



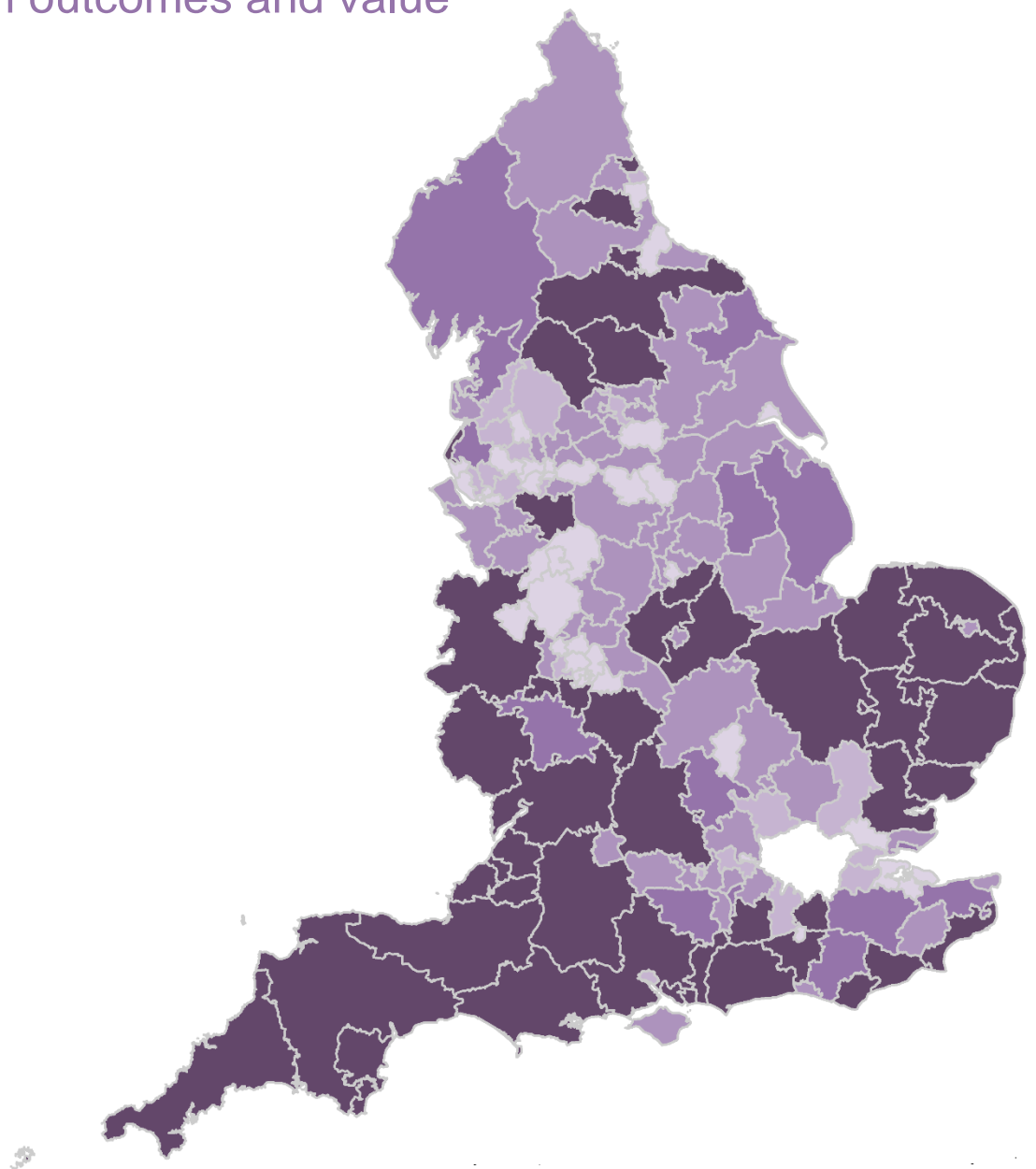
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Atlas of variation for palliative and end of life care in England

October 2018

Reducing unwarranted variation to
improve health outcomes and value



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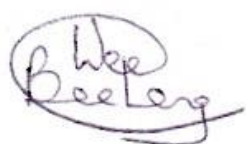
Foreword

I welcome this Atlas of variation for palliative and end of life care in England as a significant contribution to efforts to improve end of life care for the population. It clearly demonstrates the range and magnitude of challenge we are facing, not least to raise standards across the country to those of the best. The Atlas not only shows statistically significant variation across its 29 indicators but for 21 of these there is also trend data. It is helpful not only to have a clear indication of direction of travel for England but also whether the degree of variation across the country is narrowing or widening. This Atlas clearly illustrates the importance for local providers and commissioners to understand the needs and indicators of care for their local population as these vary significantly across England and there is a helpful list of resources to guide action.

We are facing a significant challenge to provide not only more but better quality palliative and end of life care, tailored to the needs of individuals and their families. As the population ages, in particular the baby-boomer population, the number of people dying each year has started to increase and as shown in the Atlas will increase further although different parts of the country will be affected in different ways with some seeing a greater effect than others.

The Atlas shows that local populations differ significantly in their age, socioeconomic and ethnic make-up and these factors influence what people die from, at what age and what type of care they will need. The section on indicators for care in hospital provides some clear indications for opportunities for improvement not least in the new CCG Improvement and Assessment Framework indicator of 3 or more emergency admissions to hospital in the last 90 days of life. We know that frequent transfers between home and institutions at the end of life are distressing for both patients and their families. While some of these admissions may be unavoidable, probably a large number could be avoided if there were to be more timely identification of patients entering the final stage of life, better anticipatory care planning and better response to unscheduled needs as close to home as possible. The indicators from the Royal College of Physicians End of life care audit – dying in hospital¹ show clear opportunities for improving the quality of direct patient care in hospitals. The section on community care identifies both challenges and opportunities. There are clear challenges in some areas in terms of provision of care in care homes as some areas have low numbers per 100 population aged 75 years and older. In these areas this may contribute to higher hospital admission rates at the end of life for elderly patients. There are clear opportunities for GPs and other clinicians to initiate conversations with people approaching the end of life to offer them opportunities to discuss and document their wishes for care.

This Atlas supports the Ambitions Framework² and a plethora of initiatives which are led by NHS England as part of the Palliative and End of Life Care Partnership. I recommend that everyone interested in palliative and end of life care should read and use it.



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¹ Royal College of Physicians (2016) [End of Life Care Audit – Dying in Hospital: National report for England 2016](#) [Accessed August 2018]

² National Palliative and End of Life Care Partnership (2015) [Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020](#) [Accessed August 2018]


Preface

This first Atlas of variation for palliative and end of life care in England builds on a decade of increasing awareness about the importance of using comparative and trend data to understand aspects of the need for, and provision of, palliative and end of life care. In the 2008 End of life care strategy¹ the need for a national resource for the production of intelligence on palliative and end of life care was identified and in 2010 the National End of Life Care Intelligence Network (NEoLCIN) was established. The NEoLCIN moved to Public Health England (PHE) in April 2013. The close proximity to other intelligence teams in PHE has encouraged cross-fertilisation of ideas in terms of data analysis and presentation. This Atlas of variation is a fruit of such collaboration and the NEoLCIN has worked closely with the PHE Healthcare Variation and Value team who produce the Atlases of variation in healthcare series. It will be latest addition to the series of Atlases of variation in healthcare, published jointly with NHS RightCare.

This Atlas presents 29 indicators. For every indicator shown in this Atlas there is evidence of variation across England. The indicators are presented in a new format to show maps of geographical variation for each indicator's range of values but also an accompanying map showing the statistical significance of this variation from the England value. The extent of geographical variation in each indicator is also displayed using a column chart showing the distribution for the most recent period of data and a box and whisker plot showing the statistical degree of variation. For 21 indicators it is statistically possible to analyse trend data over time both for the England value and degree of variation.

Each map has a short introduction describing the context for the indicator, a description of the magnitude of variation and where possible trend and suggestions for local consideration. The Atlas also contains a list of resources.

In previous Atlases, it has been possible to identify clear evidence of unwarranted variation. In the Atlas of variation for palliative and end of life care this is much more challenging because need varies geographically, dependent on the age, socioeconomic factors and ethnic make-up of the population as well as major causes of mortality. Models of care provision also vary, so even for areas with similar demographic characteristics and mortality profiles the balance between different modes of care provision may be different. Finally, patient and family wishes are also important and choices or even ability of families to provide support may vary depending on what is provided locally. It is unlikely that there is not unwarranted variation in palliative and end of life care as the Atlas series shows this is highly prevalent across all other types of health services. However, local interpretation is key to judge what may need to change at a local level. The Atlas can be used to identify potential problems especially where an area is a statistically significant outlier. It is therefore essential that health and social care service providers and commissioners use the data provided in the accompanying Data File, alongside Public Health England's End of life care profiles² and End of life care Sustainability and Transformation Partnership (STP) Tool³ and other resources referred to within the Atlas to understand more about their local picture to determine priorities for action.



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¹ Department of Health and Social Care (2008) [End of life care strategy: promoting high quality care for adults at the end of their life](#) [Accessed August 2018]

² Public Health England (PHE) [End of Life Care Profiles](#) [Accessed August 2018]

³ Public Health England (PHE) National End of Life Care Intelligence Network (2017) [End of Life Care data to inform Sustainability and Transformation Partnerships \(STPs\): Updated Tool and Metadata Guide](#) [Accessed August 2018]

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Introduction

Background

The need for good quality palliative and end of life care in England has never been greater and is projected to rapidly increase because of the ageing population. Approximately half a million people die in England each year, more than two-thirds of whom are aged 75 years and older¹. Death for many is now preceded by frailty and slow ‘dwindling’². Research shows that this can place significant resource pressures on the health and care system, with an estimated one-third of NHS costs accrued in the last year of life³. Good, personalised end of life care that reflects individuals’ needs and choices is a vital component of good quality health and social care services, and can reduce pressures on acute services⁴.

In 2008, the End of life care strategy⁵ outlined a clear vision for improving access and quality of end of life care for all. Since then the Strategy for good quality end of life care has been set out in national guidance, including from the National Institute for Health and Care Excellence (NICE)^{6,7}, the Leadership Alliance for the Care of Dying People⁸ and in the Ambitions framework⁹. Progress has been made in delivering elements of the Strategy for example the proportion of people dying in hospital decreased from 57.9% in 2004 to 46.9% in 2016¹⁰. However, variable levels of success have been achieved against the strategy’s vision of high quality care for all irrespective of age, diagnosis, gender, socioeconomic deprivation, and ethnicity.

The ‘Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020’⁹ has set out 6 ambitions for palliative and end of life care. One of the founding principles is fair access to end of life care. This includes tackling unwarranted variation in care due to where people live, their age, diagnosis, background or income. For example, patients with cancer currently appear to have greater access to specialist palliative care than patients with other conditions. This is particularly the case outside of hospitals.

One of the key aims of the Atlas of variation series is to highlight geographical variation and to try to differentiate between warranted and unwarranted variation. Warranted variation in health care services may occur because they are appropriately meeting different levels of health care need between areas. These different levels of need may reflect geographical variations in sociodemographic characteristics of the population, risk factors and disease prevalence. John Wennberg, who founded the pioneering Dartmouth Atlas of Health Care¹¹, defined unwarranted variation in healthcare as

“variation that cannot be explained on the basis of illness, medical evidence, or patient preference”¹².

Some variation in indicators of palliative and end of life care may be due to the underlying variation in the sociodemographic characteristics between geographical areas as factors such as age, gender, socioeconomic status and ethnicity which will influence the end of life health and social care needs of the local population. These sociodemographic factors may also influence unwarranted variation if they are associated with differing levels of fair access to services.

The wide variety of models of provision of end of life care delivered by statutory and voluntary, acute and community health, and social care services and the range of individual needs within a population makes the interpretation of unwarranted variation especially challenging in end of life care, especially as not all elements of care can be measured. Some variation in end of life care may be explained by the local configuration of health, social care and specialist palliative care services, for example, the availability of community social and health care services to look after people at home at the end of life varies across England¹³. This can put a considerable strain on the system for providing good quality end of life care and reduce choices for people about where they can be cared for before death.

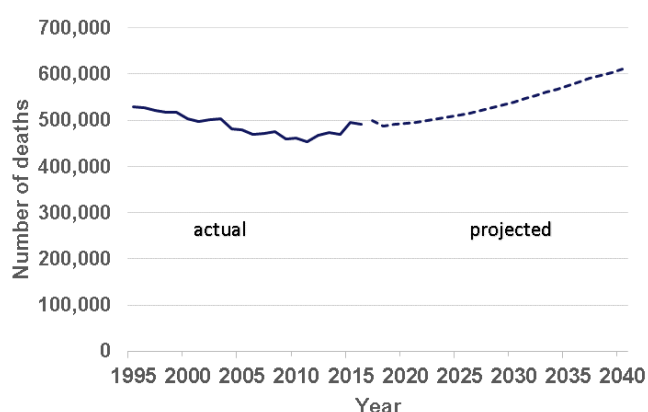
Due to the complexity of assessing unwarranted variation in health care services for palliative and end of life care it is recommended that providers and commissioners use the indicators shown in this Atlas alongside the End of life care profiles¹⁴ and local data, to create a picture of need, provision and outcomes. This can help to identify whether local variation is unwarranted or responding to local need appropriately.

This first ever Atlas of variation for palliative and end of life care in England presents data on 29 indicators across 3 sections: 'Need for palliative and end of life care services', 'The role of hospitals in palliative and end of life care', and 'Palliative and end of life care in the community setting'. Importantly, it shows the degree of geographical variation across these 3 domains and their associated indicators, and where possible trend data. Additional data and resources are provided to assist local stakeholders in developing and evaluating their service delivery strategies. An explanation of the data presentation is given in the section 'Introduction to the data' which follows this introduction.

Changing pattern of deaths in England

In England 490,791 people died in 2016¹. The current trend is for the number of deaths to increase. Figure 1 shows this follows over a decade of year on year fall in the number of deaths since 1995 when there were 529,034 deaths. There is projected to be a 26% increase in the number of deaths between 2016 (490,791) and 2040 (616,479).

Figure 1: Actual and projected number of deaths, England 1995 to 2040^{15 16}



Age distribution of deaths

The majority of people who die in England are aged 75 years and older (68% in 2016) and this proportion has changed little over recent years although, the age at which people die over the age of 75 years has been increasing significantly. Improvements in health care are leading to increased life expectancy, with more people living to the oldest ages. Towards the end of their life many people are living with multiple co-morbidities, and this is most likely for older people.

Figure 2 shows that the proportion of all deaths that occurred in those aged 85 years or older has increased (40% in 2016 compared with 35% in 2007), while the proportion that occurred in those aged between 75 and 84 years has decreased (28% in 2016 compared with 32% in 2007).

The age distribution of deaths projected for future years is shown in figure 3. In 2040, 51% of all deaths (317,038 deaths) are projected to be in those aged 85 years or older, compared to 194,715 deaths in 2016 (40% of all deaths). The difference in the age at death between males and females is projected to reduce, with females making up 55% of people dying aged 85 years or older in 2040 compared to 62% in 2016.

Figure 2: Number of deaths by age at death, England 2006-2016¹⁵

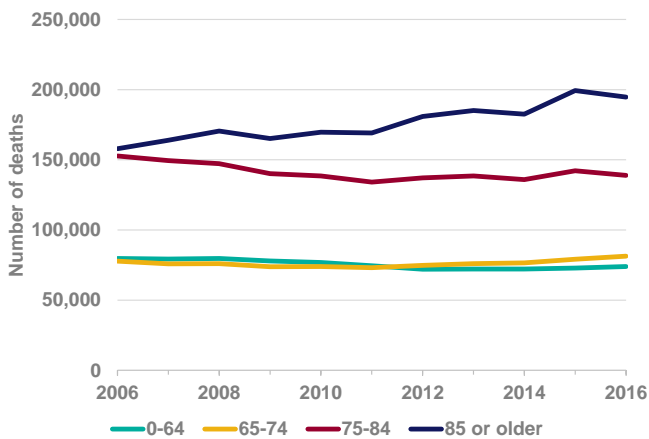
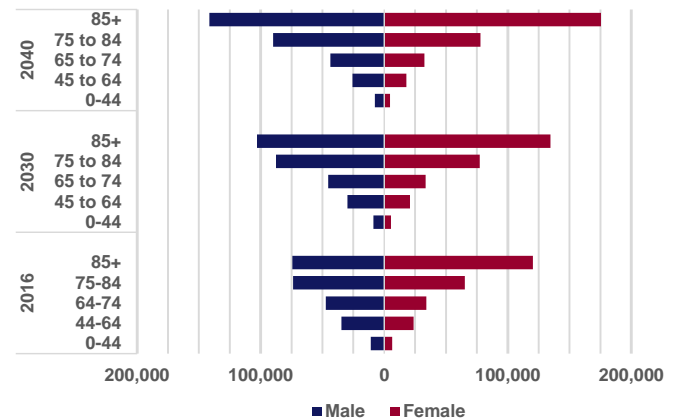


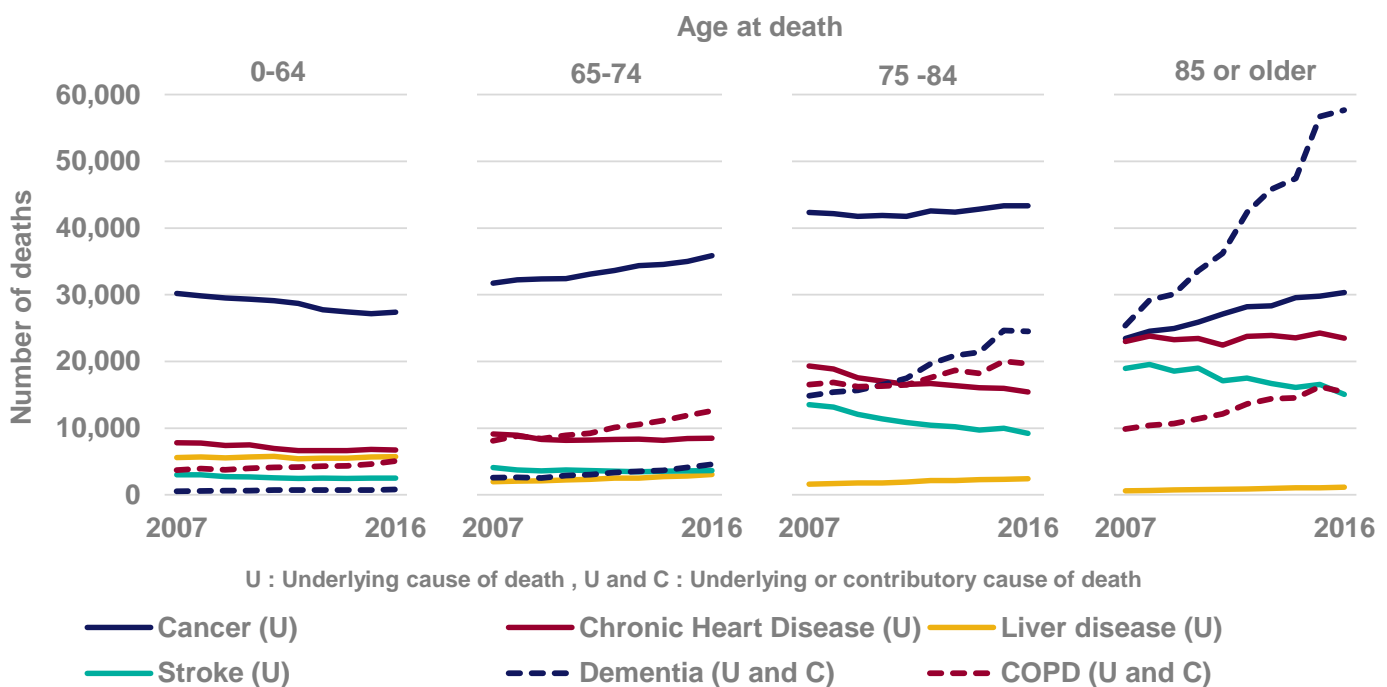
Figure 3: Current and projected number of deaths by age and sex, England 2016, 2030 and 2040^{15 16}



Trends in causes of death

The specific care needs of people towards the end of their life are influenced by their underlying illnesses. Some of the changing patterns of cause of death in the past decade are illustrated in figure 4. There have been reductions in the number of people dying from stroke and heart disease, especially between 75 and 84 years of age and the number of people dying with dementia recorded as an underlying or contributory cause of death has increased considerably. The future is likely to see this trend continue, with even more people at the end of their life suffering from dementia due to the expected increase in the number of people dying in their late 80s or later¹⁷.

