying in a care home (53%) and just 29% who died in hospital

Source: Office for National Statistics (ONS): National Bereavement Survey (VOICES), 2011
www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/stb-statistical-bulletin.html

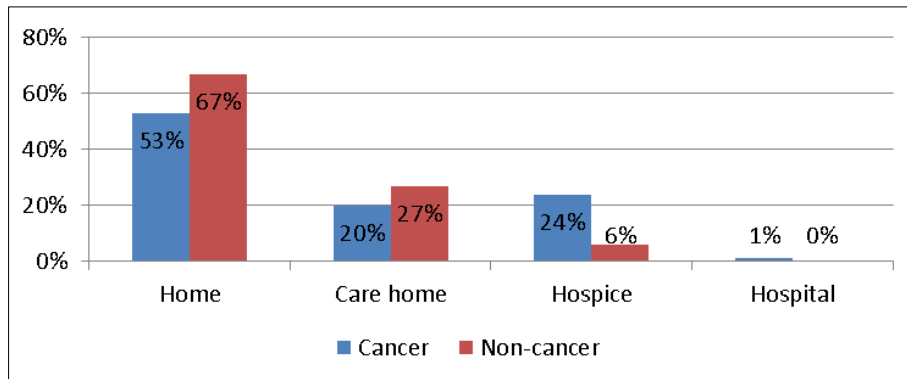
- Sufficient choice in place of death varied across England: for example, 61% of relatives of people who died in Somerset considered they had enough choice compared with 41% of relatives of people who died in Durham and Darlington

Source: Office for National Statistics: National Bereavement Survey (VOICES) by PCT Cluster, 2011
www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices--by-pct-clusters/2011/index.html

3.5 A retrospective cohort study of 970 people using hospice services in South West England found that:

- 75% of people using hospice services who had completed advance care planning (ACP) achieved their choice of place of death
- 11% of people using hospice services who had completed ACP died in hospital compared with 26.5% of those who had not completed ACP
- The preferred place of death for people in hospices in South West England varied between those with cancer and non-cancer diagnoses

Figure 2: Preferred place of death for hospice patients in South West England



Source: The impact of advance care planning of place of death, a hospice retrospective cohort study Abel J, Pring A, Rich A et al
BMJ Support Palliat Care doi:10.1136/bmjspcare-2012-000327
www.spcare.bmj.com/content/early/2013/03/14/bmjspcare-2012-000327.full#T4

4 What we know about place of death trends

At the beginning of the 20th century it was common for people to die at home, but as the century progressed the rate of home deaths fell while the rate of hospital deaths increased.

4.1 Population-based studies exploring patterns in the place of death in England between 1993 and 2010 found:

- Hospital remains the most common place of death
- An increase in home and hospice deaths mirrors the decrease in hospital deaths in cancer since 2005, and a reversal of British trends in deaths suggest that the National End of Life Care Programme made a difference in end of life care
- The proportion of deaths in inpatient hospices increased slightly among people with cancer and non-cancer (0.4% and 0.3%, respectively)

Source: Ago W, Ho YK, Verne J, Glickman M, Higginson IJ, et al. (2013) Changing Patterns in Place of Cancer Death in England: A Population-Based Study. *PLoS Med* 10(3): e1001410. doi:10.1371/journal.pmed.1001410

Source: Gomes B, Calanzani N, Higginson IJ. Reversal of the British trends in place of death: time series analysis 2004-2010. *Palliat Med*. 2012 Mar; 26(2):102-7. doi: 10.1177/0269216311432329. Epub 2012 Jan 18

- For people with cancer, marital status was the second most important factor associated with their place of death, next to type of cancer. Married people were more likely to achieve a home death than those who were single, divorced or widowed
- People with cancer who live in less deprived areas were more likely to die at home or in a hospice
- People over 85 who died from cancer during 2006–10 were more likely to die at home or in a hospice than in earlier periods
- Men with cancer were less likely than women to die at home or in a hospice

Source: Gao W, Ho YK, Verne J, Glickman M, Higginson IJ, et al. (2013) Changing Patterns in Place of Cancer Death in England: A Population-Based Study. *PLoS Med* 10(3): e1001410. doi:10.1371/journal.pmed.1001410

4.2 The presence of a family or informal carer is a key component in achieving a home death: effective and sustained carer support, especially during longer illnesses, is likely to increase home death rates.

Source: Murtagh FEM, Bausewein C, Petkova H, Sleeman KE, Dodd RH, Gysels M, et al. Understanding place of death for patients with non malignant conditions: a systematic literature review National Institute for Health Research Service Delivery and Organisation Programme NIHR website, 2012
www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1813-257_V01.pdf (accessed 03 June 2013)

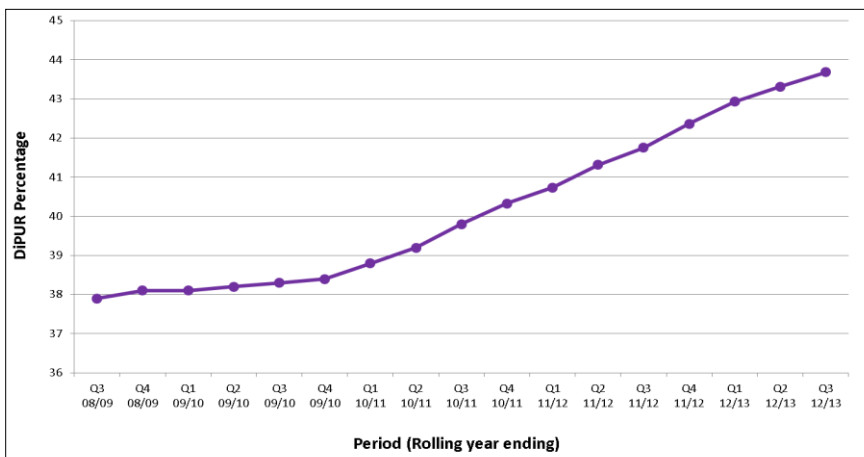
4.3 Some evidence suggests that the time of death may influence the place of death:

- Around 6% of all deaths occur during the holiday weeks (Christmas, New Year, Easter)
- The place of death varied by holiday periods – it was less likely to occur in hospital over Christmas

Source: Gao W, Verne J, Glickman M, Higginson IJ. Place of death is associated with holiday periods: implications for end of life care. Poster 13th World Congress of the European Association for Palliative care, May 30- June 2, 2013, Prague, Czech Republic

4.4 The proportion of deaths in the usual place of residence (DIUPR, deaths in own home or a care home) continues to increase and correspondingly the proportion of deaths in hospital is falling. The DIUPR figure for England was 43.7% in 2012, up from 37.9% in 2008.

Figure 3: Proportion of deaths in usual place of residence (DIUPR) England trend Q3 2008/09 to Q3 2012/13



Source: Proportion of deaths in usual place of residence ONS data available from NEoLCIN www.endoflifecare-intelligence.org.uk/data_sources/place_of_death

4.5 There is geographical variation in place of death:

- Home deaths are most likely to occur in the Midlands and East of England (21%), with 22.5% dying at home in Norfolk, Suffolk, Cambridgeshire and Essex and 21.1% in Lincolnshire, Leicestershire, Nottinghamshire and Derbyshire
- People are least likely to die at home in Sussex, Surrey and Kent (18.7%) and Bedfordshire, Hertfordshire and Northamptonshire (18.8%). These areas also record the highest percentage of hospice deaths (7.8% and 6.7% respectively)
- Cambridgeshire has the highest proportion of deaths in a person's own home (27.2%)
- London has the widest range of values for deaths at home. Sutton and Enfield (15.9% and 16% respectively) have the lowest percentage of home deaths while the City of Westminster has the second highest percentage (24.9%) in England

Source: NEoLCIN local authority profiles using Office for National Statistics data 2009-2011

Table 1: Proportion of deaths in hospital 2009 to 2011. Local authorities with highest and lowest rates

	Local authority code	Local authority	Hospital deaths (%)
Lowest	12UB	Cambridge	37.9
	40UE	Taunton Deane	38.5
	36UB	Craven	39.3
	12UG	South Cambridgeshire	40.6
	00HH	Torbay	41.5

	Local authority code	Local authority	Hospital deaths (%)
Highest	00MD	Slough	63.6
	00AK	Enfield	64.3
	00BC	Redbridge	66.1
	00BB	Newham	66.7
	00BH	Waltham Forest	69.1

Source: NEoLCIN using Office for National Statistics mortality data 2009 to 2011

4.6 An economic evaluation found evidence implementing Electronic Palliative Care Co-ordination Systems (EPaCCS) affected the place of death, with an extra 90 deaths occurring in the usual place of residence per 200,000 population each year above the underlying increase in rates experienced across England.