Figure 4: Number of deaths by selected cause of death by age at death, England 2007-2016¹⁵

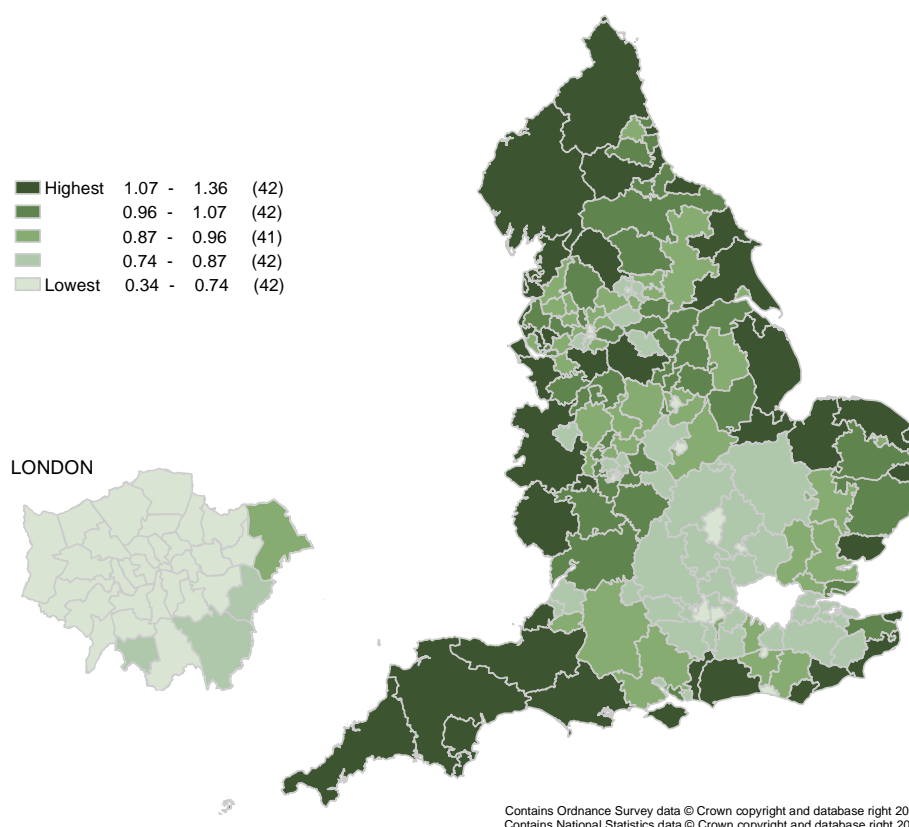


The variation in death rates across England

There is considerable variation in the sociodemographic characteristics of the population across England, including variations in age, health, income and ethnicity. These variations contribute to the number of deaths, what people die from, and their preferences for, and access to, palliative and end of life care services.

On average in England, approximately 1% of the population die each year¹⁸. As figure 5 shows this varies across Clinical Commissioning Groups (CCGs) from 0.3% to 1.4%, with higher rates in the geographic extremes of England.

Figure 5: Variation in crude death rate (%) by CCG, England 2016^{15 19}



For service planning at a local level, it is important to take into account both the current numbers of deaths and projected numbers of deaths in the future. In 2016, the number of deaths by CCG varied from 509 to 9,641. The projected change in the number of deaths by CCG varies widely from a fall of approximately 10% to an increase of 36% suggesting that some areas will see a big change in the demand for palliative and end of life care. Data on current and projected numbers of deaths is provided in two appendices: Appendix 1 shows number of deaths and crude death rate by CCG (2016) and Appendix 2 shows projected deaths for 2030 at lower tier local authority level. These give an indication of the level of local need, which of course varies with the absolute population size and social demographics.

Place of death

Place of care at the end of life and place of death are important to many people although recent surveys have shown that it is not the most important factor for patients and their families ^{20 21 22 23}.

Since the publication of the 2008 End of life care strategy⁵ much of the focus of policy and implementation of improvements in end of life care has been focussed on increasing patient choice particularly, but not exclusively, in relation to location. With good advance care planning, patients are more likely to die in their preferred place of death^{24 25}. Research suggests that home and hospice are the preferred place of care and of death for many people²⁶, however, nearly half of all deaths occur in hospital. Many factors affect where people are cared for and where they die including, the proximity of acute and community hospitals, the distribution and availability of care home places, the availability of community services and the clinical needs and wishes of dying patients. Table 1 shows the number and percentage of deaths by place of death in 2007 and 2016. Over this period the proportion of deaths in hospital has fallen by 9.0%, from 55.9% to 46.9% while the proportion of deaths in care homes, home and hospices have increased.

Age affects place of death, with the oldest people most likely to die in a care home and least likely to die in a hospice (figure 6). Cause of death also affects place of death, with a particularly high proportion of deaths from liver disease, stroke and COPD occurring in hospital, a high proportion of deaths with dementia occurring in care homes and a dominance of cancer deaths in hospice (figure 7).

Table 1: The number and percentage of deaths by place of death, England 2007 and 2016¹⁵

Place of death	2007		2016	
	Number of deaths	Percentage of deaths	Number of deaths	Percentage of deaths
Hospital	261,798	55.9%	229,095	46.9%
Home	91,757	19.6%	114,700	23.5%
Care Home	79,644	17.0%	106,641	21.8%
Hospice	24,644	5.3%	27,721	5.7%
Other Places	10,725	2.3%	10,779	2.2%

Figure 6: Distribution of deaths by place of death and age at death, England 2016¹⁵

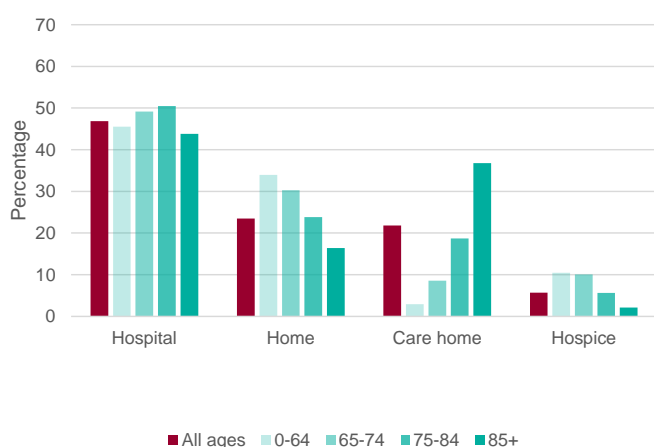
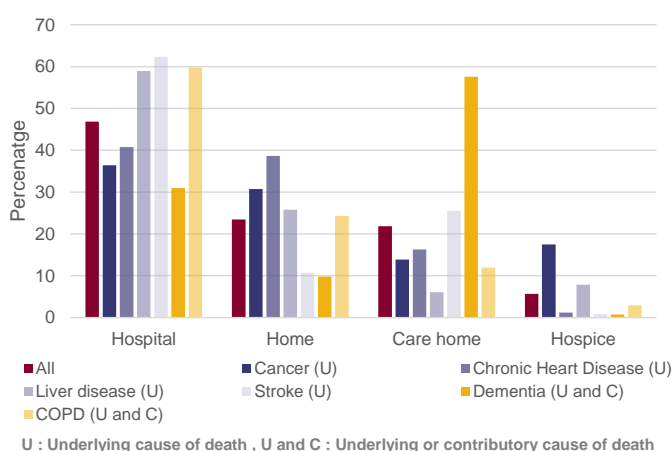


Figure 7: Distribution of deaths by place of death and cause of death, England 2016¹⁵



Inequalities

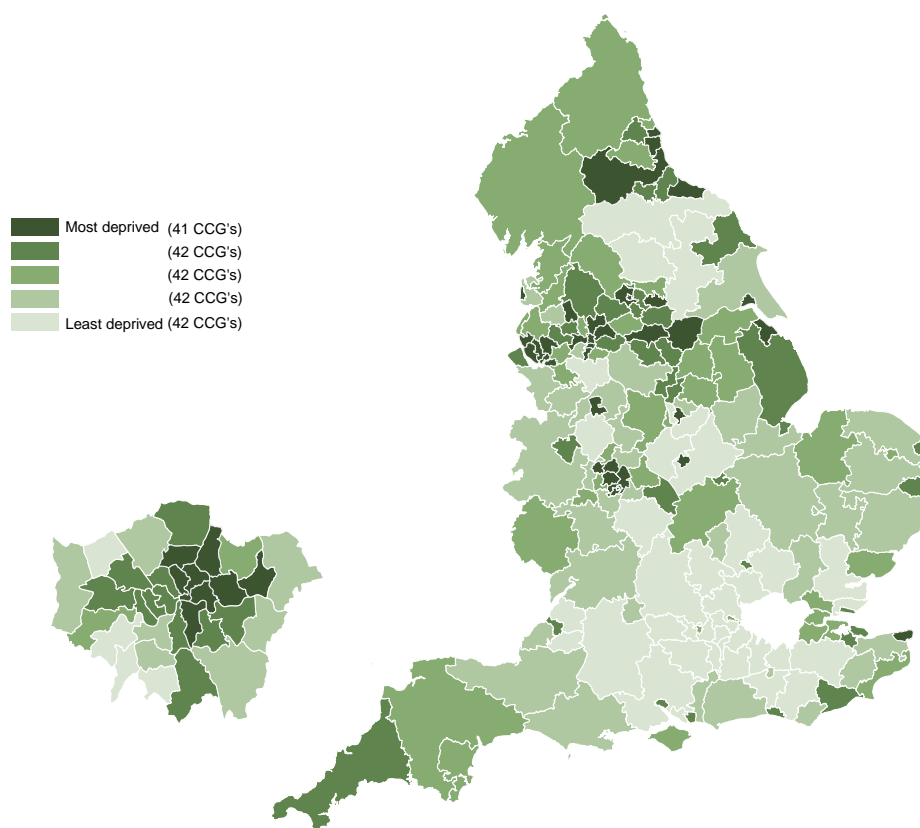
Palliative and end of life care is provided across many service delivery settings, and commissioning these services requires shared responsibilities. Commissioners and providers are required to consider equity of access when planning and delivering their palliative and end of life care services (Equality Act, 2010). It is important that local stakeholders look at the diverse needs of patients at end of life to ensure they have enabled adequate personalised end of life care. A different ending: End of life care review¹³ looked at inequalities in end of life care. Evidence for some of these groups are presented in this Atlas:

- people experiencing income deprivation
- people from ethnic minority groups
- lesbian, gay, bisexual and transgender (LGBT) people
- people with learning disabilities
- people who are homeless
- people in prison

Some evidence suggests that need for palliative and end of life care is higher in more deprived areas²⁷. Certainly, deprivation influences age at death (by impacting on life expectancy) and cause of death.

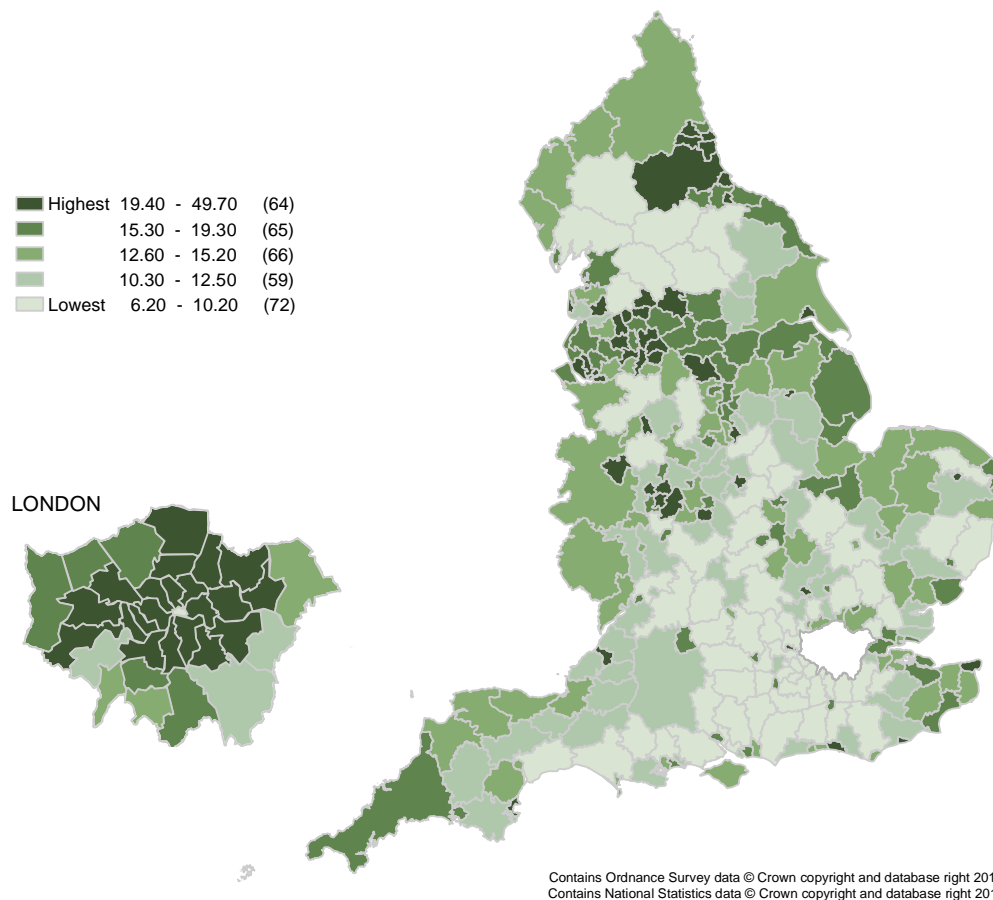
Figure 8 shows the variation across CCGs in average lower layer super output area (LSOA) scores for the Index of multiple deprivation divided by equal quintiles.

Figure 8: Index of multiple deprivation 2015 average LSOA score CCG quintiles²⁸



As the majority of people who die are aged 75 years and older, pensioner poverty will be a particular issue. The variation in pensioner poverty is shown in figure 9. This indicator describes the proportion of all those aged 60 or over who experience income deprivation.

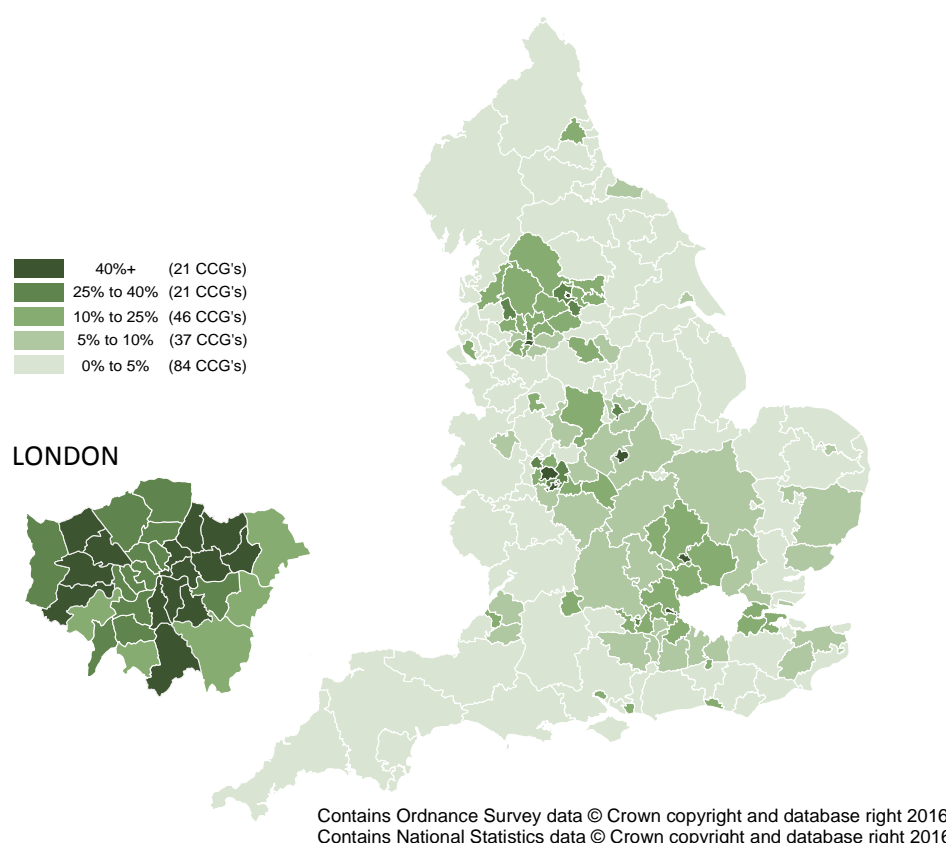
Figure 9: Pensioner poverty in England, 2015²⁸



Ethnicity interacts in a complex way with socioeconomic deprivation^{29 30}, and also influences life expectancy³¹ and causes of death³². The interaction between ethnicity and need and choices in palliative and end of life care are complex and vary across and within ethnic groups⁴. Figure 10 shows variation by CCG in the percentage of the population from Black, Asian and Minority Ethnic (BAME) groups³³. As in socioeconomic deprivation, there may also be obstacles to accessing health care and social services due to cultural barriers^{34 35 36}, poor health literacy³⁷ and or failure of the services to appropriately recognise or respond to need^{38 39 40 41 42}.

Ethnicity may have important influences on palliative and end of life care for several reasons including:

- the role of religion, spirituality, customs and traditions as death is approaching and after death
- attitudes to place of death
- family structure and support
- health literacy and ability to access and benefit from health services

Figure 10: Percentage of the population with Black, Asian and Minority Ethnic groups by CCG, 2011⁴³

Two publications 'Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK'³³ and 'Place of death by ethnic group for people who died from cancer'⁴⁴ describe and expand upon these issues.

Recent research suggests that the experience of LGBT people at the end of life has often been overlooked even though they experience higher incidence of life-limiting illness^{45 46}. There is evidence that discrimination continues to have an adverse impact on people's access, needs and experience of services at end of life³³. Research also suggests that health and care staff should acknowledge people's sexual orientation and gender identity, and ask about these as part of planning treatment and care at the end of life enabling LGBT people to discuss their needs and concerns⁴⁵.

People who are homeless have a much lower life expectancy than the rest of the population; the average age of death of a homeless person is just 47 years old⁴⁷. They are a marginalised group with often highly complex health needs. Recent research has shown that a lack of specialist provision for homeless people can lead to them being cared for in hostels at the end of life, where staff are often not equipped to deal with high levels of health and care needs^{48 49}.

Similarly, people with a learning disability have a life expectancy that is significantly lower than the UK average, and also a high incidence of premature and avoidable death⁵⁰. It is important that reasonable adjustments are made in providing palliative and end of life care for people with learning disabilities⁵¹.

The prison population is ageing, and people aged over 50 and 60 years are the two fastest growing prison population groups⁵². However, there is insufficient investment to meet the increasing needs of elderly prisoners. There are challenges in delivering good end of life care in prison, and the experience of prisoners at the end of life is variable⁵².

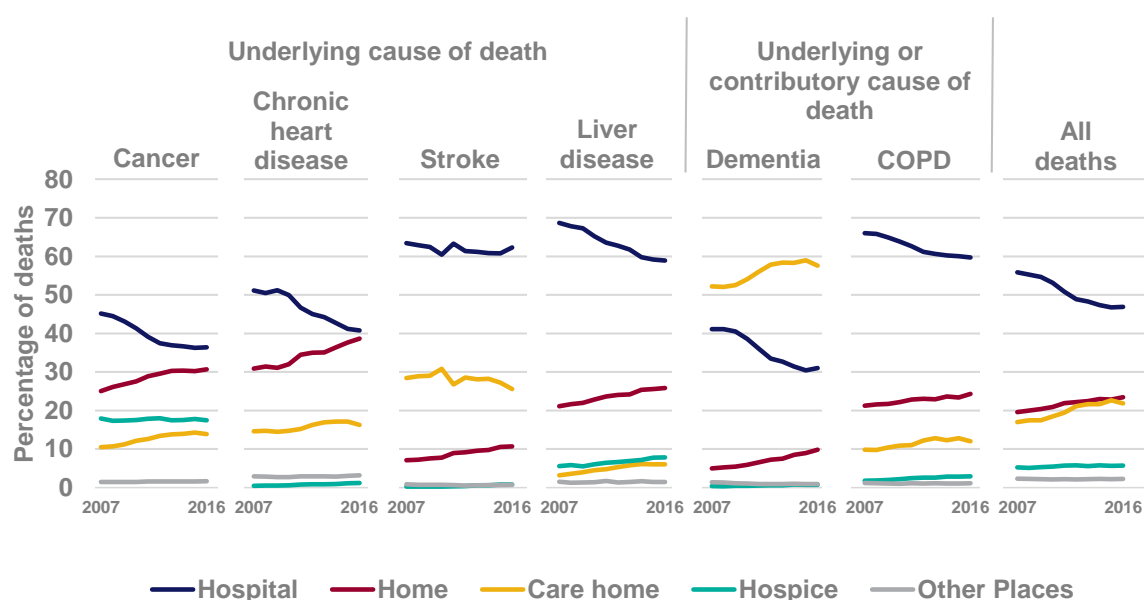
The role of hospitals in end of life

The last decade has seen a significant reduction in the proportion of deaths that occur in hospital – down 9% from 55.9% (2007) to 46.9% (2016). However, there is significant variation by CCG (35.2% to 63.1%, 2016). Hospitals are important places of care towards the end of life for many patients even if they die in the community. Given the importance of hospitals in caring for patients approaching the end of life there have been a number of initiatives to improve the quality of palliative and end of life care⁵³. Factors associated with a higher risk of dying in hospital include age, gender, social deprivation, underlying or contributory cause of death, ethnicity and marital status⁵⁴.

The total number of deaths in hospital in 2016 was 229,095. Older adults account for the majority of these deaths – (155,388) 67.8% are aged 75 years and older at death and (85,262) 37.2% are aged 85 years and older at death. The age profile of deaths in hospital reflects the age profile of deaths in the population 68% and 40% for people aged 75 years or 85 years and older respectively.

The percentage of deaths in hospital and the rate of decrease varies by disease group. This is illustrated in figure 11.

Figure 11: Percentage of deaths in each place of death by selected cause of death, England 2007-2016¹⁵



For some medical conditions there are factors related to the terminal stages of the disease and patient factors which make hospital the preferred place of death. Examples of this are liver disease and respiratory diseases. In addition many patients die in hospital after admission for potentially life-saving interventions. It has been estimated at least 25% of all deaths are unexpected deaths from sudden causes⁵⁵.

In 2015, two-thirds of people who died had a hospital admission in the final 90 days of their life and on average, 1 in 14 (6.9%) had 3 or more emergency hospital admissions during the last 90 days of life. Some of these emergency admissions may be avoidable and can be disruptive and distressing for patients and their carers⁵⁶. There is some suggestion that not all patients who die in hospital have medical needs requiring them to be there⁵⁷, however, this needs further evaluation to quantify more accurately. A number of practical tools have been identified as good end of life care practice and these have been shown to improve the quality of care for patients and their families. These include: advance care planning; Transforming end of life care in acute hospitals⁵³; Electronic palliative care co-ordination systems (EPaCCS); the AMBER care bundle⁵⁸; Rapid discharge home; Recommended summary plan for emergency care and treatment (ReSPECT)⁵⁹; and Priorities for care of the dying person from 'One chance to get it right'⁸.

NHS RightCare Delivery

Since becoming an NHS England national programme in 2015 NHS RightCare has worked with systems on transformational change programmes, working on a large number of priority pathways, across a wide range of conditions.

NHS RightCare Delivery Partners and their teams work collaboratively with systems to present a diagnosis of data and evidence to identify opportunities and priorities. This identifies variation among similar healthcare communities and encourages systems to focus efforts in these areas, leading to improvements in outcomes and quality.

NHS RightCare's Intelligence work includes the production of data packs, pathways and implementation resources, plus a knowledge management function, ensuring local systems have the data, evidence, tools and practical support to identify opportunities to address variation and improve population health.

NHS RightCare Delivery has 3 phases that build on strong evidence as a starting point as shown in figure 12.

Diagnose

The NHS RightCare teams work locally with systems to present a diagnosis of data and evidence across that population. Using nationally collected robust data, this collaborative working arrangement helps systems to make improvements in both spend and patient outcomes. Together they complete delivery plans on a continuous basis, to evaluate the system and establish a baseline to identify and maximise opportunities and turnaround issues. Throughout this process they ensure patient care is at the top of agenda by promoting the strong clinical interventions developed with the Senior Clinical Advisors and key stakeholders.

This Atlas allows local areas to identify where they differ significantly from the England value, providing a starting point for further investigation into what is behind this variation.

The underpinning data files, which includes the data for every time period and organisation, is provided alongside this report.

Understanding the population and its associated needs will enable local health economies to commission appropriate services, to improve the provision and quality of palliative and end of life care in their areas, thereby reducing unwarranted variation. Examples of questions local areas should consider are:

- how many people are living with a progressive life-limiting illness and dying in our area and what services do we have in place to support them at the end of their lives?
- what is the projected future need for palliative and end of life care services and will we have the appropriate services to serve our population – considering local demography such as age profiles and population projections?
- are our local services tailored to reflect the patients' differing needs given the types of diseases people die from?
- what is the provision of palliative and end of life care services in my local area – including 24/7 specialist palliative care services, social care provision, hospice provision, nursing home beds, community support?
- how good are the quality of palliative and end of life care services – using proxy measures such as 3 or more emergency hospital admissions in the last 90 days?

Figure 12: NHS RightCare Delivery

Alongside this comprehensive Atlas there is a wealth of other supporting data and profiles which are available from both PHE and NHS RightCare including:

- end of life care profiles¹⁴
- end of life care Sustainability and Transformation Partnership (STP) Tool⁶⁰
- end of life care health economics planning tool⁶¹
- number and proportion of deaths by place of occurrence⁶²
- dementia profile⁶³
- NHS RightCare 'Where to look' packs⁶⁴
- NHS RightCare Long Term Conditions packs⁶⁵

These data and information sources provide a comprehensive picture of the opportunities for change. A much wider collection of useful resources are provided in the 'Palliative and end of life care resources' section later in this Atlas. These resources have been thematically organised and include: general guidance, commissioning and contracting, condition specific, data and intelligence and learning and training resources.

Develop

Using NHS RightCare products and publications, combined with local knowledge and best practice, systems have a conversation to agree a starting point for change and develop solutions that work for their population.

NICE guidance⁶ and the Ambitions Partnership⁹ highlight specific areas where local communities should focus attention to improve the quality of palliative and end of life care. Additionally, reviews of good practice – for example Care Quality Commission (CQC) inspection reports on end of life care services will also inform the 'what to change' phase.

Key questions for consideration are:

- are there sufficient trained staff and facilities?
- are there protocols for advance care planning?
- are there barriers to access, such as available nursing home beds or hospice at home care?
- is there sufficient palliative and end of life care service provision for all regardless of their diagnosis?
- is there sufficient access to specialist palliative care for those who need this?
- how are personalised care and patient choice facilitated?

Nearly one-tenth of people have 3 or more emergency admissions (map 13) and approximately half the admissions that ended in death were eight days or longer (map 14). There is significant scope for looking at proactive approaches to care, including strengthening community based services, shared decision making and personalised care and support planning. This could ensure that services support patients to have as good an experience of palliative and end of life care as possible wherever they die (maps 11, 20, 23 and 24).

Deliver

Following conversations and development of solutions, these are then put into practice to drive transformational change and improve efficiency and patient outcomes in the long-term for a sustainable NHS.

Co-ordinating high quality palliative and end of life care can be complicated as care is provided in many sectors. Commissioning of services therefore requires careful consideration and co-ordination across a number of organisations.

When identifying where to focus efforts to make a change to palliative and end of life care service provision it is important that all affected organisations are involved in the design process. Local authorities, CCGs, social care providers, specialist palliative care providers, primary healthcare workers and clinicians need to be brought together to understand how these data relate to each other and there should be processes in place to ensure that patients with end of life care needs are identified early and referred into the relevant services. Identifying patients requiring end of life care early, may enable them to make informed choices about their treatment and care and may possibly reduce the need for costly emergency hospital admissions or unnecessary interventions.

Service planning and/or reconfiguration needs to consider the balance between the earlier identification of patients who might require palliative and end of life care and the care of patients known to be dying within the next hours or days. It is important to take into account local facilities and workforce, including the number of community and hospital staff who have been adequately trained to provide good end of life care.

The need to plan for and co-ordinate palliative and end of life care services across local authority, community, hospital and specialised services may mean that commissioners wish to consider commissioning services on a bigger footprint, such as at STP or regional level. This could improve equity in access to services at a local level and may also be more cost effective with better outcomes in the long term. Indeed, as of April 2017 – 11 STPs had embedded end of life care as one of their strategic priorities⁶⁶.

At a national level, clinical leadership in palliative and end of life care has come together under the Ambitions Partnership, which has produced a framework based on published evidence⁹. This group has outlined 6 ambitions to bring that vision about:

- each person is seen as an individual
- each person gets fair access to care
- maximising comfort and wellbeing
- care is co-ordinated
- all staff are prepared to care
- each community is prepared to help

The foundations for these ambitions are: personalised care planning, education and training, evidence and information, co-design, shared records, 24/7 access, support for carers, and leadership.

Significant progress has been made in developing good practice models in palliative and end of life care⁶⁷. These include:

- Health Education Yorkshire and the Humber funded training which significantly increased practice based advance care planning in settings across the district⁶⁸
- Coordinate My Care (CMC): joining up London's end of life care services – CMC is an integrated model of care, underpinned by an IT system, which is currently being rolled out across London⁶⁹
- University Hospital Southampton NHS Foundation Trust: A whole system approach to improving acute end of life care⁷⁰
- Leeds – Improved recognition and shared decision making through the use of EPaCCS⁷¹

How the Atlas is structured

The Atlas comprises the following:

Introduction to the data

Provides technical guidance to assist data interpretation and understanding for each of the maps. This covers: maps, column charts, statistical significance, box and whisker plots, box plot summary statistics table and confidence intervals.

Magnitude of variation summary

Provides a concise summary of all the key data for each of the 29 maps which include: geography, map title, range, fold difference, significance, variation trend and median trend.

The maps

There are 29 maps exploring palliative and end of life care over 3 sections: Section 1: Need for palliative and end of life care; Section 2: The role of hospitals in palliative and end of life care; and Section 3: Palliative and end of life care in the community. These maps contain an 'Introduction', (which provides the background to the indicator) and a 'Local considerations' section (what providers and commissioners should consider). These should be used alongside the relevant thematic domain within the 'Palliative and end of life care resources' section which signposts key guidelines and policy statements. This together with information on local performance can be used to highlight and improve services.

Section 1 - Need for palliative and end of life care has 10 maps. This section, presents data on numbers of deaths, demography and major causes of death. Maps 1 to 3 show sociodemographic data of potential need, especially for social care services and wider community support. The inadequate provision of these services may lead to unwarranted and/or unwanted emergency hospital admissions towards the end of life. Map 1 presents variation in the proportion of all people who died who were aged 75 years and older. This may give insight into variation in the distribution of causes of death such as dementia (map 5). Map 2 presents variation in the proportion of adults who are aged 65 years or older who are living alone. This can be used to investigate community based end of life care need as described in section 3 of this Atlas. Map 3 presents variation in the population aged 16 years or older who are unpaid carers. Although not all carers are caring for those near end of life, the majority of those being cared for are older (65 years or older) and have life-limiting conditions.

The second half of section 1 focusses on the major causes of death at CCG population level. These are presented as proportions of deaths from each major cause. This enables CCGs to consider the need for care tailored to specific causes. For cancer (map 4), chronic heart disease (map 6), stroke (map 8), and liver disease (map 9) this proportion is based on the underlying cause of death. For dementia (map 5) and COPD (map 7) it is based on underlying or contributory cause of death. The final indicator in this section looks to the future. Map 10 shows the variation in the percentage change in the annual number of people dying between 2014 and 2030 by lower tier local authority.

Section 2 looks more closely at palliative and end of life care in hospitals and contains 8 maps. This section looks at hospital usage in the last 90 days of life. These maps present data on admissions (map 12), length of admissions (map 14), and whether people have had 3 or more emergency admissions in the last 90 days (map 13). Map 14 looks at admissions ending in death of over a week raising the question whether some of these patients could have been discharged home if that was their wish and services in the community could have been organised to support them. Emergency hospital readmissions within 30 days are usually considered to be undesirable, so there should be special concern over patients admitted 3 or more times in their last 90 days of life and what that reflects about care planning for these patients. This section also contains 4 maps presenting data from the 'End of life care audit – dying in hospital'⁷² (maps 15 to 18). These reflect levels of adherence to standards established in the audit covering recognition of dying, communication, holistic needs assessment and the provision of specialist palliative care services.

Section 3 focuses on palliative and end of life care in the community and presents 11 maps. This section presents data on where people die in the community – home (map 23), care home (map 24) and hospice (map 20). It also shows the number of patients in need of palliative care/support, as recorded on GP disease registers – a marker of identification and co-ordination of end of life care (map 19). The final group of maps in this section look in more detail at the role played by care homes in end of life care. These care home maps include: care home population (map 25), care home and nursing home bed rates (maps 26 and 27), the proportion of permanent residents who die in a care home (map 28) and the proportion of temporary care home residents who die in a care home (map 29).

A summary of the sections and maps are presented in Table 2.

Table 2: Summary of maps

Section 1: Need for palliative and end of life care	Section 2: The role of hospitals in palliative and end of life care	Section 3: Palliative and end of life care in the community
<ul style="list-style-type: none"> • number of deaths • projected number of deaths • sociodemographic data <ul style="list-style-type: none"> ○ older people living alone ○ unpaid carers • cause of death <ul style="list-style-type: none"> ○ cancer ○ dementia ○ heart disease ○ COPD ○ stroke ○ liver disease 	<ul style="list-style-type: none"> • deaths in a hospital • hospital admissions in last 90 days • 3 or more emergency admissions in last 90 days • admissions ending in death that lasted 8 days or longer • recognition of dying • communication about dying • holistic needs assessment • provision of specialist palliative care services 	<ul style="list-style-type: none"> • patients in need of palliative care/support recorded on GP disease registers • deaths in hospices <ul style="list-style-type: none"> ○ all causes of death ○ caused by cancer • deaths at home • deaths in a care home • deaths in usual place of residence • care home population • care home bed rate • nursing home bed rate • care home residents who die in a care home • temporary residents who die in a care home

Palliative and end of life care resources

This provides a catalogue of useful palliative and end of life care resources. These are thematically organised into 5 domains: general; commissioning and contracting; condition specific; data and intelligence; and learning and training.

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Introduction to the data

Data sources

The data for the indicators in the Atlas of variation for palliative and end of life care, has been provided by a range of organisations: Public Health England (PHE), The Office for National Statistics (ONS), NHS Digital, NHS England (NHSE) and the Care Quality Commission (CQC) with a variety of sources:

- NHS Digital Hospital Episode Statistics (HES)
- ONS mid-year population estimates
- ONS Annual Birth and Mortality statistics
- CQC care home register
- ONS population projections
- ONS Census
- RCP End of life care audit – dying in hospital
- Ordnance Survey data

An Atlas data sheet with all indicator values, including quintiles and significance bandings. A metadata document which includes methodology, data extraction coding schemes and data sources for each indicator is available at: <https://fingertips.phe.org.uk/profile/atlas-of-variation>

The data analysis, column charts and box plots were produced using Microsoft Excel 2013. The maps were created using ArcGIS version 10.2.

Denominators

Indicators have been calculated using a variety of population denominators including resident CCG populations, lower-tier local authority, strategic and transformation partnership (STP) populations.

Innovations in statistical methods and presentation in this Atlas

New for this Atlas, is a map for each indicator where areas are categorised by equal range quintiles. This accompanies a map based on the local areas statistical significance which is common with previous Atlases.

Compared to previous Atlas publications the equal range quintile map has replaced an equal number of areas quintile map. 'Equal number of areas' quintiles only give information about the ranking of a geography compared to others, for example, that a CCG falls in the top 20% of all CCGs. The equal range quintile map has the advantage of describing the nature of the distribution of values.

Statistical comparator

In the statistical significance map and column charts, the England value is used as the statistical benchmark against which organisations are compared. It is important to note that this does not imply that the England rate is the optimal or aspirational level for that indicator, as this value is often not established, but gives a sense of the performance of organisations compared with the national value.

Maps

For each indicator, data is presented visually in the form of thematic maps and a column chart. London is shown as an enlarged page inset on selected maps to show detail that might otherwise be lost.

Interpretation of the maps

Each map is a presentation of the indicator values for a single time period. The maps assign each geographical area to a single category although variation will also exist within each area.

The maps show two different approaches to categorising data, while often showing a similar picture there will be differences between them. When comparing the maps side by side, there will be examples where on the quintile map an area will have the darkest shading indicating it has one of the highest values of all the organisations, but on the significance map it may have a lighter shade denoting that it is not statistically significant and vice versa. At a local level, organisations will need to consider whether having a higher or lower value is important even if statistically they are not different to the England value. The same is true where an area is statistically significantly different to the England value, but the actual value is within the mid-range. Local decision makers will then need to decide whether this warrants further investigation.

Quintile maps

The quintile maps categorise each area into 1 of 5 quintiles according to the indicator value. The quintiles are determined by dividing the range of the indicator values into 5 equally sized sub-ranges:

$$\text{Quintile Interval} = (\text{Max value} - \text{Min value})/5$$

The quintile interval is used to calculate quintile boundary values which are presented in the map legend. Should a particular area have an indicator value exactly equal to a boundary between 2 quintiles it will be assigned to the higher quintile.

Equal range quintiles describe the spread or distribution of values. Areas are shaded from dark purple (those with the highest value) to light purple (those with the lowest value) on the quintile maps (table 3).

Statistical significance maps

For each indicator, individual areas are allocated to 1 of 5 groups (table 3) based on comparing the confidence interval of the estimate with the England value to indicate how statistically significantly different their value is from the England value (the horizontal black line across the column charts). The column charts and significance maps are colour classified according to significance banding.

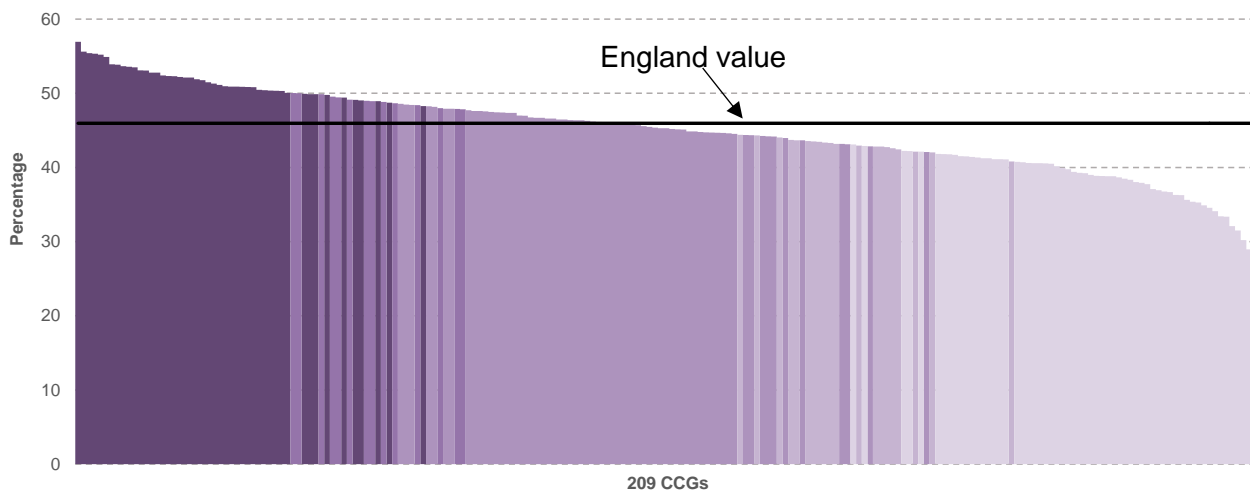
The shading of each area indicates the degree of statistical significance of each indicator value in terms of its difference from the England value. The key to the map shows the significance level for each of the 5 shades compared with the England value for that indicator. The two darkest shaded bars indicate that an indicator value is significantly higher than the England value at the 99.8% and 95% significance levels. The two lightest shades indicate that an indicator value is significantly lower than the England value at the 99.8% and 95% significance levels. Mid-shaded areas are those with an indicator value that is not significantly different to the England value. Where data is unavailable or excluded for an area/organisation, the corresponding map area/symbol is shaded grey.