Source: Economic Evaluation of the Electronic Palliative Care Co-ordination System (EPaCCS) Early Implementer Sites. NHS Improving Quality. May 2013

5 What we know about hospital care in the last year of life

The majority of people die in hospital and it is important that quality end of life care is provided.

Analysis of hospital care and local authority-funded social care services provided in the final 12 months of life for over 72,000 deaths in England found:

5.1 89.6% had some hospital care in the final year.

Source: Theo Georghiou et al., Understanding patterns of health and social care at the end of life, Nuffield Trust (in partnership with the NEoLCIN), October 2012

5.2 Hospice patients who had advance care planning (ACP) spent significantly less time in hospital. The average time spent in hospital in the last year of life was 18.1 days for people with ACP compared to 26.5 days for those without.

Source: The impact of advance care planning of place of death, a hospice retrospective cohort study Abel J, Pring A, Rich A et al BMJ Support Palliat Care doi:10.1136/bmjspcare-2012-000327
www.spcare.bmj.com/content/early/2013/03/14/bmjspcare-2012-000327.full#T4

5.3 There is geographical variation in emergency admissions for end of life patients who died in hospital. Greater Manchester (92.4%) and Cheshire and Merseyside (92.4%) have the highest percentages of people who died in hospital following an emergency admission (Table 2).

5.4 The lowest percentages are in Devon, Cornwall and Somerset (83.4%), and the Thames Valley (85.7%).

Table 2: Hospital admissions that end in death

PHE centres and regions	% of people dying in hospital following an emergency admission	% of people dying in hospital aged 85 years or older who died following an emergency admission	% of people dying in hospital following an emergency admission who were in hospital for between 8 & 90 days in that admission	Average length of stay in hospital (days) per person for admissions that ended with the person's death
North of England	91.0	34.6	48.7	12.7
Greater Manchester	92.4	33.8	48.7	13.0
Cheshire and Merseyside	92.4	33.9	48.4	12.6
Cumbria and Lancashire	91.8	35.5	47.5	12.4
North East	90.1	34.0	50.8	13.2
Yorkshire and Humber	89.9	35.4	48.0	12.3
Midlands and East of England	90.1	37.8	48.7	12.5
Bedfordshire, Hertfordshire and Northamptonshire	90.8	39.8	48.7	12.5
Norfolk, Suffolk, Cambridgeshire and Essex	90.8	39.7	47.8	12.2
West Midlands	89.8	37.3	49.7	13.1
Lincolnshire, Leicestershire, Nottinghamshire and Derbyshire	89.4	35.5	48.0	12.2
South of England	88.4	41.3	48.2	12.5
Sussex, Surrey and Kent	91.4	42.9	48.0	12.7
Avon, Gloucestershire and Wiltshire	89.0	38.9	49.7	12.6
Hampshire, Isle of Wight and Dorset	89.0	41.9	49.8	13.6
Thames Valley	85.7	37.8	48.3	12.8
Devon, Cornwall and Somerset	83.4	42.5	45.4	10.8
London	88.2	38.4	50.9	13.8
ENGLAND	89.8	37.8	48.8	12.9

Source: Data: Hospital Episode Statistics (HES) from Public Health England (NEoLCIN). End of life care profiles summary statistics 2008 to 2010. Forthcoming 2013

5.5 The proportion of people who died in hospital following an emergency admission varies considerably within PHE Centre areas:

- In Lincolnshire, Leicestershire, Nottinghamshire and Derbyshire, values range from 79.7% in Rutland to 93.9% in the City of Derby
- In the North East values range from 83.4% in Redcar and Cleveland to 95.5% in Hartlepool
- In the West Midlands values range from 80.4% in Herefordshire to 95.3% in Solihull
- In Avon, Gloucestershire and Wiltshire values range from 81.6% in Gloucestershire to 94.6% in Bristol
- In Yorkshire and the Humber values range from 83.4% in Sheffield to 94.3% in Kingston upon Hull

- In London values range from 78.5% in Tower Hamlets to 93.7% in Barking and Dagenham
- In Hampshire, Isle of Wight and Dorset values range from 83.2% in Dorset to 93.9% in the Isle of Wight

Source: Public Health England (NEoLCIN). End of life care profiles summary statistics 2008 to 2010. Forthcoming 2013.

5.6 The average length of stay for people who die in hospital is 12.9 days.

Source: Hospital Episode Statistics (HES) FY 2010/11 (NEoLCIN)

5.7 A retrospective analysis compared people who received Marie Curie Nursing Service (MCNS) care with a closely matched control group and found that:

- People who received MCNS care were significantly less likely to use all forms of hospital care
- 11.7% of MCNS patients had an emergency admission at the end of life, compared to 35% among the control group
- 7.9% of people receiving MCNS had an A&E attendance compared to 28.7% of the controls
- Across most types of care, people receiving MCNS used between a third and half the level of hospital care than the control group

Source: Chitnis et al., The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life, Nuffield Trust, November 2012

5.8 The national VOICES survey of the bereaved reports on hospital care. It found that:

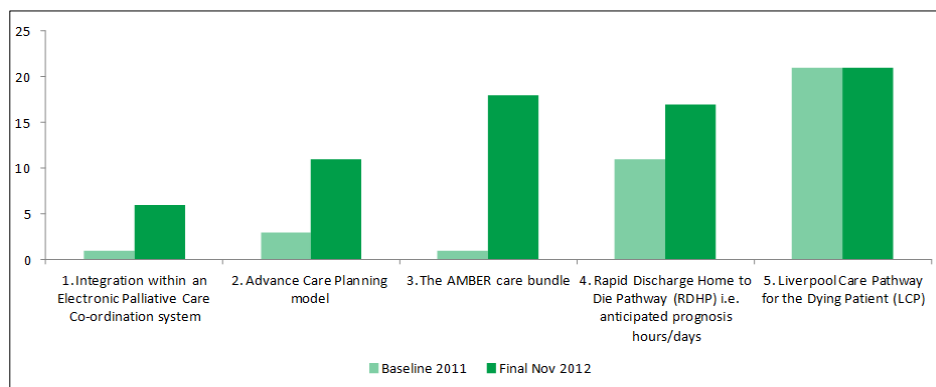
- For people who spent some time in hospital in the last three months of life, only one third (33%) of their bereaved relatives reported that hospital services definitely worked well together with GP and other community services
- Relatives said that dignity and respect for the deceased shown 'all the time' by staff was lowest in hospitals – 57% for hospital doctors and 48% for hospital nurses compared with 72% for GPs
- According to relatives, only 29% of people who died in hospital had enough choice about where they died compared with 70% in a hospice and 88% at home

- Only 36% of bereaved relatives said that pain was relieved ‘completely all the time’ during the final hospital admission compared with 62% in a hospice and less than 17% at home
- For hospitals, relatives rated excellent quality of care as 38% for doctors and 35% for nurses. This did not vary by cause of death

Source: Office for National Statistics: National Bereavement Survey (VOICES), 2011
www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/stb-statistical-bulletin.html

5.9 Over 40% of all acute hospital trusts in England have joined the Transforming End of Life Care in Acute Hospitals Programme launched in September 2011. Evaluation of 22 of the hospitals involved in phase one demonstrated substantial change in adopting the five key enablers over the first 12 months.

Figure 4: Hospital implementation of the five enablers in November 2012 fully implemented, in process of implementing or have defined plans to implement



Source: Data collected from participating sites for phase one Transform Programme: transforming end of life care in acute hospitals. National End of Life Care Programme, January 2013

5.10 Independent evaluation of the Phase 2 Gold Standards Framework for acute hospitals training programme for eight hospitals in 2011-12 found evidence of a reduced length of stay (six days/patient), improved communication with GPs, improved staff knowledge, awareness and confidence in end of life care, improved early identification of people approaching the end of life and use of Electronic Palliative Care Co-ordination Systems (EPaCCS), increased advance care planning discussions and improved numbers dying in their preferred place of choice/usual place of residence. Further work was needed on earlier identification, use of multidisciplinary team meetings, support for carers and full integration of advance care planning for future phases of the programme.