Table 3: Five shade quintile and significance bands used in the maps and column chart

Shade	Equal Range Quintiles	Significance Band
	Areas within the highest 20% of the range	Significantly higher than England at the 99.8% level
		Significantly higher than England at the 95% level
		Not significantly different from England
		Significantly lower than England at the 95% level
	Areas within the lowest 20% of the range	Significantly lower than England at the 99.8% level

Column charts

Figure 14: Example column chart to show statistical significance compared to the England value



The range of local area indicator values and the England value are presented in the column chart accompanying both maps. The same statistical methodology is used to determine the shading in the significance map and column chart. This is based on statistical significance of difference from the England value.

Interpretation of the column charts

For each indicator, the data presented in the column charts is that for the most recent time period. The column chart visualisations give the reader two sets of information about the data:

1. The height of each bar in the chart shows the indicator value for each geography– the columns are ordered from the highest value on the left to the lowest value on the right.
2. The shading of each column indicates the degree of statistical significance of each indicator value in terms of its difference from the England value (the black horizontal line across the chart). The colour shading used in the column charts is the same as that used in the corresponding significance map (figure 14). For 3 maps (18, 26 and 27) it is not appropriate to assign statistical confidence. For maps 26 and 27 all the bars of the column chart are coloured the same shade. For Map 18 the column chart has been replaced by a pie chart.

Conventional column charts display the confidence interval bar for each area to enable the reader to determine whether or not the local area value is significantly higher or lower than the national value represented by a horizontal line. However, column charts in this Atlas have so many columns and use two sets of confidence intervals (95% and 99.8%) that the chart can become difficult to interpret. The 5 shades replace the use of displayed confidence intervals on column charts.

Figure 14 is an example of the column charts presented in this Atlas. It shows that differently shaded columns are mixed at both ends of the chart, rather than same-shaded columns appearing in adjacent blocks. This is because being statistically significantly different from the England value depends not only on the size of the indicator value, but also on statistical confidence. This may be influenced by the size of the population for which the indicator value is shown, as smaller populations tend to have wider confidence intervals.

Statistical significance interpretation

The significance band does not indicate whether a high or low value represents good or bad performance, merely whether or not the indicator value is significantly higher or lower than the England value, and the degree of statistical confidence that the difference is not due to random variation.

- indicator values that are not significantly different from the England value (mid-shade) are said to display 'random' variation alone
- indicator values that are higher or lower than the England value at the 95% significance level are deemed statistically significantly different. However, as so many indicator values (209 in the case of CCGs) are being simultaneously tested against the England value, the likelihood of finding indicator values that are significantly different from the England value is raised by chance alone. For this reason a more stringent 99.8% significance level is also applied
- there is much greater certainty that indicator values found to be different from the England value at the 99.8% significance level (the lightest and the darkest shades) are due to a systematic non-random variation that requires investigation. In these localities it is likely that the process or system of generating these values is markedly different from that in other CCGs

If a large number of indicator values are significantly different from the national value at the 99.8% level this may be due to what is known as overdispersion, characterised by many localities having indicator values at the extremities of the distribution, and fewer indicator values around the central value of the distribution.

Overdispersion typically occurs when there are factors influencing the values that have not been accounted (or adjusted) for in the method of calculating the statistic, such as demographic risk factors, casemix or localised service configuration, which is particularly relevant to specialised services. These factors may account for the larger than expected number of areas with values greatly different from the England value. It is important to consider whether all known warranted factors have been adjusted for when assessing whether the observed variation is unwarranted.

Box and whisker plots

For each indicator, where sequential data over a number of time periods is available, this is presented visually in a time series of box and whisker plots that shows the median and spread of local area values across England at consecutive time points. Importantly, the tables accompanying the box and whisker plots show whether there has been any statistically significant change in the median, or in the degree of variation over time. It should be noted that the central value on the box plot is a median for the reported data, not the indicator value for England as a whole.

Interpretation of the box and whisker plots

Time series data is presented in the form of box and whisker plots (referred to as box plots in following sections). The purpose of the box plot is to give an impression of the level and spread, or distribution, of the data points. The box plots presented in this Atlas are a customised version of conventional box and whisker plot used elsewhere (figure15). The box plots use a methodology which is unrelated to the method determining the significance map and column chart shading, they do not represent statistical significance. This box plot shows how variable the indicator is across all of the geographical areas. A single box plot is displayed for each time period so that comparisons can be made through time of the level and spread of values.

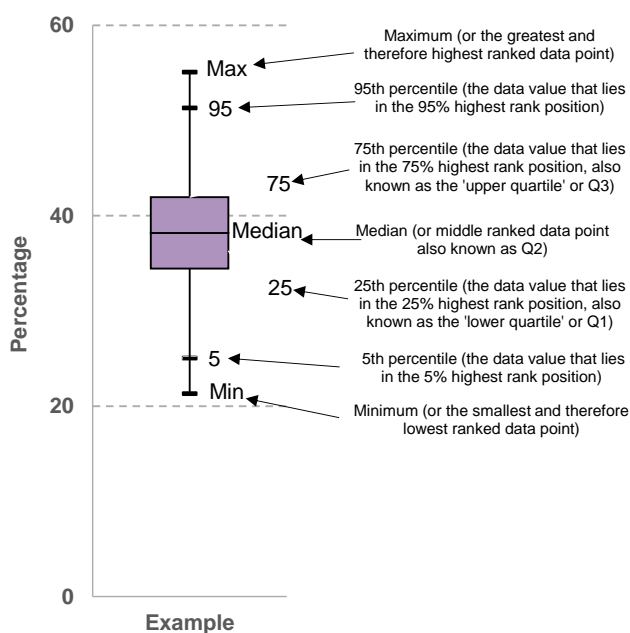
The 'box' and its 'whiskers' represent the data values of the following rank positions in the data:

- maximum (or the greatest and therefore highest ranked data point)
- 95th percentile (the data value that lies in the 95% highest rank position)

- 75th percentile (the data value that lies in the 75% highest rank position, also known as the 'upper quartile' or Q3)
- median (or middle ranked data point also known as Q2)
- 25th percentile (the data value that lies in the 25% highest rank position, also known as the 'lower quartile' or Q1)
- 5th percentile (the data value that lies in the 5% highest rank position)
- minimum (or smallest and therefore lowest ranked data point)

The 'box' runs from the upper quartile (Q3 or 75th percentile) to the lower quartile (Q1 or 25th percentile) and represents the middle 50% of data points. The height of the box between Q1 and Q3 is known as the interquartile range (IQR) and is calculated as Q3 minus Q1.

Figure 15: Example box plot



Inside the box is a horizontal line, which shows where the median (or Q2) lies. The median is the middle point of the dataset. Half of the data points are above the median and half of the data points are below it. The median is different from the value of the indicator for England as a whole, the more skewed the distribution of data the greater the difference between the median and the England value.

The 'whiskers' extend out from either end of the box and show the highest and lowest values contained within the dataset, in other words they show the entire range of values contained within the dataset.

Box plots split the data into 4 equal parts in terms of the number of data points represented. Twenty-five per cent of data points lie between the maximum and the upper quartile, 25% of data points lie between the

upper quartile and the median, 25% of data points lie between the median and the lower quartile, and 25% of data points lie between the lower quartile and the minimum. An unconventional aspect of the box plots presented in this Atlas, is that the 95th percentile and the 5th percentile are also represented by tick marks on the 'whiskers'.

A box plot enables the user to obtain information about the shape or spread of the data points and in particular, whether or not the data points have a symmetric or skewed distribution. A dataset with a normal distribution is symmetric (non-skewed) around the mean (average), the mean and the median are equal to each other, and each half of the distribution is a mirror-image of the other half. In a distribution that is skewed there is a lack of symmetry between the upper and lower halves of the dataset, the median and the 'box' is not centrally located between the maximum and minimum.

Box plot summary statistics table

Presented below the box plot time series is a table of statistics summarising the trend in the absolute degree of variation and the median:

- **max–min (range):** This is the absolute difference between the maximum value and the minimum value of the dataset, ie the full range of the data. However, extreme outliers can heavily influence this statistic and consequently mislead about the extent of variability across the majority of the dataset. It may therefore be more helpful to use the 95th to 5th percentile (see below)
- **95th–5th percentile:** This shows the range of the data between the 95th percentile and the 5th percentile of the dataset; if there are extreme outliers this statistic may give a better impression of variation across the majority of data values because the highest 5% of values and lowest 5% of values have been discounted
- **75th–25th percentile:** These percentiles are the upper and lower limits of the middle 50% of data values. This statistic indicates the dispersion or spread of the data for the middle 50% of values. The absolute difference between these percentiles is also known as the interquartile range (IQR). It is related to the median (see below): if the IQR is small it indicates that the central 50% of data values are close to the median; if the IQR is large it indicates that the data is spread out from the median and there is more dispersion in the middle 50% of values in the dataset
- **median:** The median is the middle value in a dataset, identified by arranging each of the values in ascending order from the smallest value to the highest value. If there is an even number of values the median will be the average of the 2 central data points. It is not the mean or average

The final column of the table is a summary of whether each of these 4 statistics is narrowing or widening (or median increasing/decreasing) and whether the trend is statistically significant at the 95% level. The statistical significance was determined using a two-tailed t-test on the slope of a linear regression line fitted to the values in the table over time, where the null hypothesis is that the slope equals zero. The significance test is only performed for indicators with data at 3 or more time periods. This regression line and the detailed results of the t-test are not presented in this Atlas.

Data frequency

The length of time for which data is presented directly affects the number of observations represented in the visualisations. Statistical power, that is the ability to detect true differences, tends to increase with an increasing number of observations. The 'data frequency' selected for each Atlas indicator is intended to yield a sufficiently large number of observations to reveal patterns and trends that are statistically robust.

Confidence intervals

Confidence intervals are used to represent the level of uncertainty of an estimate (area) value. Statistical uncertainties usually arise because the indicators are based on a random sample or subset from the population of interest or over a defined time period, both of which may not be representative of the whole population. A smaller confidence interval indicates that the estimate is more reliable, and a larger confidence interval indicates that the estimate is less reliable. Confidence intervals were used to determine the shading in the column charts and the significance maps. The 2 main methods of calculating confidence intervals in this Atlas are:

- the Wilson score method for proportions^{1,2}
- the Byar's method for rates^{2,3}

¹ Wilson EB. Probable inference, the law of succession, and statistical inference. J AM Stat Assoc 1927; 22: 209-212

² PH Technical Guidance. [APHO Technical Briefing 3 – Commonly used public health statistics and their confidence intervals](#)

³ Breslow NE, Day NE. Statistical methods in cancer research, volume II: The design and analysis of cohort studies. Lyon: International Agency for Research on Cancer, World Health Organization; 1987: 69

Magnitude of variation summary

Map	Geography	Title	Range	Fold difference*	Number of areas significantly higher than England (99.8% level)	Number of areas significantly lower than England (99.8% level)	Number of areas excluded or suppressed	Median trend	Variation trend
Section 1: Need for palliative and end of life care									
1	CCG of residence	Variation in the proportion of all people who died who were aged 75 years and older by CCG (2015)	51.7 - 77.8	1.5	56 (from 209)	65 (from 209)	0 (from 209)	The median increased significantly from 65.9 in 2006 to 68.9 in 2015	The 75 th to 25 th percentile gap widened significantly
2	Lower tier local authority of residence	Variation in the proportion of adults who are aged 65 years or older and who are living alone by lower tier local authority (2011)	24.7 - 45.0	1.8	97 (from 324)**	162 (from 324)**	2 (from 326)**	Trend data unavailable	Trend data unavailable
3	CCG of residence	Variation in the proportion of the population aged 16 years or older who are unpaid carers by CCG (2011)	7.6 - 15.5	2.0	109 (from 209)	74 (from 209)	0 (from 209)	Trend data unavailable	Trend data unavailable
4	CCG of residence	Variation in the proportion of all people who died with an underlying cause of cancer by CCG (2015)	22.9 - 31.6	1.4	5 (from 209)	2 (from 209)	0 (from 209)	There was no change in the median	There was no significant change in any of the 3 variation measures between 2006 and 2015
5	CCG of residence	Variation in the proportion of all people who died with an underlying or contributory cause of dementia by CCG (2015)	12.3 - 23.8	1.9	19 (from 209)	19 (from 209)	0 (from 209)	The median increased significantly from 8.2 in 2006 to 17.2 in 2015	There has been significant widening of all 3 measures of variation
6	CCG of residence	Variation in the proportion of all people who died with an underlying cause of chronic heart disease by CCG (2015)	8.0 - 21.7	2.7	17 (from 209)	14 (from 209)	0 (from 209)	The median decreased significantly from 12.6 in 2006 to 11.0 in 2015	The 75 th to 25 th percentile gap narrowed significantly
7	CCG of residence	Variation in the proportion of all people who died with an underlying or contributory cause of chronic obstructive pulmonary disease (COPD) by CCG (2015)	6.5 - 18.1	2.8	39 (from 209)	37 (from 209)	0 (from 209)	The median increased significantly from 8.0 in 2006 to 10.7 in 2015	There has been significant widening of all 3 measures of variation

Map	Geography	Title	Range	Fold difference*	Number of areas significantly higher than England (99.8% level)	Number of areas significantly lower than England (99.8% level)	Number of areas excluded or suppressed	Median trend	Variation trend
8	CCG of residence	Variation in the proportion of people who died with an underlying cause of stroke by CCG (2015)	4.3 - 10.9	2.5	11 (from 209)	6 (from 209)	0 (from 209)	The median decreased significantly from 8.7 in 2006 to 6.5 in 2015	Both the 95 th to 5 th percentile gap and the 75 th to 25 th percentile gap narrowed significantly
9	CCG of residence	Variation in the proportion of all people who died with an underlying cause of liver disease by CCG (2015)	1.2 - 4.5	3.9	14 (from 209)	5 (from 209)	0 (from 209)	The median increased significantly from 2.0 in 2006 to 2.4 in 2015	There was no significant change in any of the 3 variation measures between 2006 and 2015
10	Lower tier local authority of residence	Variation in the percentage change in the annual number of people dying between 2014 and 2030 by lower-tier local authority	-9.7 - 36.2	NA	67 (from 324)**	48 (from 324)**	2 (from 326)**	NA	NA
Section 2: The role of hospitals in palliative and end of life care									
11	CCG of residence	Variation in the proportion of all people who died in hospital by CCG (2015)	36.1 - 68.1	1.9	54 (from 209)	51 (from 209)	0 (from 209)	The median decreased significantly from 57.5 in 2006 to 47.7 in 2015	There was no significant change in any of the 3 variation measures between 2006 and 2015
12	CCG of residence	Variation in the proportion of all people admitted into hospital during the last 90 days of their life by CCG (2015)	56.1 - 74.9	1.3	52 (from 209)	44 (from 209)	0 (from 209)	There was no change in the median	The maximum to minimum narrowed significantly
13	CCG of residence	Variation in the proportion of people who have 3 or more emergency hospital admissions during the last 90 days of life by CCG (2015)	2.9 - 12.6	4.3	32 (from 209)	30 (from 209)	0 (from 209)	The median increased significantly from 4.9 in 2007 to 7.1 in 2015	Both the maximum to minimum range and the 95 th to 5 th percentile gap widened significantly
14	CCG of residence	Variation in the proportion of hospital admissions ending in death in hospital which are 8 days or longer by CCG (2015)	36.0 - 62.7	1.7	22 (from 209)	19 (from 209)	0 (from 209)	The median decreased significantly from 52.7 in 2007 to 50.1 in 2015	The maximum to minimum range widened significantly

Map	Geography	Title	Range	Fold difference*	Number of areas significantly higher than England (99.8% level)	Number of areas significantly lower than England (99.8% level)	Number of areas excluded or suppressed	Median trend	Variation trend
15	Acute hospital trust site	Variation in proportion of all people who died in hospital that had documented evidence of recognition that they would probably die in the coming hours or days by acute hospital trust site (2015)	63.6 - 100.0	1.6	2 (from 140)	4 (from 140)	5 (from 145)##	Trend data unavailable	Trend data unavailable
16	Acute hospital trust site	Variation in the proportion of all people who had documented evidence that a health professional had recognised during the last episode of care the person was dying and had discussed this with a nominated person(s) important to the dying person by acute hospital trust site (2015)	60.0 - 100.0	1.7	0 (from 140)	3 (from 140)	5 (from 145)##	Trend data unavailable	Trend data unavailable
17	Acute hospital trust site	Variation in proportion of all people who died in hospital that had documented evidence in the last 24 hours of a holistic assessment of their needs regarding an individual plan of care by acute hospital trust site (2015)	3.8 - 100.0	26.7	36 (from 140)	30 (from 140)	5 (from 145)##	Trend data unavailable	Trend data unavailable
18	Acute hospital trust site	Variation in provision of face-to-face access to specialist palliative care at least 9am to 5pm, Monday to Sunday by acute hospital trust site (2015)	Yes, No, No reply	n/a	n/a	n/a	5 (from 145)##	Trend data unavailable	Trend data unavailable
Section 3: Palliative and end of life care in the community									
19	CCG of residence	Variation in the number of patients in need of palliative care/support, as recorded on GP disease registers per 100 deaths by CCG (2015/16)	13.1 - 115.5	8.8	67 (from 209)	101 (from 209)	0 (from 209)	The median increased significantly from 25.4 in 2012/13 to 35.6 in 2015/16	The 75 th to 25 th percentile gap widened significantly

Map	Geography	Title	Range	Fold difference*	Number of areas significantly higher than England (99.8% level)	Number of areas significantly lower than England (99.8% level)	Number of areas excluded or suppressed	Median trend	Variation trend
20	CCG of residence	Variation in the proportion of all people who died in a hospice by CCG (2015)	0.2 - 13.3	68.6	57 (from 205)#	47 (from 205)#	4 (from 209)#	The median increased significantly from 5.2 in 2006 to 5.8 in 2015	The 75 th to 25 th percentile gap widened significantly
21	STP of residence	Variation in the proportion of all people that died in a hospice with a recorded cause of death as cancer by STP (2015)	77.4 - 94.3	1.2	4 (from 44)	5 (from 44)	0 (from 44)	The median decreased significantly from 94.0 in 2006 to 87.6 in 2015	There has been significant widening of all 3 measures of variation
22	CCG of residence	Variation in the proportion of all people who died in their usual place of residence by CCG (2015)	28.5 - 56.9	2.0	48 (from 209)	61 (from 209)	0 (from 209)	The median increased significantly from 34.7 in 2006 to 45.3 in 2015	There was no significant change in any of the 3 variation measures between 2006 and 2015
23	CCG of residence	Variation in the proportion of people that died at home by CCG (2015)	18.2 - 30.1	1.7	27 (from 209)	22 (from 209)	0 (from 209)	The median increased significantly from 18.9 in 2006 to 22.6 in 2015	The 95 th to 5 th percentile gap widened significantly
24	CCG of residence	Variation in the proportion of people that died in a care home by CCG (2015)	6.7 - 34.4	5.2	53 (from 209)	65 (from 209)	0 (from 209)	The median increased significantly from 16.3 in 2006 to 22.1 in 2015	Both the maximum to minimum range and the 95 th to 5 th percentile gap widened significantly
25	Lower tier local authority of residence	Variation in the proportion of the population who are living in a care home by lower tier local authority (2011)	0.1 - 1.6	17.5	141 (from 324)**	113 (from 324)**	2 (from 326)**	Trend data unavailable	Trend data unavailable
26	CCG of residence	Variation in the number of care home beds per 100 people living who are aged 75 years or older by CCG (2017)	2.7 - 22.9	8.5	NA	NA	0 (from 209)	The median decreased significantly from 11.2 in 2012 to 10.3 in 2017	Both the maximum to minimum range and the 75 th to 25 th percentile gap narrowed significantly
27	CCG of residence	Variation in the number of nursing home beds per 100 people living who are aged 75 years or older by CCG (2017)	1.3 - 8.6	6.8	NA	NA	0 (from 209)	The median decreased significantly from 5.4 in 2012 to 4.9 in 2017	Both the maximum to minimum range and the 75 th to 25 th percentile gap narrowed significantly

Map	Geography	Title	Range	Fold difference*	Number of areas significantly higher than England (99.8% level)	Number of areas significantly lower than England (99.8% level)	Number of areas excluded or suppressed	Median trend	Variation trend
28	CCG of residence	Variation in the proportion of care home residents that died in a care home by CCG (2015)	44.5 - 83.8	1.9	28 (from 209)	35 (from 209)	0 (from 209)	The median increased significantly from 58.0 in 2006 to 70.0 in 2015	There has been significant narrowing of all 3 measures of variation
29	CCG of residence	Variation in the proportion of people who died in a care home who were temporary residents by CCG (2015)	17.7 - 67.4	3.8	34 (from 209)	28 (from 209)	0 (from 209)	There was no change in the median	Both the maximum to minimum range and the 95 th to 5 th percentile gap narrowed significantly

Notes:

* The fold-difference value may differ from the ratio of the maximum and minimum values presented in the 'Range' column due to rounding.