Source: GSF AH Training Programme Phase 2 2011-12. Ahmad.N and Battye.F. ICF GHK Thomas. K Corner.H GSF Centre in End of Life Care. European Journal of Palliative Care. Abstracts. Abstract P2-243 May 2013 – 13th World Congress of the European Association For Palliative Care May 30 – June 2 2013 – Prague
www.congressinfo.org/filerun/weblinks/?id=e94550c93cd70fe748e6982b3439ad3b&filename=EAPC-Abstract_Book_FINAL%20Version_small.pdf

6 What we know about social care in the last year of life

End of life care is often given by multiple providers across a range of sectors, including social care.

6.1 An analysis of hospital care and local authority-funded social care services provided in the final 12 months of life for over 73,000 deaths in England found:

- Individuals with highest social care costs had relatively lower hospital costs, irrespective of age
- 24.9% received social and hospital care during the last year of life, 64.7% received only hospital care, 2.9% received only social care and 7.5% received neither
- 27.8% of people who died received some form of local authority-funded social care
- On average 14.9% of people who died had some residential or nursing care service in the last year of life
- In the final month before death 24.4% received social care (50% more individuals used care homes in the final months before death than 11 months previously)
- 51.9% of those aged 95 and over had some form of social care compared to only 6% of those under 55

Source: Theo Georghiou et al., Understanding patterns of health and social care at the end of life, Nuffield Trust (in partnership with the NEEoLCIN), October 2012

6.2 Analysis by NEEoLCIN shows geographical variation in social care need and provision for people aged 65 and over:

- London and the Midlands and East of England have the highest rate of people aged 65 and over discharged from hospital to their normal place of residence. The North of England has the lowest. Days lost through delayed transfers of care are generally lowest in the North of England and highest in the Midlands and East of England and the South of England

- The highest rates for people aged 65 and over receiving self-directed support are in the North of England and the lowest in the South of England
- The highest rate of new completed social care assessments is in the South of England. Demand for and access to social care by new clients aged 65 and over is variable within PHE centre areas
- The North of England has the highest rate of social care package delivery. Rates of delivery are most variable in the South of England
- The North of England has more carers per 100,000 population aged 65 and over receiving social care support than the South of England, the Midlands and East of England or London
- The North of England and London has the highest rates of people receiving social care support. The Midlands and East of England has the lowest
- Crude rates of people entitled to carer's allowance (per 100,000 population aged 65 and over) are highest in the North of England and lowest in London, the Thames Valley and Sussex, Surrey and Kent
- London and the North of England are the biggest spenders on gross residential and nursing care, home care, day care or day services and meals. Expenditure is least in the South of England
- The highest levels of satisfaction with social care services are in the North of England and the South of England. The lowest levels of satisfaction are in London

Source: Public Health England (NEoLCIN). End of life care profiles summary statistics 2008 to 2010. Forthcoming 2013

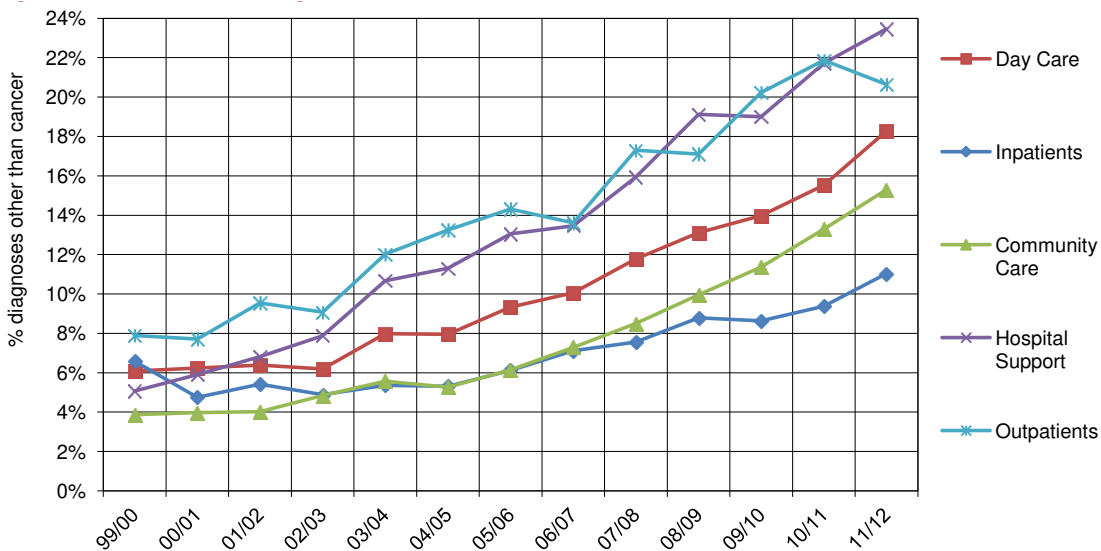
7 What we know about specialist palliative care

Specialist multidisciplinary palliative care teams include palliative medicine consultants, palliative care nurse specialists, and a range of expertise provided by physiotherapists, occupational therapists, dieticians, pharmacists, social workers and those who can give spiritual and psychological support.

The National Council for Palliative Care in partnership with NEOLCIN conduct an annual survey of specialist palliative care services. The latest survey found:

- 7.1 The proportion of people with non-cancer diagnoses accessing specialist palliative care services is increasing. The most striking increases have been in hospital support and outpatient services, where non-cancer diagnoses now account for over one fifth of all diagnoses. For specialist palliative care inpatient units the proportion of patients with a diagnosis other than cancer has increased from 3% in 1997-98 to 11% in 2011.

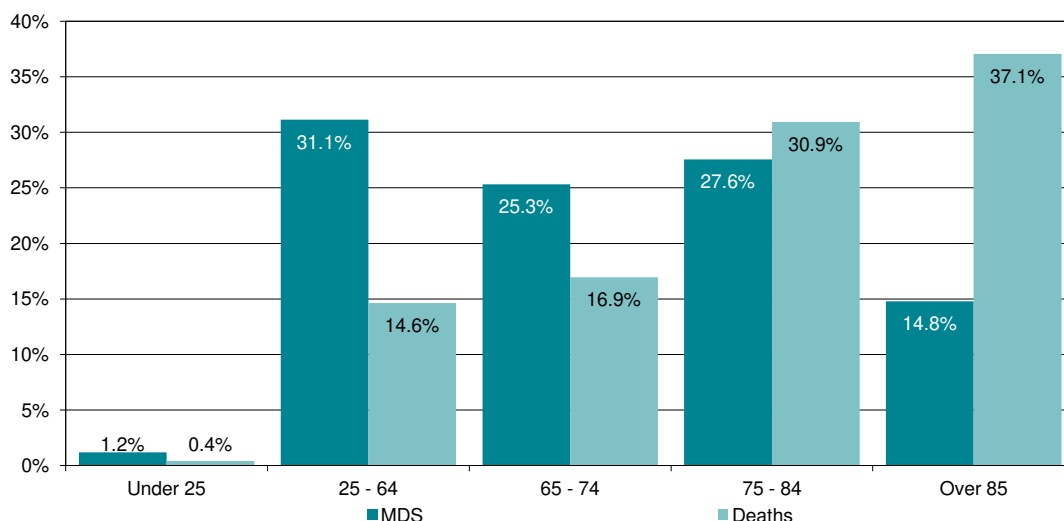
Figure 5: Growth in diagnoses other than cancer



Source: National Council for Palliative Care and Public Health England (NEoLCIN). National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS full report for the year 2011-2012. 2013.

- 7.2 On average, there are 5.5 specialist palliative care inpatient beds per 1,000 deaths across England, Wales and Northern Ireland but there is large regional variation from 3.2 per 1000 deaths in the East Midlands to 8.4 per 1000 deaths in London.
- 7.3 The mean number of people seen in inpatient units is at its highest in more than ten years, with the average number of available beds (those in use or potentially in use) also at a high. The proportion of occupied beds has also remained high at 74.8%, reflecting efficient use of beds, although there remain considerable variations across the country. The mean length of stay for inpatient specialist palliative care is 13.4 days.
- 7.4 The report finds that people receiving specialist palliative care are more likely to die at home. Nearly half the people receiving specialist palliative care in the community (49.8%) died in their home and less than a quarter (23.9%) died in hospital. This compares with ONS data for all deaths, which shows that 21.8% died at home and 51.5% in hospital.
- 7.5 Most people (56.4%) accessing specialist palliative care services are under 75. Of all the people who died, most were 75 or older (68%).

Figure 6: Comparison of age of people accessing palliative care with recorded deaths



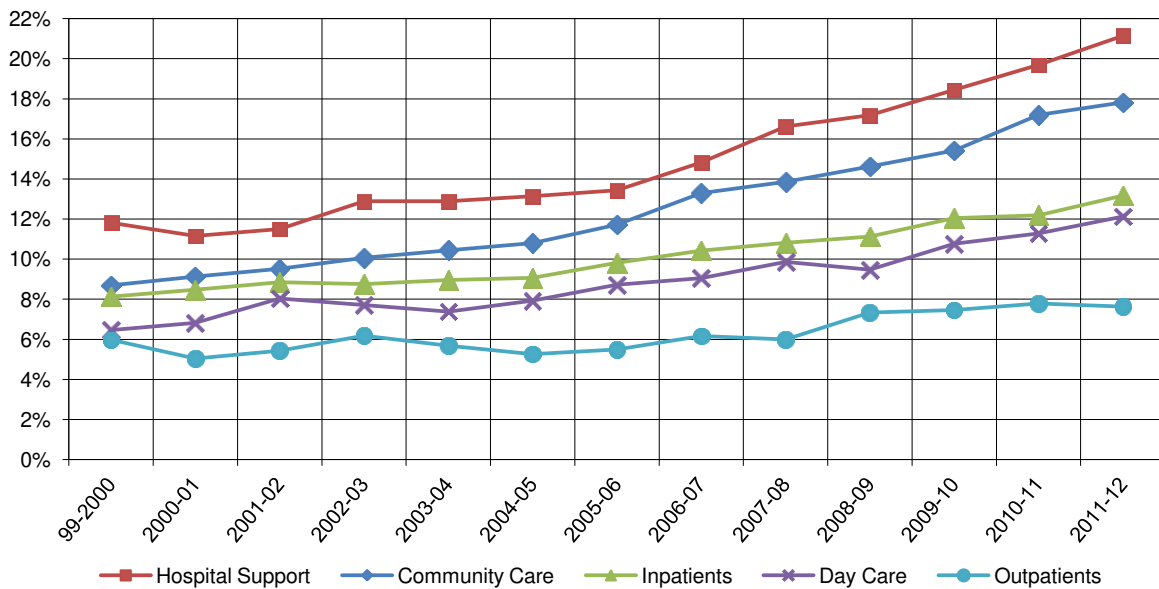
Note: Mortality data excludes deaths from external causes

Source: Data from Office for National Statistics VS3 data 2011. Chart from National Council for Palliative Care and Public Health England (NEoLCIN). National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS full report for the year 2011-2012. 2013.

7.6 The proportion of people receiving specialist palliative care aged 85 and over is increasing.

Source: National Council for Palliative Care and Public Health England (NEoLCIN). National Survey of Patient Activity Data for Specialist Palliative Care Services: MDS full report for the year 2011-2012. 2013.

Figure 7: Percentage of people in each setting who were aged 85 and over



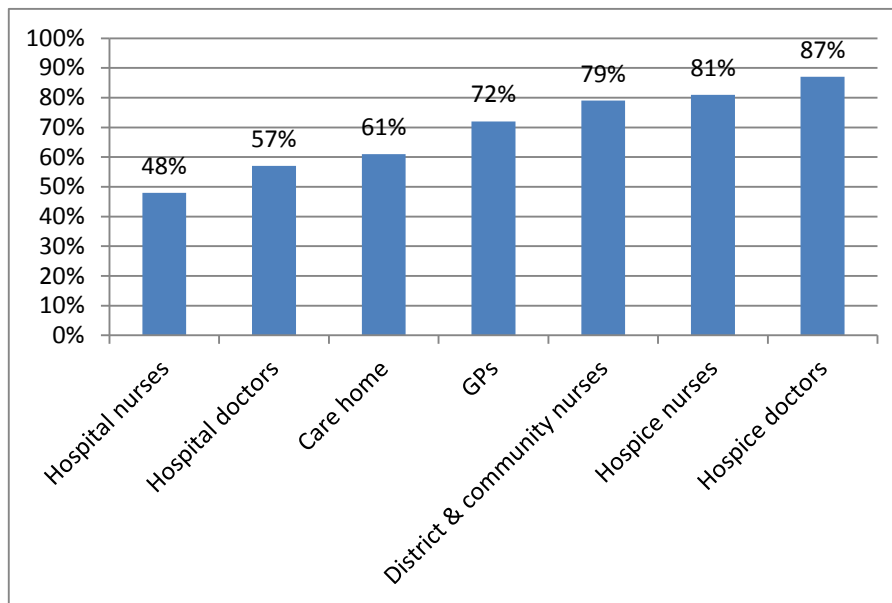
Source for all and graphs: National Survey of Patient Activity Data for Specialist Palliative Care Services, Minimum Data Set for 2011-12 (MDS), NCPIC and NEoLCIN
www.endoflifecare-intelligence.org.uk/resources/publications/patient_activity_data

7.7 A study of hospice patients in the south west region found that 77% completed advance care planning (ACP) before death, suggesting it is possible to make ACP routine in a hospices.

Source: The impact of advance care planning of place of death, a hospice retrospective cohort study Abel J, Pring A, Rich A et al BMJ Support Palliat Care doi:10.1136/bmjspcare-2012-000327
www.spcare.bmj.com/content/early/2013/03/14/bmjspcare-2012-000327.full#T4

7.8 The first national VOICES survey of the bereaved found variation in the reported dignity and respect shown by staff all the time. It was highest in hospices.

Figure 8: Proportion of people reported by the bereaved to have been treated with dignity and respect 'all of the time'



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

7.9 A Cochrane review assessing the effectiveness and cost-effectiveness of home palliative care services analysed 23 studies (five conducted in the UK), including 7,561 patients and 4,042 family caregivers, largely with advanced cancer but also congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), HIV/AIDS and multiple sclerosis (MS), among other conditions. It found that:

- Receiving home palliative care services increased the odds of dying at home (odds ratio 2.21, 95% confidence interval 1.31 to 3.71)
- There was evidence of a small but statistically significant reduction in the symptom burden that people may experience as a result of advanced illness, without increasing grief for family caregivers after the person dies, compared to usual care
- Evidence on cost-effectiveness was inconclusive (six studies)

Source: Gomes B, Calanzani N, Curiale V, McCrone P, Higginson IJ. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database of Systematic Reviews 2013, Issue 6, Art. No.: CD007760. DOI: 10.1002/14651858.CD007760.pub2

8 What we know about primary care and community services in the last year of life

GPs and primary care teams often play a key role in supporting people approaching the end of life. Each full-time GP will have an average of about 20 deaths per annum on their caseload.¹

- 8.1 The national primary care snapshot audit in End of Life Care 2010/11 of the provision of EoLC based on use of Palliative Care/GSF Registers in primary care for 502 GP practices in 15 PCTs and 7,200 case notes, over a two-month period found 27% of people who died were included on the palliative care register and of these 23% had a non-cancer diagnosis. Most significantly though it found that those people included on the palliative care register were more likely to receive well-co-ordinated care (handover to out-of-hours, anticipatory prescribing, etc) and more likely to have been offered an advance care planning discussion and to die in their preferred place of choice. This sets the scene for further development of GPs' registers and EPaCCS.