** Map 2, 10, 25: The number of local authorities is reduced from 326 to 324 due to the combination of the Isles of Scilly with Cornwall (maps 2, 10, 25) and the City of London with Westminster (map 25) and the City of London with Hackney (map 2, 10).

Map 20: Data based on 205 CCGs. Four CCGs have been excluded (Nottingham City, Nottingham West, Rushcliffe and Southampton) due to small numbers.

The source for maps 15 to 18 is an audit of 145 hospitals. The individual figures for community hospitals, Isle of Man and one other hospital whose return was too small to report individually have not been reported here.

The maps

There are 29 maps exploring palliative and end of life care over 3 sections:

Section 1 – Need for palliative and end of life care	Pages 37 - 56
Section 2 – The role of hospitals in palliative and end of life care	Pages 57 - 72
Section 3 – Palliative and end of life care in the community	Pages 73 - 95
The map references	Pages 95 - 100

SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 1: Variation in the proportion of all people who died who were aged 75 years and older by CCG (2015)

Equal-sized quintiles by value

Highest	72.59 - 77.80	(50)
	67.36 - 72.58	(79)
	62.14 - 67.35	(57)
	56.92 - 62.13	(14)
Lowest	51.69 - 56.91	(9)

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Significance level compared with England

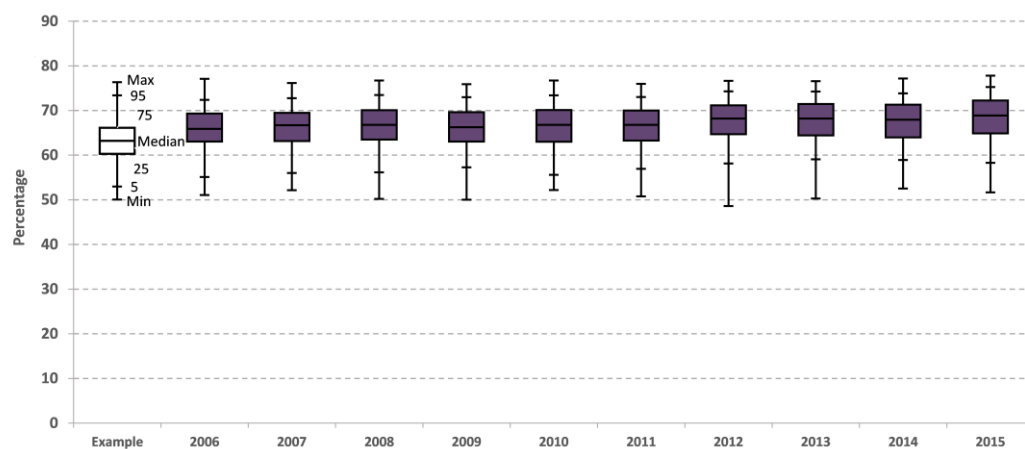
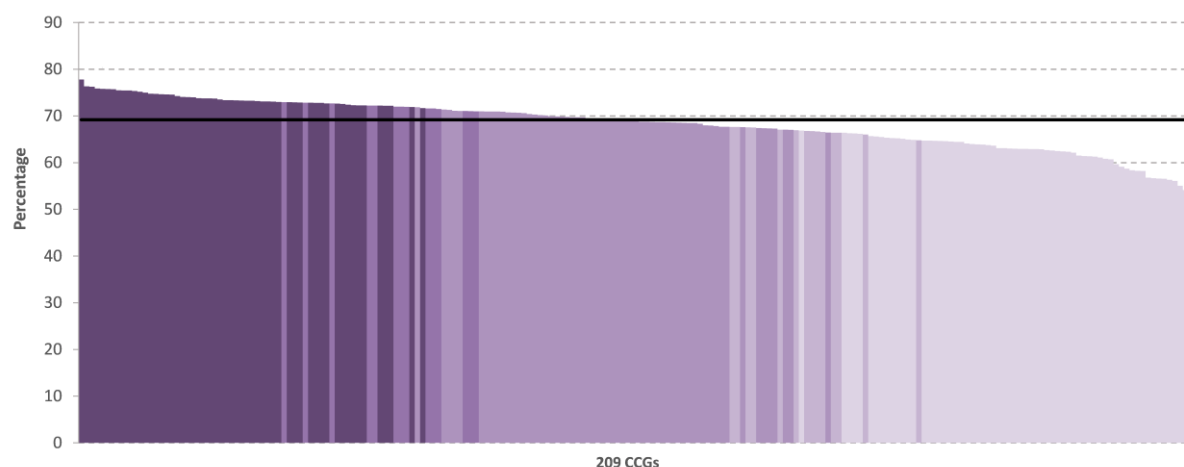
Significantly higher than England (99.8%)	(56)
Significantly higher than England (95.0%)	(14)
Not significantly different from England	(60)
Significantly lower than England (95.0%)	(14)
Significantly lower than England (99.8%)	(65)

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Variation in the proportion of all people who died who were aged 75 years and older by CCG (2015)



	Example	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
Max - Min (Range)		26.0	24.0	26.5	25.9	24.5	25.2	28.0	26.3	24.6	26.1	No significant change
95th - 5th Percentile		17.3	16.7	17.3	15.7	17.8	16.1	16.2	15.2	14.9	17.0	No significant change
75th - 25th Percentile		6.3	6.3	6.6	6.6	7.1	6.7	6.5	7.0	7.3	7.4	WIDENING Significant
Median		65.9	66.7	66.8	66.2	66.8	66.8	68.2	68.2	67.9	68.9	INCREASING Significant

Introduction

The proportion of people who die aged 75 years and older varies from about half to just over three-quarters. This means that CCGs face quite different challenges in terms of palliative and end of life care dependent on the age profile of their population. For those CCGs in the middle of the range the differences between them is widening. CCGs with large elderly populations need to particularly focus on the provision of good end of life care in care homes and in the community and look at the quality of care for elderly patients dying in hospitals.

Trends and magnitude of variation

In 2015 the value for England was 69.2% with a variation between 51.7% and 77.8% by CCG. The box plot shows the distribution of CCG values for the period 2006 to 2015 calendar years. The 75th to 25th percentile gap widened significantly. The CCG median increased significantly from 65.9% in 2006 to 68.9% in 2015.

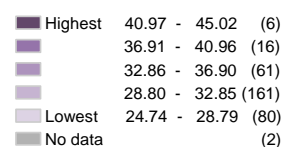
Local considerations

Commissioners and providers are advised to consider how the age profile at death impacts on need for care including cause of death (maps 4 to 9) and place of death (maps 11, 20, 23 and 24). Maps 24 to 29 give insight into the geographical variation in the role played by care homes at the end of life, especially for older people, many with multi-morbidity. In addition, commissioners should review community based social care services.

SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

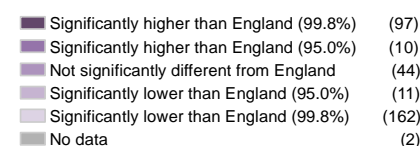
Map 2: Variation in the proportion of adults who are aged 65 years or older and who are living alone by lower tier local authority (2011)

Equal-sized quintiles by value



LONDON

Significance level compared with England

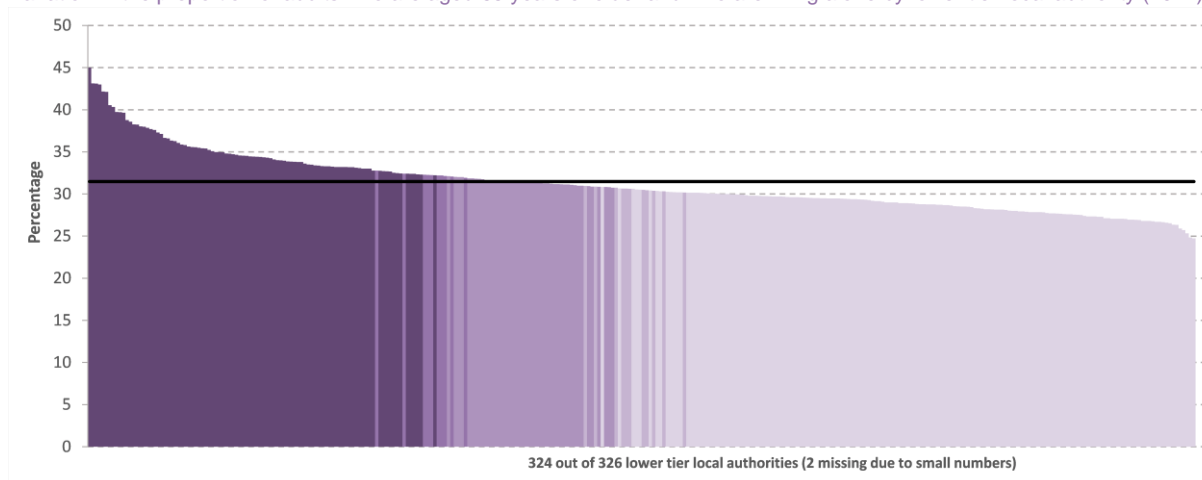


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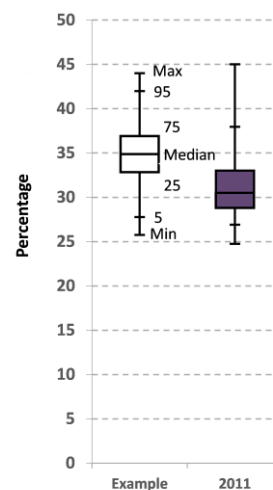
Variation in the proportion of adults who are aged 65 years or older and who are living alone by lower tier local authority (2011)



Introduction

This indicator gives insight into the local authority areas with the highest proportion of people aged 65 years or older who are living alone showing that this ranges from a quarter to almost a half. The most recent data is from the 2011 Census. Understanding how many elderly people live alone is important as they may have greater need for social care as well as healthcare as they approach the end of life. Living alone not only presents care challenges but also loneliness which impacts on people's wellbeing especially at the end of their life. A number of recent research reports identify loneliness as a major factor for older people^{1 2 3}.

Interestingly, it is parts of London and the north-west and East that have among the highest proportions of people aged 65 or older who are living alone but there are small pockets throughout the country and this emphasises the need to understand local data.



Max - Min (Range)		20.3
95th - 5th Percentile		11.1
75th - 25th Percentile		4.2
Median		30.5

Magnitude of variation

In 2011 the value in England was 31.5% with a variation between 24.7% and 45.0% by local authority which is a 1.8-fold difference. The box plot shows the distribution of local authority values for the 2011 calendar year and a local authority median of 30.5%.

Local considerations

Commissioners and providers should review this map and underlying data to examine the relationship between living alone and care home and nursing home bed rates (maps 26 and 27). They should also consider their local community health and social care service provision and the opportunities presented by social prescribing⁴.

SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 3: Variation in the proportion of the population aged 16 years or older who are unpaid carers by CCG (2011)

Equal-sized quintiles by value

Highest	13.94 - 15.51	(29)
	12.37 - 13.93	(95)
	10.79 - 12.36	(53)
	9.22 - 10.78	(20)
Lowest	7.63 - 9.21	(12)

LONDON

Significance level compared with England

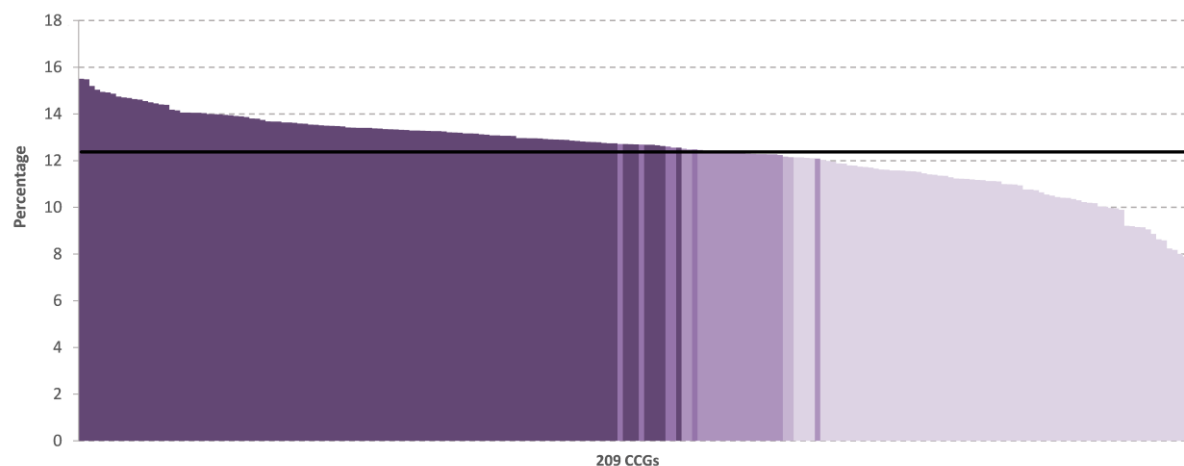
Significantly higher than England (99.8%)	(109)
Significantly higher than England (95.0%)	(5)
Not significantly different from England	(19)
Significantly lower than England (95.0%)	(2)
Significantly lower than England (99.8%)	(74)

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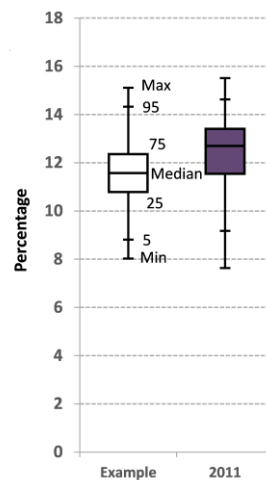
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Variation in the proportion of the population aged 16 years or older who are unpaid carers by CCG (2011)



Introduction

The data in this indicator comes from the 2011 Census. While it does not relate directly to end of life care it gives an indication of the variation in the proportion of adult carers engaged in unpaid caring. Much of this care will be at home and for frail elderly people at the end of their life. While many of these unpaid carers and those they are caring for receive support from the NHS and social care it is important to ensure the carers, themselves, receive adequate support and care. Seventy per cent of carers come into contact with health professionals yet health professionals only identify one in 10 carers and GPs identify 7%¹. Sixty-six per cent of carers feel that healthcare staff do not help to signpost them to relevant information or support, and when information is given, it tends to come from charities and support groups².



Max - Min (Range)		7.9
95th - 5th Percentile		5.5
75th - 25th Percentile		1.9
Median		12.7

Magnitude of variation

In 2011 the England value was 12.4% with a variation between 7.6% and 15.5% by CCG, which is a 2.0-fold difference. The box plot shows the distribution of CCG values for the 2011 calendar year and a local authority median of 12.7%.

Local considerations

Commissioners and providers should review this map and underlying data in combination data on the proportion of people who died at home (map 23). They should also look at their local policies, plans and budgets to support carers including service provision of bereavement services and the referral of carers for carer's assessments³.

SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 4: Variation in the proportion of all people who died with an underlying cause of cancer by CCG (2015)

Equal-sized quintiles by value

Highest	29.85 - 31.58	(18)
	28.12 - 29.84	(53)
	26.38 - 28.11	(91)
	24.65 - 26.37	(44)
Lowest	22.90 - 24.64	(3)

LONDON

Significance level compared with England

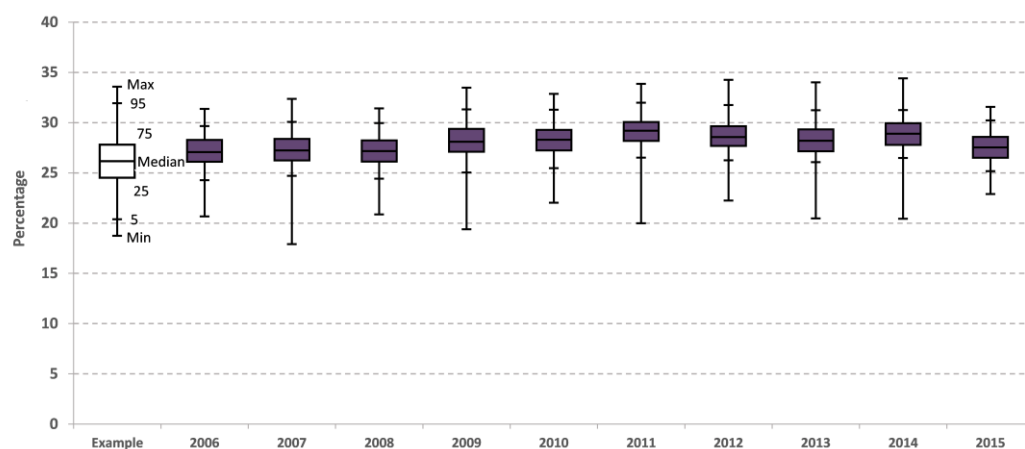
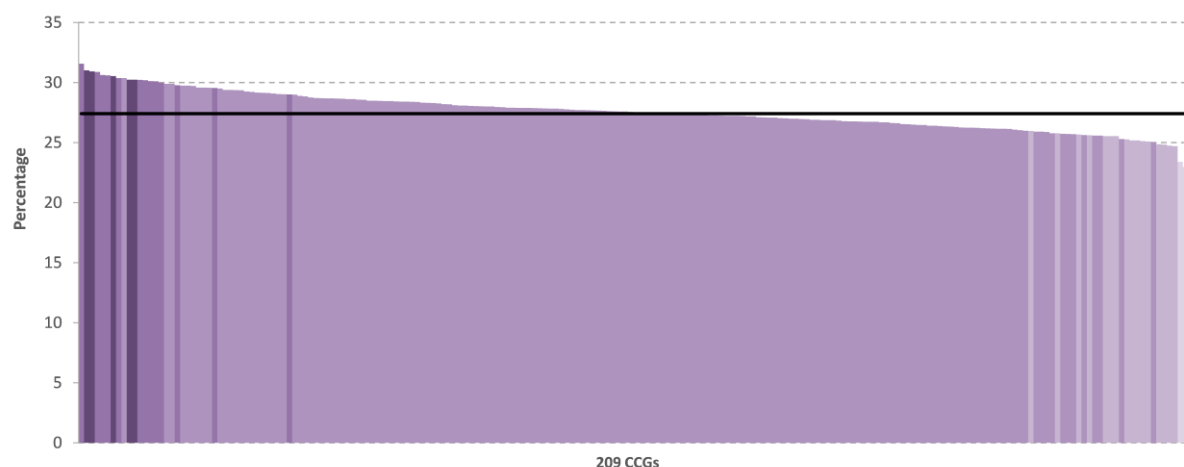
Significantly higher than England (99.8%)	(5)
Significantly higher than England (95.0%)	(13)
Not significantly different from England	(172)
Significantly lower than England (95.0%)	(17)
Significantly lower than England (99.8%)	(2)

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Variation in the proportion of all people who died with an underlying cause of cancer by CCG (2015)



Max - Min (Range)		10.7	14.4	10.6	14.1	10.8	13.9	12.0	13.5	14.0	8.7	No significant change
95th - 5th Percentile		5.4	5.4	5.5	6.3	5.8	5.5	5.5	5.2	4.8	5.1	No significant change
75th - 25th Percentile		2.2	2.1	2.1	2.3	2.0	1.9	2.0	2.2	2.2	2.1	No significant change
Median		27.1	27.2	27.2	28.1	28.3	29.2	28.6	28.2	28.9	27.5	No significant change

Introduction

Cancer is the disease group that accounts for the greatest proportion of deaths in England. Patients dying of cancer often have a more predictable end of life trajectory than patients with other conditions, which can facilitate end of life planning. Cancer site-specific NICE guidance¹ emphasises the importance of involving specialist palliative care in decision making for patients with advanced cancer. However, there are documented inequalities in access to specialist palliative care advice^{2,3}. A lower proportion of cancer patients die in hospital compared to patients from other major disease groups. There has been a decline in the proportion of cancer patients dying in hospital over the past decade, with a reciprocal increase in deaths at home and in care homes (figure 11 in the Introduction). Cancer patients still make up the majority of patients who die in hospice inpatient units (map 21), and hospices support many more people with cancer to die at home.

Trends and magnitude of variation

One in 4 deaths (27.4%) in England in 2015 had cancer as an underlying cause, with a variation of between 1 in 5 (22.9%) and 1 in 3 deaths (31.6%) by CCG, a 1.4-fold difference. The CCG median was 27.5% in 2015, there has been no significant change in the CCG median between 2006 and 2015.

Local considerations

Commissioners and providers should review this map and underlying data in combination with maps 18, 20 and 21, the End of life care profiles⁴ on place of death and underlying cause of death and local data on provision of general and specialist palliative care services including out of hours.

SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 5: Variation in the proportion of all people who died with an underlying or contributory cause of dementia by CCG (2015)

Equal-sized quintiles by value

Highest	21.48 - 23.77	(8)
	19.18 - 21.47	(29)
	16.88 - 19.17	(87)
	14.58 - 16.87	(65)
Lowest	12.27 - 14.57	(20)

LONDON

Significance level compared with England

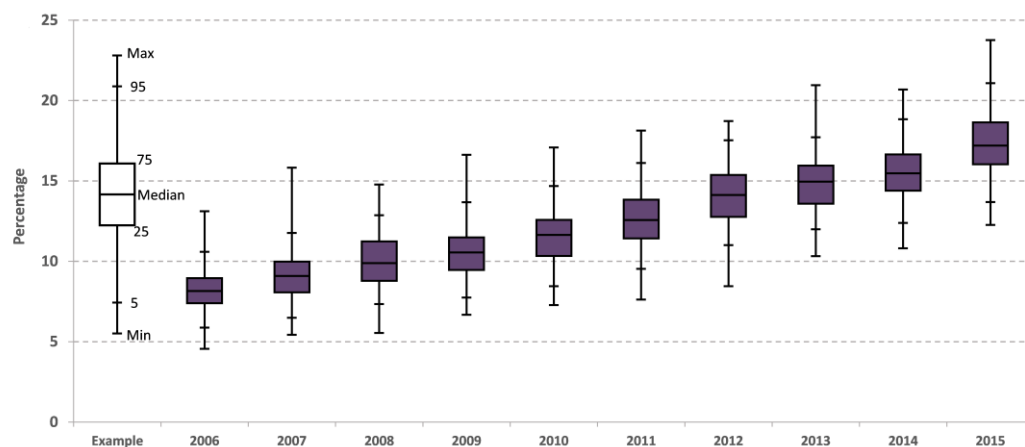
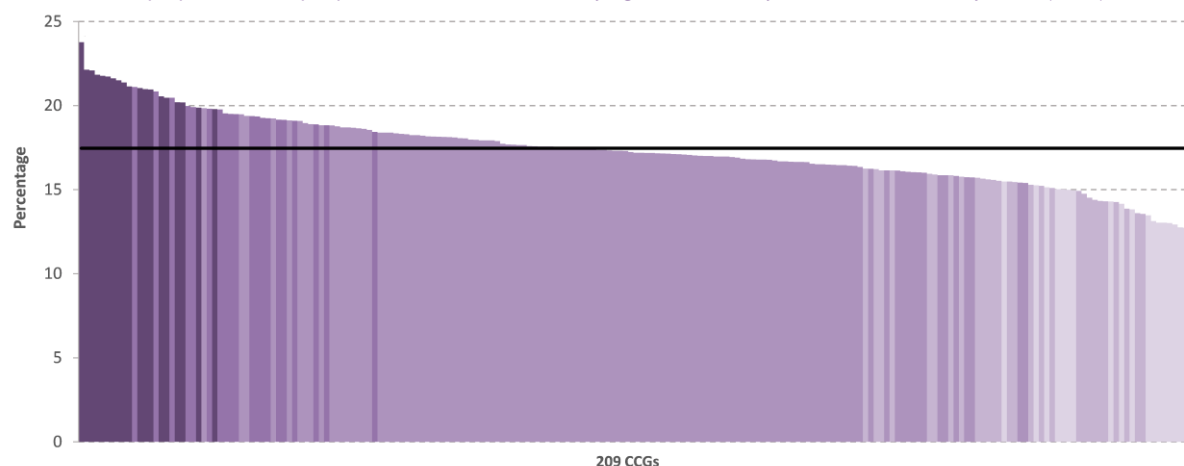
Significantly higher than England (99.8%)	(19)
Significantly higher than England (95.0%)	(20)
Not significantly different from England	(123)
Significantly lower than England (95.0%)	(28)
Significantly lower than England (99.8%)	(19)

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Variation in the proportion of all people who died with an underlying or contributory cause of dementia by CCG (2015)



Max - Min (Range)		8.6	10.4	9.2	10.0	9.8	10.5	10.3	10.6	9.9	11.5	WIDENING Significant
95th - 5th Percentile		4.7	5.3	5.5	5.9	6.2	6.6	6.5	5.7	6.4	7.4	WIDENING Significant
75th - 25th Percentile		1.6	1.9	2.5	2.0	2.2	2.4	2.6	2.4	2.2	2.6	WIDENING Significant
Median		8.2	9.1	9.9	10.6	11.6	12.6	14.1	15.0	15.5	17.2	INCREASING Significant

Introduction

People with dementia tend to have a prolonged period of dependency for months to years, with high care needs and an unpredictable end of life trajectory. Dementia policy and guidelines recommend offering early and ongoing opportunities for advance care planning for people living with dementia and those involved in their care, and offering flexible palliative care that takes into account the unpredictable disease progression^{1,2}. People with dementia are more likely to die in nursing homes than patients dying of other disease groups³, and particularly benefit from being cared for in a familiar environment. NICE guideline NG97 makes recommendations on how to assess the balance of benefits and harms before admitting patients with severe dementia to hospital¹. The Nuffield Council on Bioethics highlight the ethical considerations in care⁴.

Trends and magnitude of variation

On average 1 in 6 deaths (17.5%) in England had dementia as an underlying or contributory cause, with a variation of between 1 in 8 (12.3%) and 1 in 4 (23.8%) by CCG, a 1.9-fold difference. The median by CCG increased significantly from 8.2% in 2006 to 17.2% in 2015 as did all the measures of the range of values. The increasing median is in part due to the aging population, although improved diagnosis and recording of dementia is likely to have contributed.

Local considerations

This map should be reviewed in combination with data on deaths aged 75 years (map 1) and data on care homes (maps 24 to 29). Other resources include: the End of life care profiles⁵, Dementia profiles³, and local data on primary care assessments of the palliative care needs of people in the later stages of dementia (NICE QS1)⁶.

SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 6: Variation in the proportion of all people who died with an underlying cause of chronic heart disease by CCG (2015)

Equal-sized quintiles by value

Highest	18.96 - 21.68	(2)
	16.22 - 18.95	(4)
	13.49 - 16.21	(11)
	10.75 - 13.48	(99)
Lowest	8.00 - 10.74	(93)

LONDON

Significance level compared with England

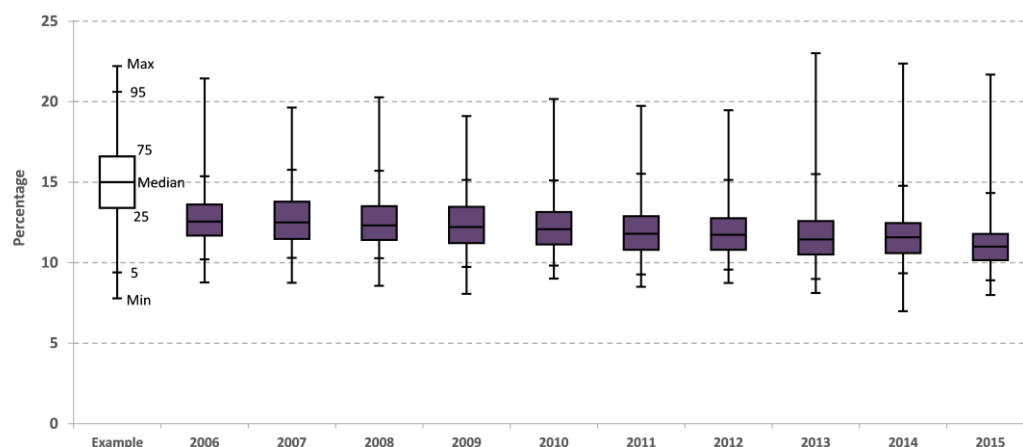
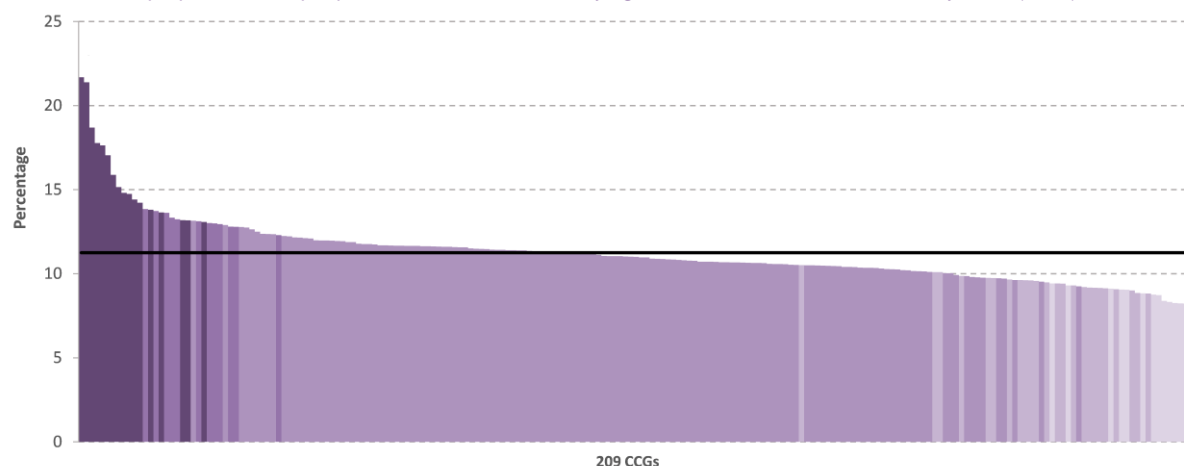
Significantly higher than England (99.8%)	(17)
Significantly higher than England (95.0%)	(12)
Not significantly different from England	(142)
Significantly lower than England (95.0%)	(24)
Significantly lower than England (99.8%)	(14)

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Variation in the proportion of all people who died with an underlying cause of chronic heart disease by CCG (2015)



	Example	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
Max - Min (Range)		12.7	10.9	11.7	11.0	11.2	11.2	10.7	14.9	15.4	13.7	No significant change
95th - 5th Percentile		5.2	5.5	5.4	5.4	5.3	6.3	5.6	6.5	5.4	5.4	No significant change
75th - 25th Percentile		1.9	2.3	2.1	2.3	2.0	2.1	2.0	2.1	1.9	1.6	NARROWING Significant
Median		12.6	12.5	12.3	12.2	12.1	11.8	11.7	11.4	11.6	11.0	DECREASING Significant

Introduction

One in 10 people in England die from chronic heart disease (CHD), including end stage heart failure, and these patients may have a high symptom burden towards the end of life. Those with CHD often have an unpredictable disease trajectory, which can make end of life planning difficult. They tend not to consider that their condition may be life-limiting despite their considerable symptom burden¹. Patients with CHD can benefit considerably from generalist and specialist palliative care^{2 3 4 5}, and this can reduce hospitalisation near the end of life⁶. NICE draft heart failure guidelines recommend assessing palliative care needs of patients with heart failure when symptoms are worsening despite optimal specialist treatment, rather than on the basis of prognostic risk tools⁷. It is also important that healthcare professionals initiate advance care planning discussions around deactivation of implantable cardiac defibrillators (ICDs) at an appropriate time⁸.

Trends and magnitude of variation

One in 10 deaths (11.2 %) in England had CHD as an underlying cause in 2015, with a variation of between 1 in 13 (8.0%) and 1 in 5 (21.7 %) by CCG, a 2.7-fold difference. There has been a significant decrease in the median by CCG from 12.6% in 2006 to 11.0% in 2015 and a narrowing in the 75th to 25th percentile range.

Local considerations

Commissioners and providers should review this map and underlying data in combination with data on place of death (maps 11, 20, 23 and 24) and local data on integrated heart failure/palliative care services and access to palliative care services for patients with CHD. PHE produces resources to support local planning⁹.

SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 7: Variation in the proportion of all people who died with an underlying or contributory cause of chronic obstructive pulmonary disease (COPD) by CCG (2015)

Equal-sized quintiles by value

Highest	15.81 - 18.13	(6)
	13.49 - 15.80	(26)
	11.16 - 13.48	(54)
	8.84 - 11.15	(80)
Lowest	6.51 - 8.83	(43)

LONDON

Significance level compared with England

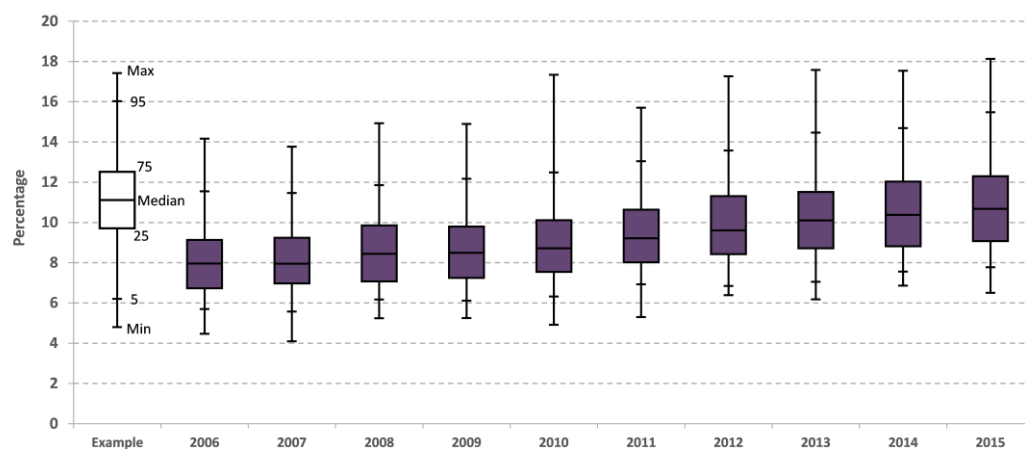
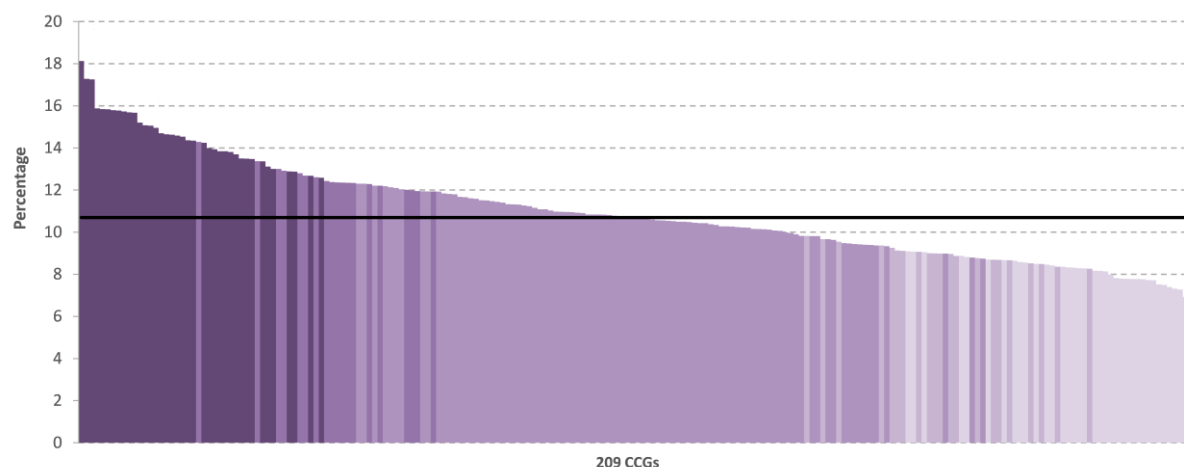
Significantly higher than England (99.8%)	(39)
Significantly higher than England (95.0%)	(19)
Not significantly different from England	(93)
Significantly lower than England (95.0%)	(21)
Significantly lower than England (99.8%)	(37)

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Variation in the proportion of all people who died with an underlying or contributory cause of chronic obstructive pulmonary disease (COPD) by CCG (2015)



	Example	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
Max - Min (Range)		9.7	9.7	9.7	9.6	12.4	10.4	10.9	11.4	10.7	11.6	WIDENING Significant
95th - 5th Percentile		5.8	5.9	5.7	6.1	6.2	6.1	6.7	7.4	7.1	7.7	WIDENING Significant
75th - 25th Percentile		2.4	2.3	2.8	2.6	2.6	2.6	2.9	2.8	3.2	3.2	WIDENING Significant
Median		8.0	8.0	8.4	8.5	8.7	9.2	9.6	10.1	10.4	10.7	INCREASING Significant

Introduction

One in 10 people die in England with a mention of COPD as either the underlying or a contributory cause to their death. They often have an unpredictable disease trajectory, which can make end of life planning difficult. Patients with end-stage COPD have a very high symptom burden, with physical and psychosocial needs¹, and patients with advanced COPD benefit from generalist and specialist palliative care^{2 3 4 5}.

The majority of patients with COPD die in hospital, with only a small reduction in hospital deaths over the past decade. Comorbidities and deprivation increase the chances of a hospital death⁶.

Trends and magnitude of variation

One in 10 deaths (10.7%) in England had COPD as an underlying or contributory cause in 2015, with a variation of between 1 in 15 (6.5%) and 1 in 6 (18.1%) by CCG, a 2.8-fold difference. There has been a small but statistically significant increase in the median value by CCG over the past decade (from 8.0% in 2006 to 10.7% in 2015), and all the measures of the range of CCG values widened.

Local considerations

Commissioners and providers should review this map and underlying data in combination with the place of death maps (11, 20, 22, 23 and 24). They should also look at local data on integrated COPD/palliative care services and access to palliative care services for patients with COPD. PHE's INHALE profile⁷ provides data on prevalence and quality of care for patients with COPD.

SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 8: Variation in the proportion of people who died with an underlying cause of stroke by CCG (2015)

Equal-sized quintiles by value

Highest	9.57 - 10.86	(1)
	8.26 - 9.56	(8)
	6.96 - 8.25	(54)
	5.66 - 6.95	(115)
Lowest	4.34 - 5.65	(31)

LONDON

Significance level compared with England

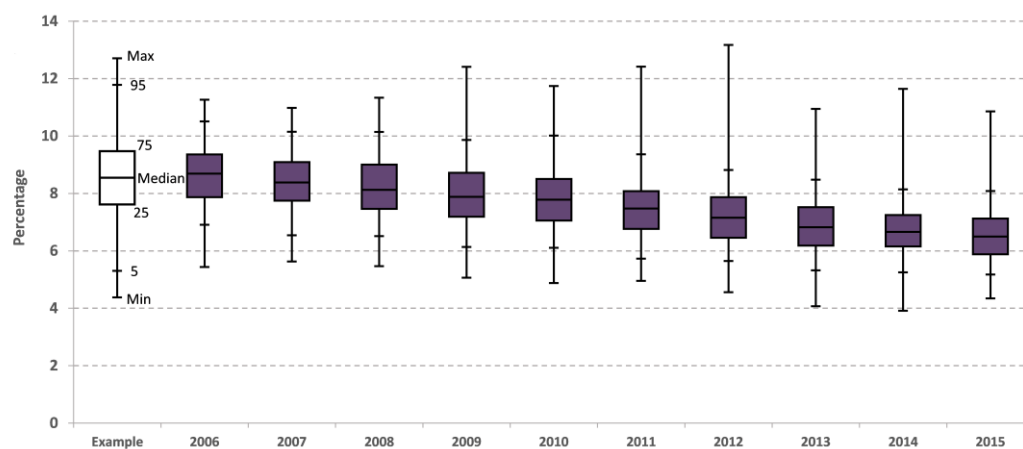
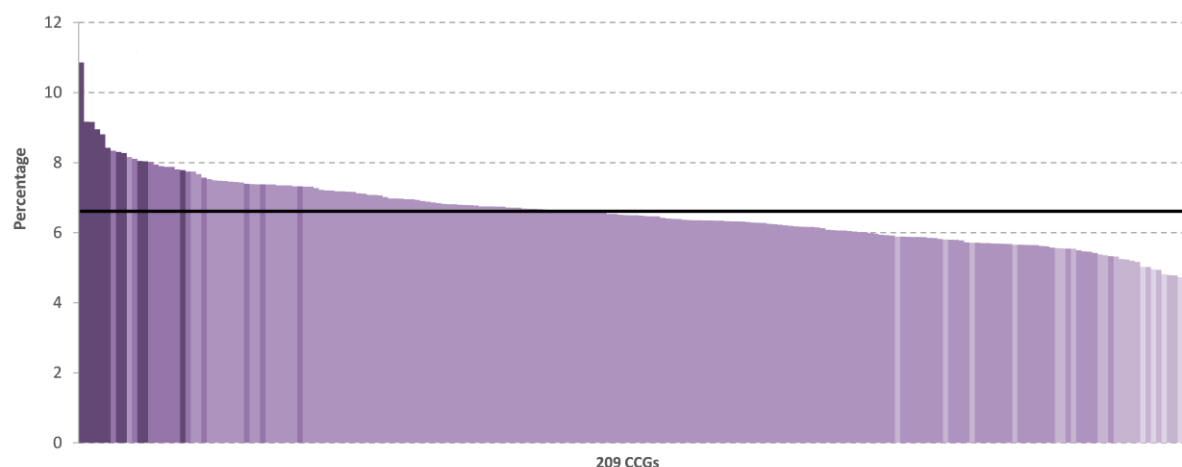
Significantly higher than England (99.8%)	(11)
Significantly higher than England (95.0%)	(13)
Not significantly different from England	(161)
Significantly lower than England (95.0%)	(18)
Significantly lower than England (99.8%)	(6)

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Variation in the proportion of people who died with an underlying cause of stroke by CCG (2015)



Max - Min (Range)		5.8	5.3	5.9	7.3	6.9	7.5	8.6	6.9	7.7	6.5	No significant change
95th - 5th Percentile		3.6	3.6	3.6	3.7	3.9	3.6	3.2	3.2	2.9	2.9	NARROWING Significant
75th - 25th Percentile		1.5	1.3	1.5	1.5	1.5	1.3	1.4	1.3	1.1	1.2	NARROWING Significant
Median		8.7	8.4	8.1	7.9	7.8	7.5	7.2	6.8	6.7	6.5	DECREASING Significant

Introduction

National guidelines recognise that high quality end of life care is a core activity for all multi-disciplinary stroke teams¹. Acute stroke patients have a high prevalence of palliative care needs². Patients who survive acute stroke with life-limiting disability have a variable and often unpredictable period of dependency and high care needs before dying, often in a care home. However, a low proportion of people with stroke are identified for end of life care in hospital and community settings. Guidelines recommend that commissioners ensure they include the whole stroke pathway from prevention to palliative care³.