Source: K. Thomas, et al., National primary care audit in end of life care and ACP and recommendations for improvement, BMJ Supportive and Palliative Care, June 2012, Vol. 2 No. 2. 1

- 8.2 Findings from the first round of GSF Going for Gold quality recognition accreditation for seven GP practices in 2012, endorsed by RCGP. GSF Going for Gold training builds on foundation level GSF as a distance-learning practice-based training programme to update practise and enable them to meet national policy targets including use of registers/EPaCCS and uptake of advance care planning. Successful practices demonstrated significant success in:

- Early recognition of people near the end of life for inclusion on the GSF/Palliative Care Register/EPaCCS (32%-69%)
- Increased numbers of people with non-cancer conditions (13%-44%) and from care homes (15%-44%)
- More recording advance care planning discussions (15%-62%) and 'do not attempt cardiopulmonary resuscitation' (DNACPR) decisions made (14%-60%)
- Improved carer's assessment (3%-60%) and bereavement care (23%-82%)

¹ Thomas K Community Palliative Care from ABC Palliative Care (2nd edition) 2006, Blackwell Publishing

- Development of practice protocols to enable sustained long-term quality improvement in all

Source: Findings from the first round of GSF Accreditation in Primary Care 2012. Thomas K, Armstrong Wilson J GSF Centre. European Journal of Palliative Care. Abstracts. Abstract P2-243 May 2013 – 13th World Congress of the European Association For Palliative Care May 30 – June 2 2013 – Prague
www.congressinfo.org/filerun/weblinks/?id=e94550c93cd70fe748e6982b3439ad3b&filename=EAPC-Abstract-Book_FINAL%20Version_small.pdf

8.3 The Quality and Outcomes Framework (QOF) is a voluntary reward and incentive scheme for GP practices in England. There are two QOF indicators for palliative care in the clinical domain:

PC001 – the practice establishes and maintains a register of all patients in need of palliative care/support irrespective of age.

PC002 – the practice has regular (at least three monthly) multidisciplinary case review meetings where all those on the palliative care register are discussed.

- In 2011-12 there was a 21.8% increase in the numbers of people recorded on QOF palliative care registers but the proportion of deaths recorded remained unchanged at 0.2% (based on all ages). The proportion in 2010-11 was 0.2% and in 2009-10 it was 0.1%

Source: Quality and Outcomes Framework 2011/12. Health and Social Care Information Centre

8.4 Research studies have explored GP communication with people with heart failure approaching the end of life. The studies found that:

- End of life care is rarely discussed with conversations focusing largely on disease management although some people would welcome such conversations
- Clinicians are unsure how to discuss the uncertain prognosis and risk of sudden death, fearing they may cause premature alarm and destroy hope. Clinicians wait for cues from people before raising end of life care issues

Source: Barclay S, Momen N, Case-Upton S, Kuhn I, Smith E. (2011). "The conversation that rarely happens". End of life care conversations with heart failure patients: a systematic literature review and narrative synthesis. British Journal of General Practice: 61; 59 – 60. Full text DOI: 10.3399/bjgp11X549018

Momen N, Barclay S (2011). "Barriers to end of life care conversations in heart failure: addressing "The elephant on the table". A literature review with narrative synthesis". Current Opinion in Supportive and Palliative Care: 5; 312 - 316. DOI:10.1097/SPC.0b013e32834b8c4d

8.5 A study exploring GP prescribing for cancer pain during last three months of life found:

- 43.6% of people with cancer received at least one prescription of opioids from their GP and prescription rates increased over time
- People aged over 60 had significantly lower chances of receiving opioids than those younger than 50 (prevalence ratio [PR] range, 0.14 to 0.78)

Source: Higginson IJ, Gao W. Opioid prescribing for cancer pain during the last 3 months of life: associated factors and 9-year trends in a nationwide United Kingdom cohort study. *J Clin Oncol.* 2012 Dec 10;30(35):4373-9. doi:10.1200/JCO.2012.42.0919. Epub 2012 Oct 29

8.6 Over 2,700 GPs have actively participated in the 'Find your 1% campaign' since its launch. A survey of 600 of these GPs has demonstrated an increase in people approaching the end of life recorded on a register, and increase in the proportion of people recorded who have a non-cancer diagnosis, an increase in people who participated in advance care planning and more proactive engagement with people in their last year of life.

Source: Find Your 1%: supporting GPs in delivering quality end of life care
www.dyingmatters.org/gp

8.7 Of individuals who received care from the Marie Curie Nursing Service (MCNS) (home-based palliative care) 76.7% died at home, while only 7.7% died in hospital. In contrast, 35.0% of a similar matched control group died at home, while 41.6% died in hospital.

8.8 The impact of the care provided by MCNS in terms of people dying at home and use of hospital care was greater for people without a history of cancer (for example, more died at home and used less hospital care).

8.9 People receiving MCNS with no recent history of cancer had 27% of the number of emergency admissions of their controls, while it was 37% for those with a history of cancer.

8.10 80.6% of people receiving MCNS with no recent history of cancer died at home compared to 28.6% of matched controls.

8.11 75.6% of people receiving MCNS with a history of cancer died at home compared to 36.7% of matched controls.

Source: Chitnis et al., The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life, Nuffield Trust, November 2012

9 What we know about care homes in the last year of life

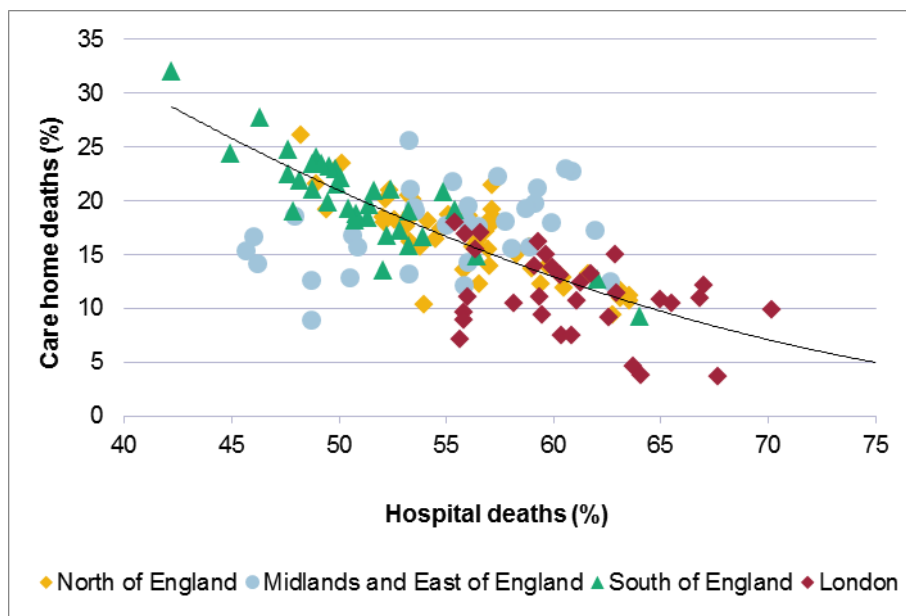
Around 18% of deaths in England occur in a residential or nursing care home (ONS 2008-10 data).

9.1 There is regional variation in the provision of care home beds:

- The South of England has the highest number of care homes per 1,000 population aged 75 and over. The North of England has the highest number of care home beds per 1,000 population aged 75 and over

9.2 Areas with high percentages of hospital deaths have the lowest percentages of care home deaths.

Figure 9: Relationship between hospital and care home deaths. England 2011 data



Source: Data from Office for National Statistics. Chart from Public Health England (NEoLCIN). End of life care profiles summary statistics 2008 to 2010.

- The relationship between hospital and care home deaths within English local authorities illustrated in the figure above suggests the percentage of hospital deaths increases as the percentage of care home deaths decreases ($R^2 = 72\%$)

- London (61%) and Greater Manchester (60%) have the highest percentage of deaths in hospitals and the lowest percentage of deaths in care homes (11.8% and 13.8% respectively). The reverse is true of the South of England, which has the lowest percentage of hospital deaths (50.3%) and the highest percentage of care home deaths (21.2%). Devon, Cornwall and Somerset record the highest percentage of care home deaths (23.8%) and the lowest percentage of hospital deaths (47.9%)

Source: Public Health England (NEoLCIN). End of life care profiles summary statistics 2008 to 2010. Forthcoming 2013.

9.3 Findings from the first national VOICES survey of the bereaved regarding people who were cared for in a care home during the last three months of life:

- 61% of respondents said they felt that their loved ones were treated with dignity and respect 'all the time' by care home staff
- 45% of respondents felt that pain had been managed 'completely all of the time'

Source: Office for National Statistics: National Bereavement Survey (VOICES), 2011
www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/stb-statistical-bulletin.html

9.4 A study of hospice patients in South West England found that where people had expressed a preference for the place of death and the preferred place is a care home, 95% of people will die in their preferred place.

Source: The impact of advance care planning of place of death, a hospice retrospective cohort study Abel J, Pring A, Rich A et al BMJ Support Palliat Care doi:10.1136/bmjspcare-2012-000327
www.spcare.bmj.com/content/early/2013/03/14/bmjspcare-2012-000327.full#T4

9.5 A qualitative study interviewing 63 care home residents over a year found that core to older people's ability to discuss end of life care is their acceptance of being in a care home, the involvement of family members in making decisions and the extent to which they believed they could influence decision making within their everyday lives.