Trends and magnitude of variation

One in 15 deaths (6.6%) in England had stroke as the underlying cause in 2015, with a variation of between 1 in 23 (4.3%) and 1 in 9 (10.9%) by CCG, a 2.5-fold difference. The median value by CCG decreased significantly from 8.7% in 2006 to 6.5% in 2015, and two measures of the variation in values across CCGs (95th to 5th percentile and 75th to 25th percentile) narrowed. This is likely to reflect reductions in mortality from stroke due to public health campaigns leading to earlier recognition, diagnosis and treatment in hospital⁴.

Local considerations

Commissioners and providers should review this map and underlying data in combination with maps 1, 10, 15 to 18 and 25, and local data on palliative care and rehabilitation services for stroke patients. Indicators on stroke prevalence, treatment and hospital admissions are available in the Cardiovascular disease profiles⁵. Data is also available on brain imaging for stroke patients⁶.

SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 9: Variation in the proportion of all people who died with an underlying cause of liver disease by CCG (2015)

Equal-sized quintiles by value

Highest	3.86 - 4.52	(6)
	3.19 - 3.85	(26)
	2.52 - 3.18	(60)
	1.85 - 2.51	(92)
Lowest	1.17 - 1.84	(25)

LONDON

Significance level compared with England

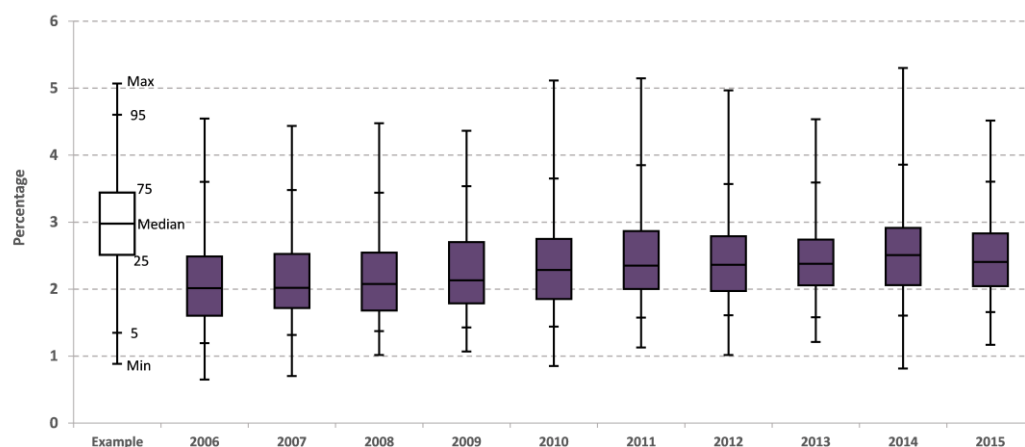
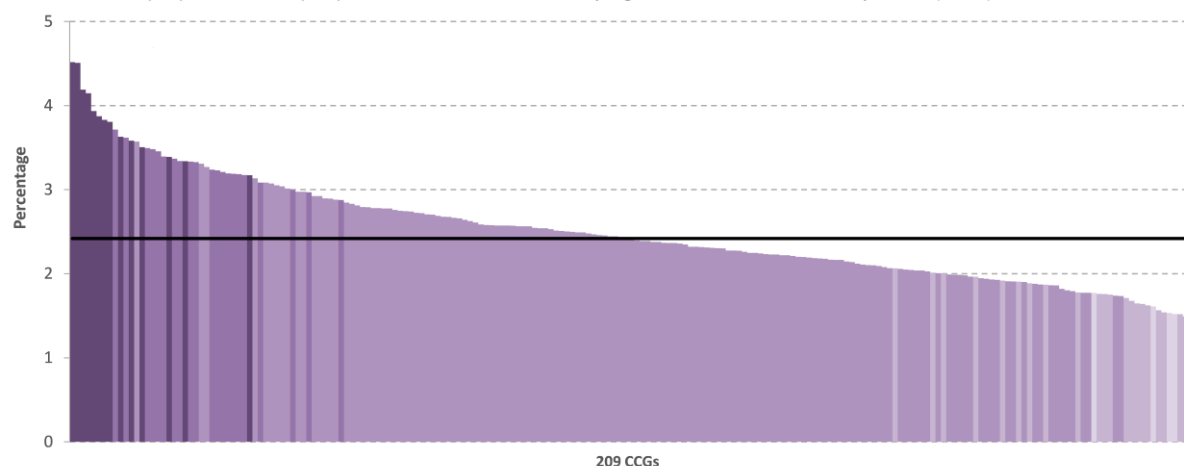
Significantly higher than England (99.8%)	(14)
Significantly higher than England (95.0%)	(21)
Not significantly different from England	(148)
Significantly lower than England (95.0%)	(21)
Significantly lower than England (99.8%)	(5)

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Variation in the proportion of all people who died with an underlying cause of liver disease by CCG (2015)



Max - Min (Range)		3.9	3.7	3.5	3.3	4.3	4.0	4.0	3.3	4.5	3.3	No significant change
95th - 5th Percentile		2.4	2.2	2.1	2.1	2.2	2.3	2.0	2.0	2.3	1.9	No significant change
75th - 25th Percentile		0.9	0.8	0.9	0.9	0.9	0.9	0.8	0.7	0.9	0.8	No significant change
Median		2.0	2.0	2.1	2.1	2.3	2.4	2.4	2.4	2.5	2.4	INCREASING Significant

Introduction

Deaths from liver disease as the underlying cause continue to increase in England, whereas they are decreasing in many other European countries¹.

Palliative and end of life care for patients with liver disease can be particularly challenging as most people who die from liver disease are young (71% are under 75 years), the prognosis in advanced liver disease can be very uncertain, there is a high symptom burden, and patients may face barriers to accessing care². A high proportion (59.2%) of deaths from liver disease occurs in hospital, and patients with liver disease have a large number of hospital admissions in the last year of life. Patients with advanced liver disease may benefit from integration of active medical management of acute crises and palliative and supportive care^{2,3}.

Trend and magnitude of variation

One in 40 deaths (2.4%) in England had liver disease as the underlying cause in 2015, with a variation of between 1 in 85 (1.2%) to 1 in 22 (4.5%) by CCG, a 3.9-fold difference. There was a significant increase in the median value by CCG from 2.0% in 2006 to 2.4% in 2015.

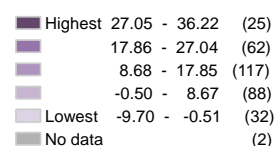
Local considerations

Commissioners and providers should review this map and underlying data in combination with hospital maps (11 to 18), the 2nd Atlas of variation in risk factors and healthcare for liver disease in England¹, Liver disease profiles⁴ and local data on the integration of palliative and social care services into local liver networks.

SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

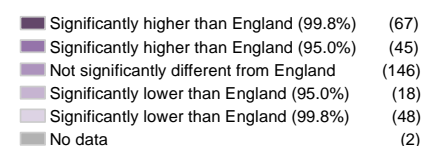
Map 10: Variation in the percentage change in the annual number of people dying between 2014 and 2030 by lower-tier local authority

Equal-sized quintiles of geographies



LONDON

Significance level compared with England

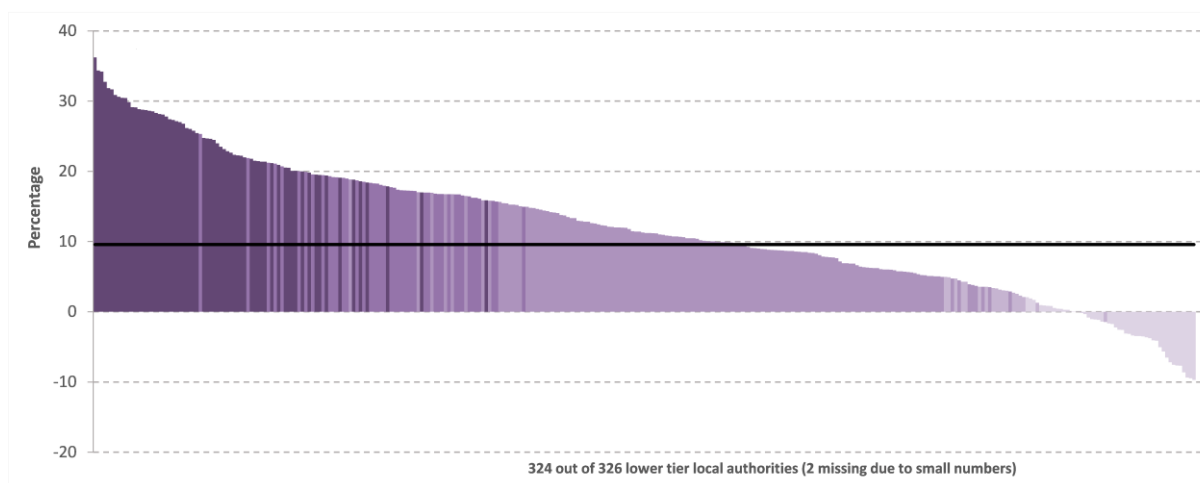


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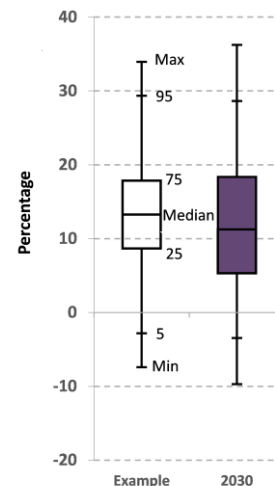
Variation in the percentage change in the annual number of people dying between 2014 and 2030 by lower-tier local authority



Introduction

A recent article describing the need for palliative and end of life care across care settings predicted that at least 42% more people will need palliative care in England and Wales by 2040¹.

This map shows the variation in projected percentage change in numbers of deaths between 2014 and 2030 by lower tier local authority. At a national level, the number of deaths are projected to increase over this period partly due to the 'baby boomer' population ageing. However, as can be seen from the data presented the percentage increase in numbers is not uniform. The actual numbers, which are important for service planning and commissioning are shown in Appendix 2 – projected deaths for 2030 at local authority level.



Max - Min (Range)		45.9
95th - 5th Percentile		32.1
75th - 25th Percentile		13.1
Median		11.3

Magnitude of variation

The map, column chart and box plot display the projected percentage change in number of deaths between 2014 and 2030, for which local authority values ranged from -9.7% to 36.2%. The percentage change for England was 9.6% and the local authority median was 11.3%.

Local considerations

Commissioners and providers should review this map and the data provided alongside Appendix 1 – number of deaths and crude death rate by CCG (2016) and Appendix 2 – projected deaths for 2030 at lower tier local authority level.

SECTION 2: THE ROLE OF HOSPITALS IN PALLIATIVE AND END OF LIFE CARE

Map 11: Variation in the proportion of all people who died in hospital by CCG (2015)**Equal-sized quintiles by value**

Highest	61.73 - 68.11	(1)
	55.33 - 61.72	(12)
	48.93 - 55.32	(66)
	42.53 - 48.92	(87)
Lowest	36.13 - 42.52	(43)

LONDON

Significance level compared with England

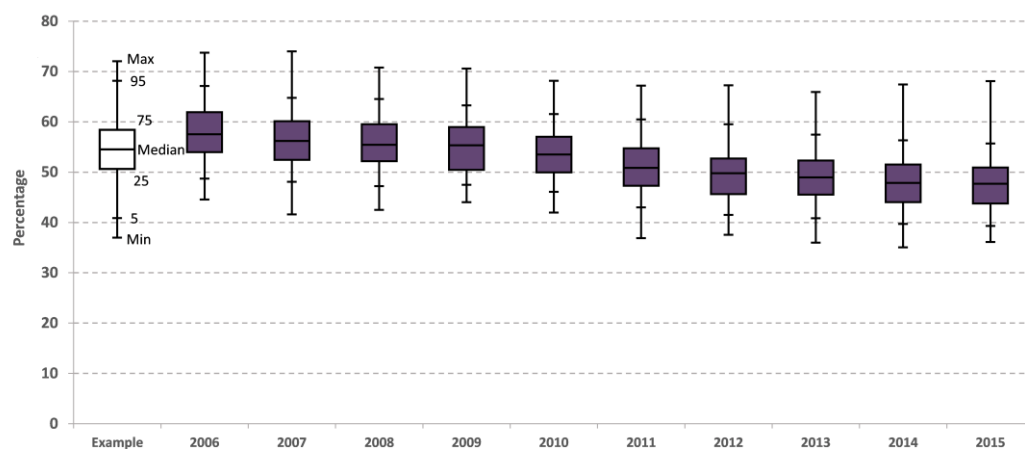
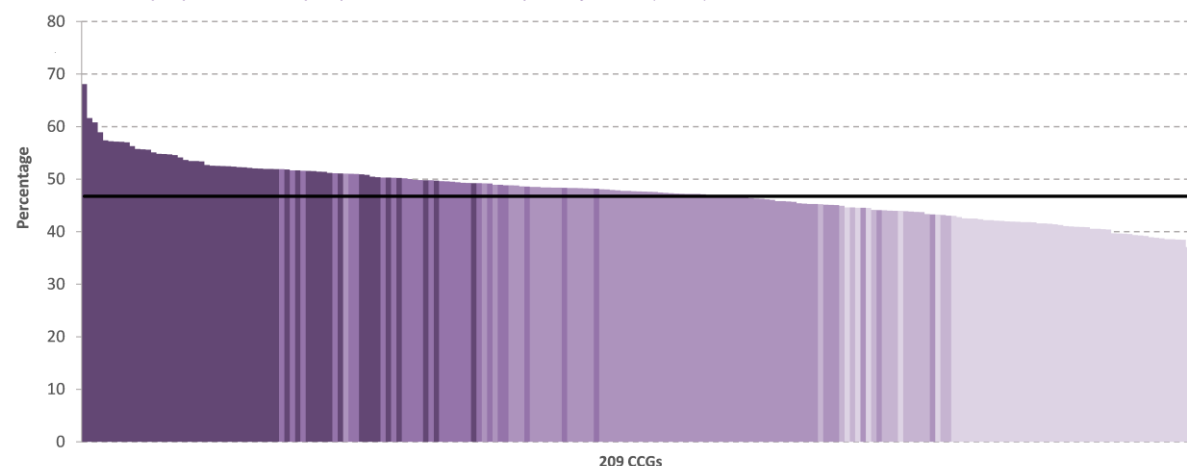
Significantly higher than England (99.8%)	(54)
Significantly higher than England (95.0%)	(26)
Not significantly different from England	(64)
Significantly lower than England (95.0%)	(14)
Significantly lower than England (99.8%)	(51)

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Variation in the proportion of all people who died in hospital by CCG (2015)



	Example	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
Max - Min (Range)		29.2	32.4	28.3	26.6	26.2	30.3	29.7	30.0	32.4	32.0	No significant change
95th - 5th Percentile		18.4	16.7	17.3	15.8	15.5	17.5	18.0	16.6	16.6	16.4	No significant change
75th - 25th Percentile		8.0	7.7	7.4	8.5	7.1	7.4	7.1	6.8	7.5	7.1	No significant change
Median		57.5	56.2	55.4	55.3	53.5	50.8	49.8	49.0	47.9	47.7	DECREASING Significant

Introduction

Hospital is the most common place of death. There is an emphasis on the importance of improving the quality of end of life care in all settings^{1 2 3}, including hospitals⁴. As described in the introduction, demographic and disease related factors influence the chances of a person dying in hospital, but so also does community end of life care provision.

Trends and magnitude of variation

On average, just under half (46.7%) of all deaths in England in 2015 occurred in hospital, with a variation of between two thirds (68.1%), and one third (36.1%) of deaths by CCG, a 1.9-fold difference. The median value by CCG decreased significantly from 57.5% in 2006 to 47.7% in 2015, with no significant change in any of the 3 measures of variation.

Local considerations

Commissioners and providers should review this map and underlying data in combination with data on end of life care in hospitals (maps 11 to 18), cause of death (maps 4 to 9) and demographic data (maps 1 to 3). Local data on general and specialist palliative care provision in hospitals and community settings and wider social care support in their locality should also be explored.