Source: Mathie E, Goodman C, Crang C, Froggatt K, Iliffe S, Manthorpe G, Barclay S. (2012) "An uncertain future: the changing views of care home residents about living and dying". Palliative Medicine: 26 (5); 734 – 743 DOI: 10.1177/0269216311412233

9.6 An evaluation by Somerset PCT Public Health of the effects of the Gold Standards Framework (GSF) Care Homes Training Programme provided to 64 Somerset care homes over two years found evidence of reduced hospital admissions, deaths and emergency calls, and improved satisfaction of care when compared with a control group that had not undertaken GSF training over the same period. Findings showed:

- 116 fewer hospital admissions/year
- 30% reduction in hospital deaths
- 20% reduction in hospital admissions
- 15% more residents dying in the care home (87%)
- Emergency admission rates significantly reduced

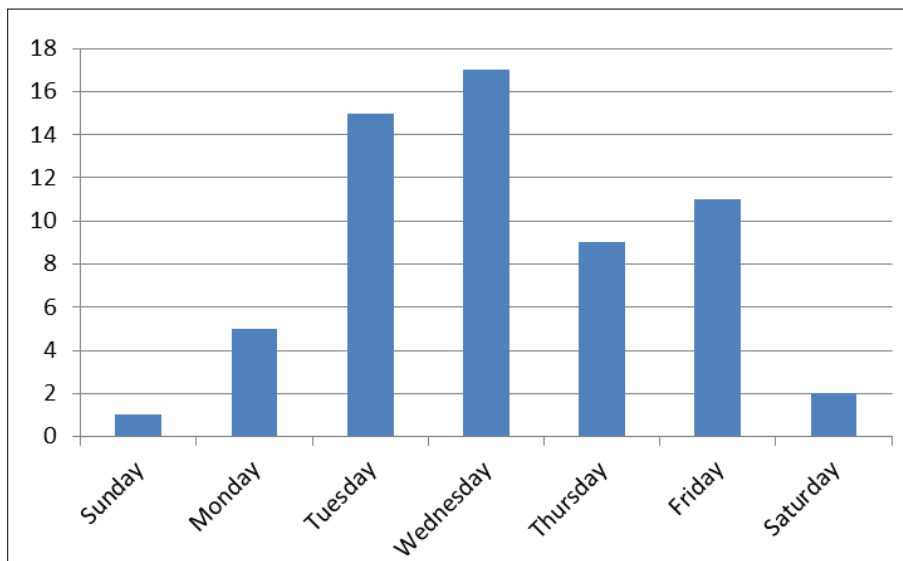
Source: Comparative study of hospitalisation rates between GSF trained Care Homes and control group homes in Somerset. Holland, I, Absolom, C, Coles J NHS Somerset GSFCH team Thomas K, Stobart Rowlands GSF Centre European Journal of Palliative Care. Abstracts. Abstract P2-243 May 2013 – 13th World Congress of the European Association for Palliative Care May 30 – June 2 2013 – Prague

10 What we know about ambulance use

Ambulance services are the method of admission to hospital for many people and so could have an important role in supporting them to stay in their own homes or care establishments at the end of life. Ambulance data may provide additional perspective about end of life care that has not previously been accessed. A small project was carried out by the South East Coast Ambulance Service NHS Foundation Trust (SECamb) and North West ambulance services using ambulance data and linking with hospital data.

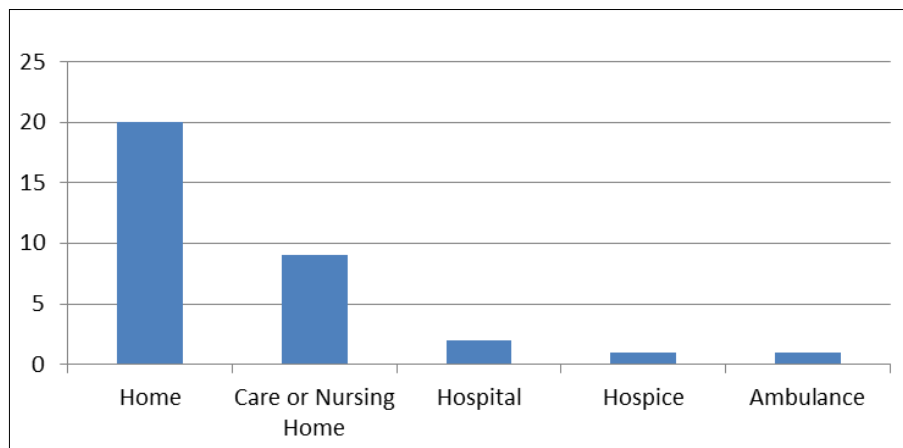
- 10.1 A list of 414 people who SECamb conveyed to a local acute Trust and who died within 14 days of admission between January and September 2012 was matched to the SECamb clinical record. Only 18% were clearly identified as at end of life at the time of the call. A further 8% were identified as query end of life.
 - 10.2 Of the 75 people conveyed to hospital who died within 14 days and were clearly identified as at end of life, 38% had a respiratory condition, 32% had cancer, 12% had heart failure and 9% had dementia.
 - 10.3 Of the 75 people conveyed to hospital who died within 14 days and were clearly identified as at end of life, 23 were resident in a care or nursing home, 50 lived at home and eight had DNACPR recorded on the ambulance IT system.
- Source: Elizabeth Davis. South East Coast Ambulance Services. Audit of local ambulance use by people at end of life over nine month period. 2012
- 10.4 Where an ambulance was called to transfer a person from hospital on the rapid transfer of the dying pathway operating in the North West, the ambulance arrived within the two-hour target time for 68.5% of calls.
 - 10.5 Of the 53 people where the destination of the transfer was recorded, 33 were transported to a care home, 13 to their own home and seven to a hospice.
 - 10.6 More people were placed on the rapid transfer of the dying pathway on weekdays than weekends.
 - 10.7 The average time from date of hospital discharge to date of death was 25.1 days.

Figure 10: Rapid transfer/discharge by day of week (n=60)



Source: Steve Barnard. Audit of the rapid transfer of the dying pathways from two acute hospitals using North West Ambulance Services. 2012

Figure 11: Location of patient death following transfer/discharge (n=33)



Source: Steve Barnard. Audit of the rapid transfer of the dying pathways from two acute hospitals using North West Ambulance Services. 2012

11 What we know about different disease groups

Specialist palliative care was traditionally focused on care for people dying from cancer. The end of life care strategy recognised that all people should expect quality end of life care regardless of their diagnosis.

- 11.1 Compared to all other cancer deaths, people with haematological cancers were more likely to die in hospital and less likely to die at home or in a hospice.

Source: Where do patients with blood cancers die? NCIN data briefing, National Cancer Intelligence Network, 2011

- 11.2 62% of urological cancer deaths occur in people aged 65-84. In testicular cancer, 79% of deaths occur in men under 65.

- 11.3 Hospital is the main place of death for those dying from urological cancer. However, the proportion of hospital deaths is lower at 46% than the average 54% for deaths from all causes (2008-10 data). 23% of urological cancer deaths occur in people's own homes compared to 20.3% for all deaths. Men with testicular cancer are most likely to die in hospital and people with kidney cancer most likely to die at home.

Source: Deaths from Urological cancers in England 2001-2010. NEoLCIN. October 2012

- 11.4 The proportion of deaths from cardiovascular disease has fallen from 37.2% in 2004 to 28.9% in 2011.
- 11.5 The proportion of deaths in the usual place of residence for all cardiovascular diseases has increased from 37.4% in 2004 to 42.6% in 2011.
- 11.6 More men than women die of acute and chronic coronary heart disease but considerably more women than men die of cerebrovascular diseases (including stroke).
- 11.7 Large numbers of people dying from cardiovascular diseases were found to have coexisting medical conditions. The proportion of cardiovascular disease deaths with a hospital record of Type II diabetes rose from 16% to 19%, between 2004 and 2008.

- 11.8 Between 2004 and 2011 a large proportion of cardiovascular disease deaths occurred in hospital (59%). Only 0.3% of all cardiovascular disease deaths in this period occurred in a hospice.

Source: Deaths from cardiovascular diseases. Implications for End of Life Care in England. NEoLCIN. Feb 2013

- 11.9 For people with conditions other than cancer, the proportions dying at home differ markedly according to the condition, with only 12% of deaths from respiratory or neurological causes occurring at home and almost all dementia deaths occurring either in care homes (55%) or hospital (39%).

- 11.10 Higher levels of co-morbidity reduce the chance of home death and increase the chance of hospital death.

- 11.11 Illnesses where there is a longer trajectory of functional impairment (even if severe) are associated with increased home death (possibly because of the time available for planning and preparation).

Source: Murtagh FEM, et al. Understanding place of death for patients with non-malignant conditions: a systematic literature review, National Institute for Health Research, Service Delivery and Organisation Programme, September 2012

- 11.12 In advanced kidney disease, three distinct symptom trajectories are described in the last year of life: 50% with stable symptoms, 24% with steadily increasing symptoms, and 21% with highly fluctuant/unpredictable symptoms. In the two months prior to death, people with advanced kidney disease also reported a sharp increase in symptom distress and health-related concerns.

Source: Murtagh FE, Sheerin NS, Addington-Hall J, Higginson IJ. Trajectories of illness in stage 5 chronic kidney disease: a longitudinal study of patient symptoms and concerns in the last year of life. *Clinical journal of the American Society of Nephrology: CJASN*. 2011 Jul; 6(7):1580-90. PubMed PMID: 21685021

- 11.13 There are significant differences in the use of social care for people with certain conditions with highest use in dementia, falls and stroke.

Source: Georghiou T et al. Understanding patterns of health and social care at the end of life: research report. London: Nuffield Trust, 2012

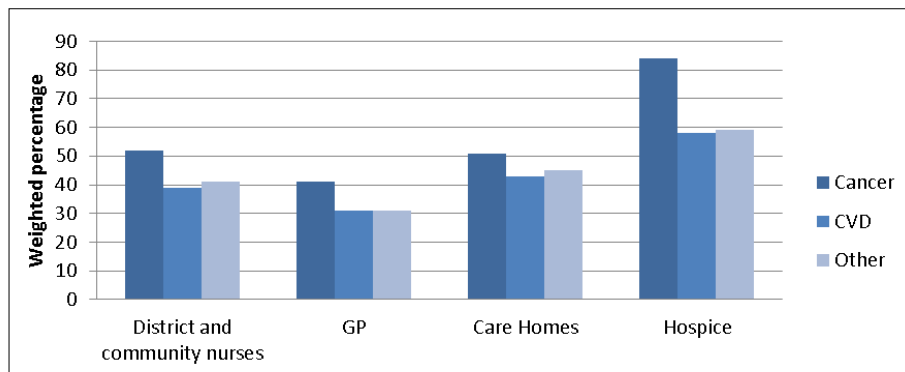
- 11.14 Deaths related to dementia and Alzheimer's disease rose between 2001 and 2011 by around 6% both for men and women.

Source: Office for National Statistics' annual report into the number, and causes of, registered deaths in England and Wales during 2011

11.15 For most care settings/services, excellent quality of care was rated more often by the bereaved for those who died of cancer compared with cardiovascular disease (CVD) or other causes:

- District and community nurses: 52% of patients who died from cancer compared with 39% CVD and 41% other causes
- GPs in the community: 41% of patients who died from cancer compared with 31% CVD and 31% other causes
- Care homes: 51% of patients who died from cancer compared with 43% CVD and 45% other causes
- Hospices: 84% of patients who died from cancer compared with 58% CVD and 59% other causes
- For hospitals, excellent quality of care was rated by relatives as 38% for doctors and 35% for nurses, and did not vary by cause of death

Figure 12: Excellent quality of care by care setting and cause of death



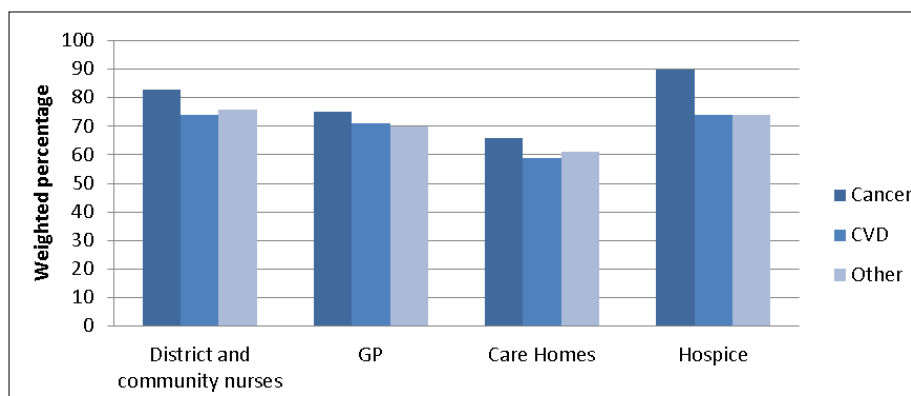
Source: Office for National Statistics: National Bereavement Survey (VOICES), 2011
www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/stb-statistical-bulletin.html

11.16 For most care settings/services, dignity and respect was shown by staff all the time more often for those who died of cancer compared with CVD or other causes.

- District and community nurses: 83% of people who died from cancer compared with 74% CVD and 76% other causes

- GPs in the community: 75% of people who died from cancer compared with 71% CVD and 70% other causes
- Care homes: 66% of people who died from cancer compared with 59% CVD and 61% other causes
- Hospices: doctors – 90% of people who died from cancer compared with 74% CVD and 74% other causes; nurses – 88% of people who died from cancer compared with 59% CVD and 58% other causes
- For hospitals, dignity and respect shown all the time was rated by relatives as 57% for doctors and 48% for nurses, and did not vary by cause of death

Figure 13: Dignity and respect shown all the time by care setting and cause of death



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

www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/stb-statistical-bulletin.html

12 What we know about the costs of care

- 12.1 Significant differences in the costs of both planned and unplanned hospital care were found between people using Marie Curie Nursing Service (MCNS) and closely matched controls.
- 12.2 Total hospital costs for MCNS patients were £1,140 per person less than for controls from the first contact with MCNS until death.
- 12.3 There was a significantly greater difference in overall crude hospital costs between people receiving MCNS and controls with no history of cancer (£1,475), compared to the difference between people receiving MCNS and controls with cancer (£1,044).

Source: Chitnis et al., The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life, Nuffield Trust, November 2012

- 12.4 A study that examined the use of health and social care services for over 73,000 people in the last 12 months of their lives found the total social care and hospital costs to be £10,130 per person in the final year of life. With over 465,000 deaths nationally in England in 2008 this represents £4.7bn in final-year hospital and social care costs. (Does not include primary care, community care and prescribing costs).
- 12.5 Hospital costs in the last year of life equated to £6,644 per person and social care costs at £3,486 per person.
- 12.6 Total hospital costs in the last year of life were approximately double those of social care services. However, for those people who did use a service, local authority social care costs exceeded hospital costs (£12,559 per social care user versus £7,415 per hospital user).
- 12.7 Emergency inpatients costs were £6,336 per person who used this service (representing 71.1% of hospital costs and 46.6% of all costs).
- 12.8 People incurring higher social care costs (for example, those in care homes) tended to use less hospital care.
- 12.9 Residential and nursing care costs were £18,788 per user and represented 80.2% of social care costs and 27.6% of all costs.

12.10 The group of people who used social care services in addition to hospital services cost on average £19,609 per person however, the highest costs were associated with the small proportion (2.9%) who used only social care service in their final year. This group had average total costs of £22,505.

Source: Theo Georghiou et al., Understanding patterns of health and social care at the end of life, Nuffield Trust (in partnership with the NEoLCIN), October 2012. This study examined the use of health and social care services for over 73,000 people in the last 12 months of their lives

12.11 The highest inpatient costs in the last year of life for urological cancers are for testicular cancers, at just over £13,000 per person. Prostate cancer has the lowest cost at less than £7,000 per person.

Source: Deaths from Urological cancers in England 2001- 2010. NEoLCIN. October 2012

12.12 There is evidence that implementation of Electronic Palliative Care Co-ordination Systems (EPaCCS) could save at least £35,910 for a 200,000 population each year based on a conservative estimate of £399 saved for each death supported in the usual place of residence rather than a hospital setting.

12.13 There is sufficient evidence, taking into account appropriate context, that where EPaCCS are set up, recurrent savings after four years will be over £100,000 per annum and a cumulative net benefit over four years of around £270,000 for a population of 200,000 people. (An online simulation tool that localities can use to carry out their own economic evaluation is available).

12.14 Compared to the cumulative net present value (NPV) of investment of around £270,000 over four years for the default set of assumptions, alternative scenarios demonstrate a wide range of possible outcomes from £124,000 to £1.1m.

Source: Economic Evaluation of the Electronic Palliative Care Co-ordination System (EPaCCS) Early Implementer Sites. NHS Improving Quality. May 2013

12.15 A retrospective cohort study on deaths of all people known to a hospice in a two-and-a-half-year period found that for people who died in hospital, the mean number of days spent in hospital in the last year was 26.5 days. For people who did not die in hospital, the mean number of days in hospital in the last year was 20.5 days. The mean cost of hospital care in the last year of life for those who died in hospital was £11,298. The mean cost of hospital care for those who died outside of hospital was £7,730, with a difference of £3,569 – p value of <0.001.

Source: The impact of advance care planning of place of death, a hospice retrospective cohort study Abel J, Pring A, Rich A et al BMJ Support Palliat Care doi:10.1136/bmjspcare-2012-000327

13 What we know about quality of care

The national VOICES survey first carried out in 2011 provides valuable data about the quality of end of life care as reported by bereaved relatives.

13.1 42.5% of respondents felt the overall quality of care received across all services in the last three months was outstanding or excellent.

13.2 The quality of care was rated as excellent for 78% of people who had been in a hospice in their last three months. This compares with 46% who had been in a care home, 45% who received care from district and community nurses, 35% from GPs, 38% for hospital doctors and 35% for hospital nurses. Quality of care from hospital nurses was rated as poorest (14.1%) compared with less than 4% for hospice care.

Source: Office for National Statistics: National Bereavement Survey (VOICES), 2011
www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/2011/stb-statistical-bulletin.html

13.3 Respondents of people who lived in the South West and North East consistently rated care quality more highly than people in London. For example, 55% in Cornwall and the Isles of Scilly rated care from a district or community nurse as excellent compared with 31% of people in south-east London. In north of Tyne, 45% rated care from hospital nurses as excellent compared with 29% in south-east London.

13.4 Similar patterns were found for dignity and respect. Respondents of people who lived in the South West, North East and North West reported they were consistently treated with dignity and respect more than people living in London. For example 59% of people in Devon, Torbay and Plymouth reported they were always treated with dignity and respect by hospital nurses compared with 40% of people in south-east London. In Cornwall and the Isles of Scilly, 89% of people reported they were always treated with dignity and respect by district and community nurses compared with 62% in north-west London.

Source: Office for National Statistics: National Bereavement Survey (VOICES) by PCT Cluster, 2011
www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices--by-pct-clusters/2011/index.html

14 What we know about inequalities

In addition to diagnosis there may be other inequalities related to age, ethnicity, culture, sexuality, place of death.

- 14.1 Population projections suggest that the numbers and proportions of people from black, Asian and minority ethnic (BAME) groups will continue to increase in the UK and they will represent a larger proportion of older people.
- 14.2 Review of the literature reported unmet needs and/or disparities in palliative and end of life care for BAME groups.

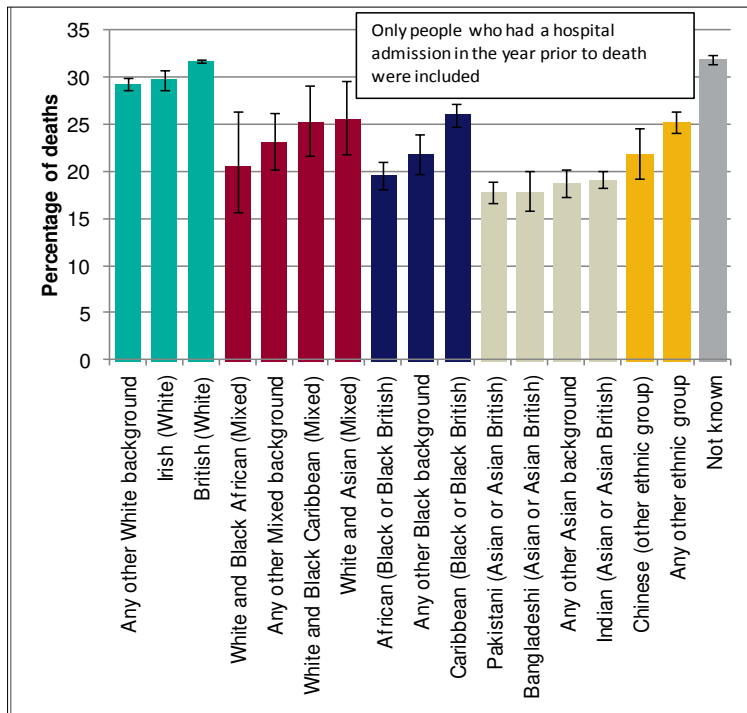
Source: Black Asian and Minority Ethnic Groups in the UK. NEoLCIN and Marie Curie Cancer Care report www.mariecurie.org.uk/Documents/WHO-WE-ARE/Diversity/Palliative%20care%20BAME%20report%20June%202013.pdf

- 14.3 Minority ethnic groups with non-cancer conditions and those with lower socio-economic status achieve lower rates of home death.

Source: Murtagh FEM, Bausewein C, Petkova H, Sleeman KE, Dodd RH, Gysels M, et al. Understanding place of death for patients with non malignant conditions: a systematic literature review National Institute for Health Research Service Delivery and Organisation Programme NIHR website, 2012 www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1813-257_V01.pdf (accessed 3rd June 2012)

- 14.4 There is variation in place of death by ethnic group:

Figure 14: Deaths in a care home or own residence, by ethnic group, England (2009-2011)



Source: Linked Hospital Episode Statistics and ONS death registrations. Public Health England, Knowledge and Intelligence Team (South West)

- 14.5 On average, 91% of specialist palliative care services responding to the survey recorded people's ethnicity. In 2004 just 49% recorded this information.
- 14.6 On average 6.2% of people receiving specialist palliative care services were described as non-white, comprising 1.5% black (African Caribbean or other), 1.1% Indian, Pakistani or Bangladeshi, 1.5% as mixed race, and 1.4% of other ethnicity including Chinese.

Source: National Survey of Patient Activity Data for Specialist Palliative Care Services, Minimum Data Set for 2011-12 (MDS), NCPIC and NEoLCIN www.endoflifecare-intelligence.org.uk/resources/publications/patient_activity_data

- 14.7 Compared with people with cancer and aged under 50, people with cancer and aged over 80 are less than half as likely to be prescribed strong analgesics.

Source: Higginson IJ, Gao W. Opioid prescribing for cancer pain during the last 3 months of life: associated factors and 9-year trends in a nationwide United Kingdom cohort study. *J Clin Oncol.* 2012 Dec 10; 30(35):4373-9. doi:10.1200/JCO.2012.42.0919. Epub 2012 Oct 29

15 What we know about end of life care education and training

The majority of end of life care is provided by non-specialist staff and it is important that all staff have the relevant competences to support people well. The one million health and one-and-a-half million social care workforces are all likely to come into contact with people approaching the end of life and their families at some point.

- 15.1 GP and district nurses in two areas of the UK reported receiving training in most areas of palliative care throughout their careers, with the exception of syringe driver use and bereavement care. It found that both staff groups had a high level of knowledge concerning key issues in pain management and syringe driver use.

Source: Momen N, Hadfield P, Harrison K, Barclay S. (2012) "Managing pain in advanced cancer: a survey of United Kingdom General Practitioners and Community Nurses". *Journal of Pain and Symptom Management*: November 2012 e-published in advance

- 15.2 An appraisal of literature reviews on end of life care for minority ethnic groups in the UK found that many studies highlighted the need for training in care that is sensitive to cultural differences.

Source: Appraisal of literature reviews on end of life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end of life care strategy, Evans et al., *BMC Health Services Research*, 2011, 11:141

- 15.3 Educators should be aware that medical students commonly experience close personal bereavement before and during their courses. A study found 23.1% of students had experienced a loss prior to entry, and 13.0% to 22.5% experienced bereavement during years one to five.

Source: Whyte R, Quince T, Benson J, Wood D, Barclay S. (2013) "Medical students' experience of personal loss: incidence and implications". *BMC Medical Education*: 13; 36. DOI: 10.1186/1472-6920-13-36

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