SECTION 2: THE ROLE OF HOSPITALS IN PALLIATIVE AND END OF LIFE CARE

Map 12: Variation in the proportion of all people admitted into hospital during the last 90 days of their life by CCG (2015)

Equal-sized quintiles by value

Highest	71.16 - 74.92	(47)
	67.39 - 71.15	(73)
	63.61 - 67.38	(58)
	59.84 - 63.60	(25)
Lowest	56.05 - 59.83	(6)

LONDON

Significance level compared with England

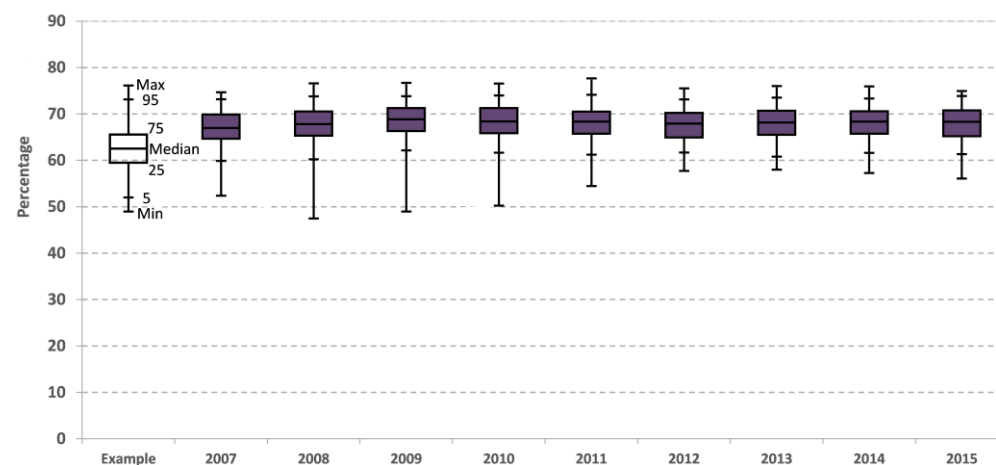
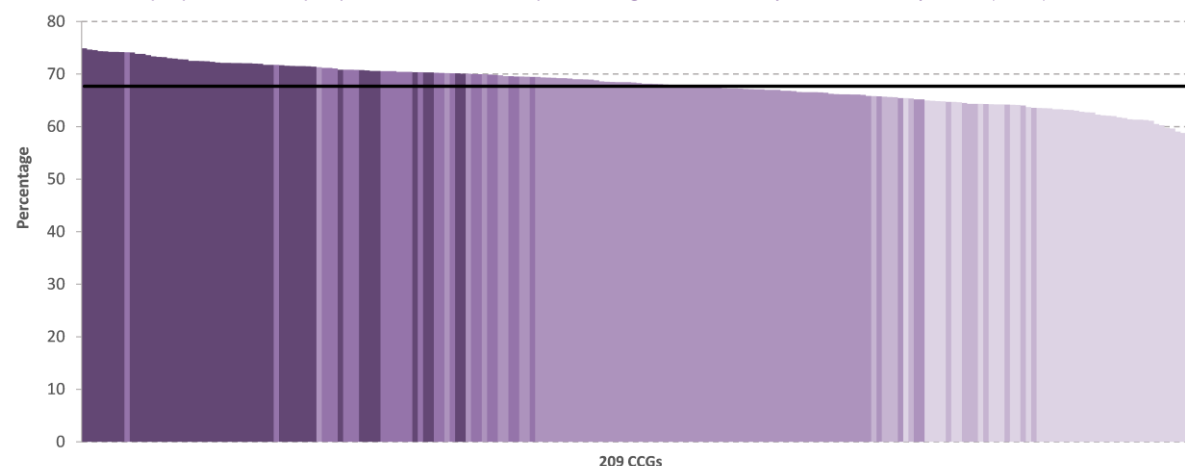
Significantly higher than England (99.8%)	(52)
Significantly higher than England (95.0%)	(25)
Not significantly different from England	(75)
Significantly lower than England (95.0%)	(13)
Significantly lower than England (99.8%)	(44)

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Variation in the proportion of all people admitted into hospital during the last 90 days of their life by CCG (2015)



Max - Min (Range)		22.3	29.1	27.7	26.3	23.2	17.8	18.0	18.6	18.9	NARROWING Significant
95th - 5th Percentile		13.3	13.6	11.7	12.4	12.9	11.4	12.7	11.7	12.5	No significant change
75th - 25th Percentile		5.2	5.3	5.0	5.4	4.7	5.3	5.2	4.8	5.6	No significant change
Median		67.0	67.8	68.9	68.4	68.4	67.9	68.1	68.4	68.3	No significant change

Introduction

Approximately two-thirds (67.7%) of all those who died in England in 2015 had a hospital admission during the last 3 months of their lives. Many could have been admitted with life-threatening conditions. Some may be clearly entering the end of life. This highlights the importance of improving the quality of care in hospitals, in addition to improving community provision^{1,2}. The importance of careful hospital discharge planning for end of life care is set out in NICE guideline NG27³. These recommend offering palliative care services according to needs, consideration of referral to a palliative care team, and ensuring that end of life care is assessed and communicated with the patient's GP.

Trends and magnitude of variation

Just over two-thirds (67.7%) of all those who died in England in 2015 had been admitted into hospital in the last 90 days of their life, with a variation of between three quarters (74.9%), and just over half (56.1%) by CCG, a 1.3-fold difference. There was no significant change in the median for CCGs which in 2015 was 68.3% but the variation in the maximum to minimum range narrowed significantly between 2007 and 2015.

Local considerations

Commissioners and providers should review this map and underlying data in combination with maps looking at end of life care in hospitals (11 to 18), cause of death (maps 4 to 9) and demographic data (maps 1 to 3). Local data on general and specialist palliative care provision in hospitals and community settings and wider social care support should also be explored.

SECTION 2: THE ROLE OF HOSPITALS IN PALLIATIVE AND END OF LIFE CARE

Map 13: Variation in the proportion of people who have 3 or more emergency hospital admissions during the last 90 days of life by CCG (2015)

Equal-sized quintiles by value

Highest	10.65 - 12.57	(5)
	8.71 - 10.64	(24)
	6.78 - 8.70	(91)
	4.84 - 6.77	(65)
Lowest	2.90 - 4.83	(24)

LONDON

Significance level compared with England

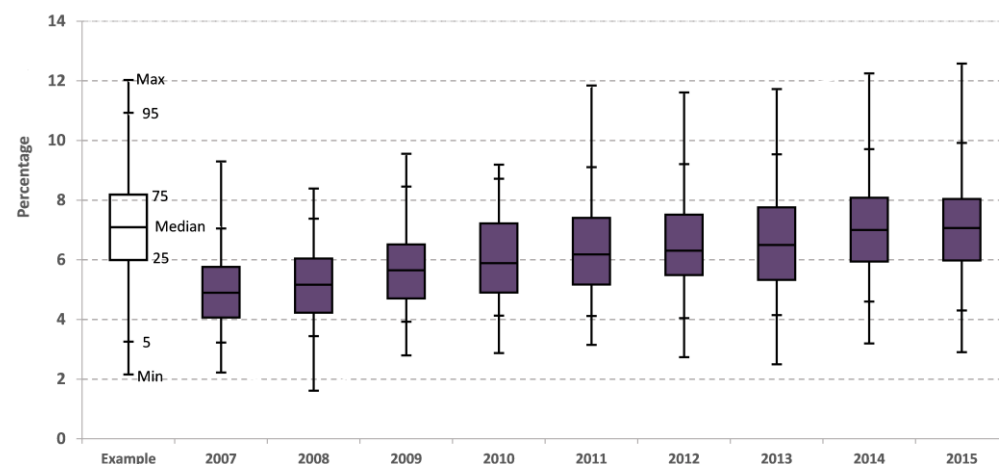
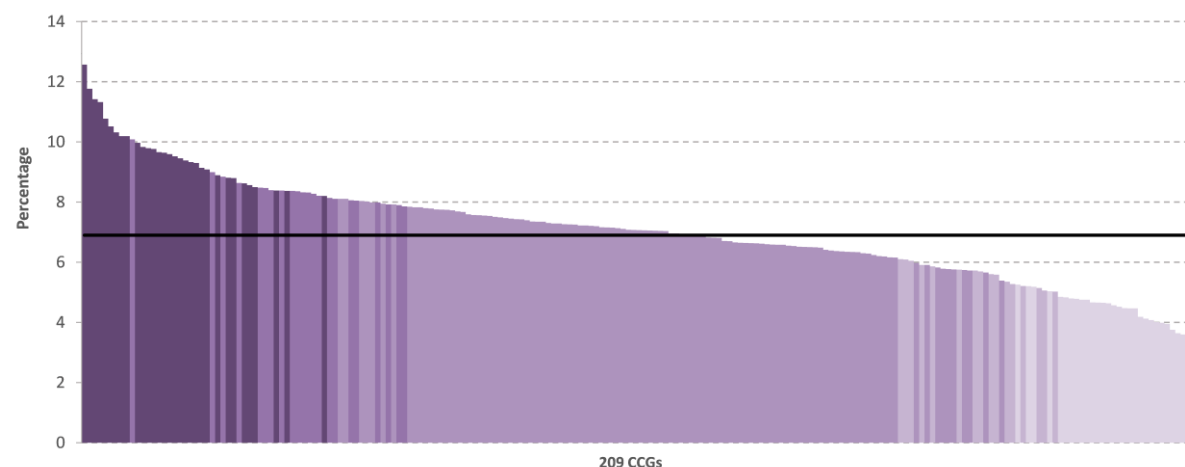
Significantly higher than England (99.8%)	(32)
Significantly higher than England (95.0%)	(22)
Not significantly different from England	(109)
Significantly lower than England (95.0%)	(16)
Significantly lower than England (99.8%)	(30)

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Variation in the proportion of people who have 3 or more emergency hospital admissions during the last 90 days of life by CCG (2015)



Max - Min (Range)		7.1	6.8	6.8	6.3	8.7	8.9	9.2	9.1	9.7	WIDENING Significant
95th - 5th Percentile		3.8	3.9	4.5	4.6	5.0	5.2	5.4	5.1	5.6	WIDENING Significant
75th - 25th Percentile		1.7	1.8	1.8	2.3	2.2	2.0	2.4	2.1	2.1	No significant change
Median		4.9	5.2	5.6	5.9	6.2	6.3	6.5	7.0	7.1	INCREASING Significant

Introduction

The End of life care strategy recognised that people who are approaching the end of life need access to care and support 24/7, and that when community services are unable to respond to these needs, patients may be admitted to hospital as an emergency¹. Emergency hospital admissions can be disruptive and distressing for patients and their carers². Advance care planning and access to palliative care can reduce hospital admissions^{3,4}. NICE guideline [NG94] recommends offering advance care planning to people in the community and in hospital who are approaching the end of life and are at risk of a medical emergency⁵. In addition local community services should be configured so that they can be responsive to patient's urgent end of life care needs.

Trends and magnitude of variation

On average, 1 in 14 (6.9%) of all those who died in England in 2015 had 3 or more emergency hospital admissions during the last 90 days of life, with a variation from 1 in 8 (12.6%) to 1 in 34 (2.9%) by CCG, a 4.3-fold difference. The CCG median increased significantly from 4.9% in 2007 to 7.1% in 2015, and both the maximum to minimum range and 95th to 5th percentile range widened significantly. This increasing trend is of great concern because of the distress this can cause to patients and families.

Local considerations

Commissioners and providers should review this map and underlying data in combination with hospital maps (11 to 18), local data on general and palliative care provision in hospitals and community settings, social care data and local initiatives to avoid unnecessary hospital admissions at end of life.

SECTION 2: THE ROLE OF HOSPITALS IN PALLIATIVE AND END OF LIFE CARE

Map 14: Variation in the proportion of hospital admissions ending in death in hospital which are 8 days or longer by CCG (2015)

Equal-sized quintiles by value

Highest	57.35 - 62.67	(9)
	52.01 - 57.34	(66)
	46.67 - 52.00	(96)
	41.33 - 46.66	(35)
Lowest	35.98 - 41.32	(3)

LONDON

Significance level compared with England

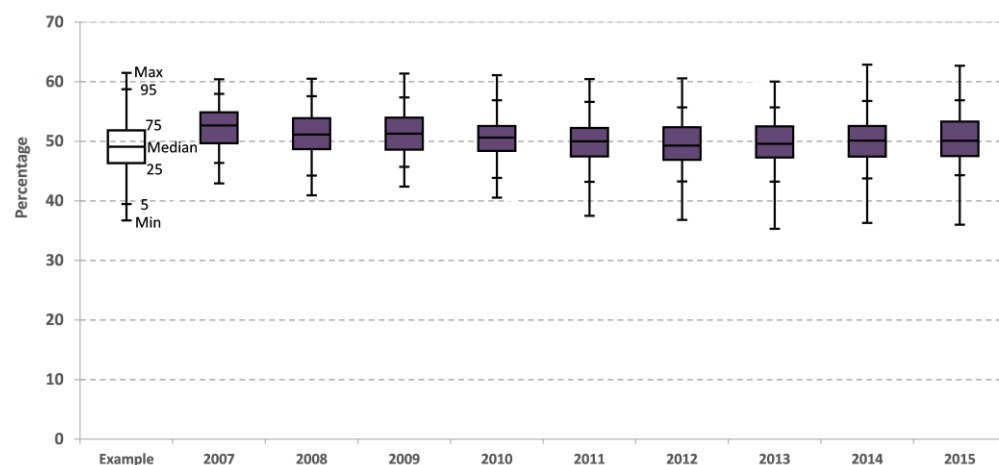
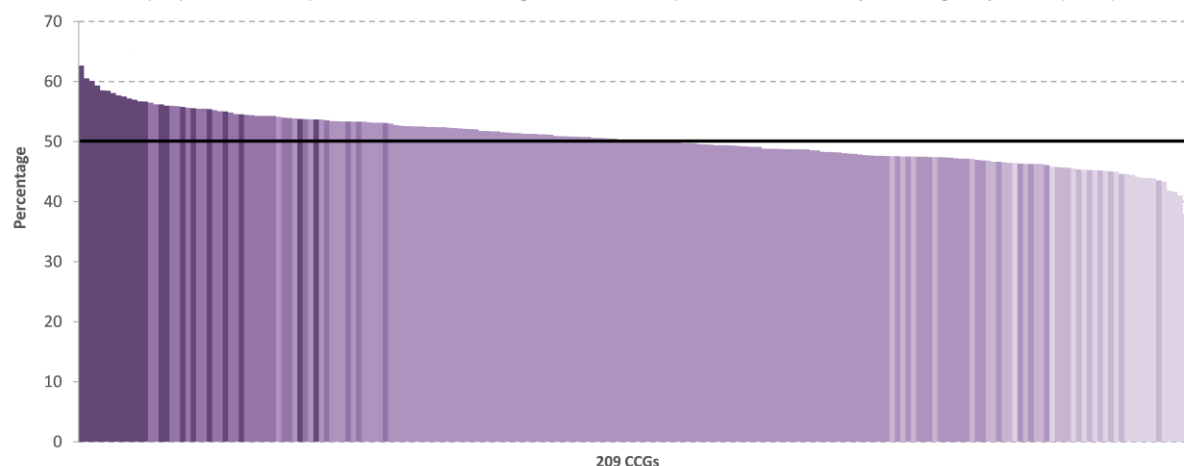
Significantly higher than England (99.8%)	(22)
Significantly higher than England (95.0%)	(24)
Not significantly different from England	(123)
Significantly lower than England (95.0%)	(21)
Significantly lower than England (99.8%)	(19)

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Variation in the proportion of hospital admissions ending in death in hospital which are 8 days or longer by CCG (2015)



Max - Min (Range)		17.5	19.6	19.0	20.6	22.9	23.7	24.7	26.6	26.7	WIDENING Significant
95th - 5th Percentile		11.6	13.3	11.6	13.0	13.4	12.4	12.5	13.0	12.6	No significant change
75th - 25th Percentile		5.2	5.2	5.4	4.2	4.8	5.5	5.2	5.1	5.8	No significant change
Median		52.7	51.1	51.3	50.6	50.0	49.3	49.6	50.1	50.1	DECREASING Significant

Introduction

A large proportion of hospital admissions ending in death which are 8 days or longer could indicate that co-ordinated care plans is not in place. There is evidence from a national survey of the bereaved that there is significant room for improvement in the co-ordination of care between hospital, GP and community services¹. NICE guideline [NG27]² outlines the importance of careful hospital discharge planning for palliative and end of life care.

Trends and magnitude of variation

The map and column chart display the latest period (2015), during which CCG values ranged from 36.0% to 62.7%, which is a 1.7-fold difference between CCGs. The England value for 2015 was 50.1%.

The box plot shows the distribution of CCG values for the period 2007 to 2015 calendar years. The maximum to minimum range widened significantly. The CCG median decreased significantly from 52.7% in 2007 to 50.1% in 2015.

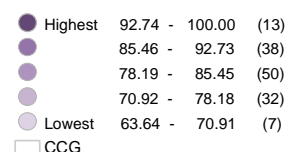
Local considerations

Commissioners and providers should review this map and underlying data in combination with hospital maps (11 to 18), demographic data (maps 1 to 3) and cause of death (maps 4 to 9). They should also explore local data on palliative care provision in hospitals and community settings in combination with local social care provision and data on delayed transfers of care³.

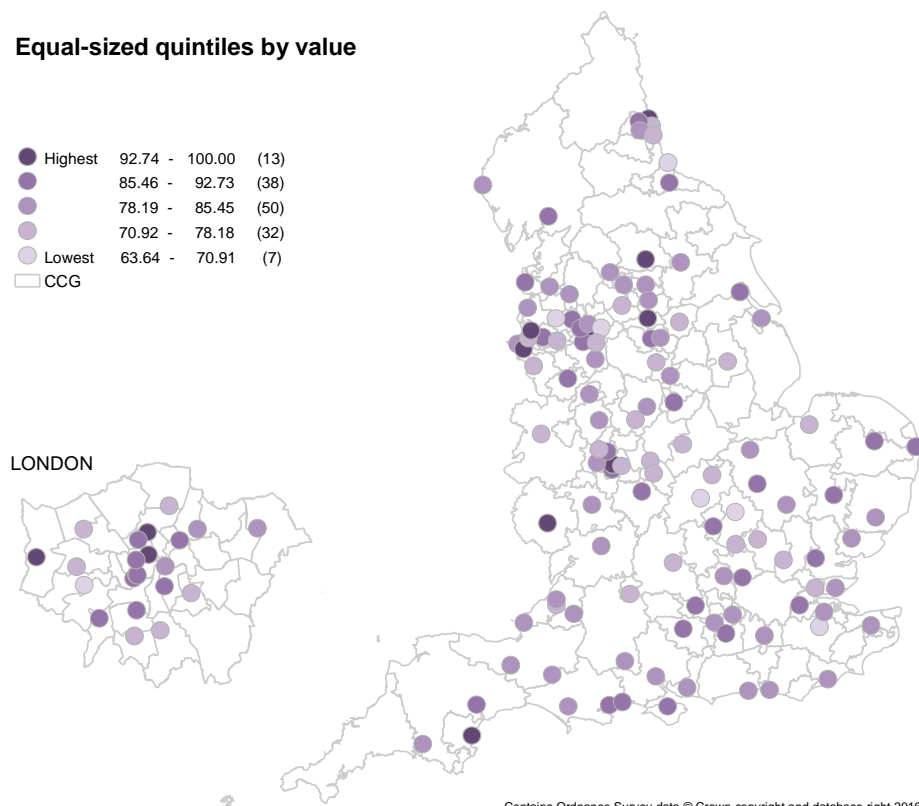
SECTION 2: THE ROLE OF HOSPITALS IN PALLIATIVE AND END OF LIFE CARE

Map 15: Variation in proportion of all people who died in hospital that had documented evidence of recognition that they would probably die in the coming hours or days by acute hospital trust site (2015)

Equal-sized quintiles by value

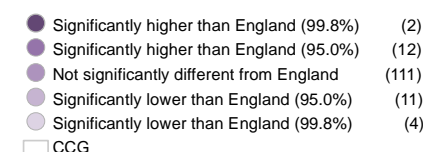


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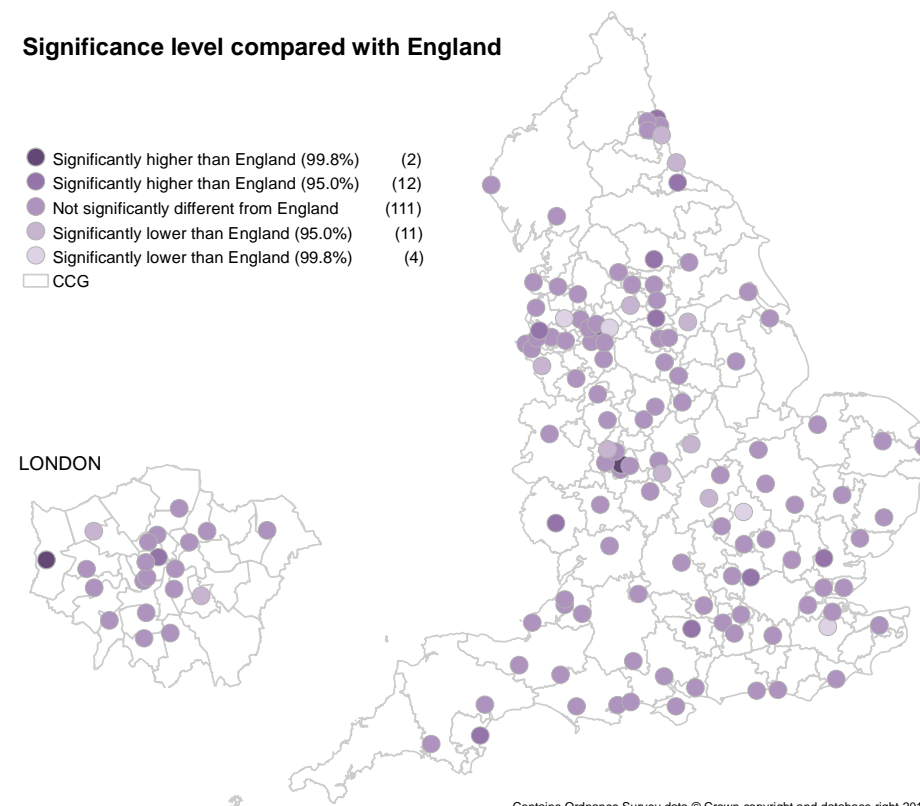


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Significance level compared with England



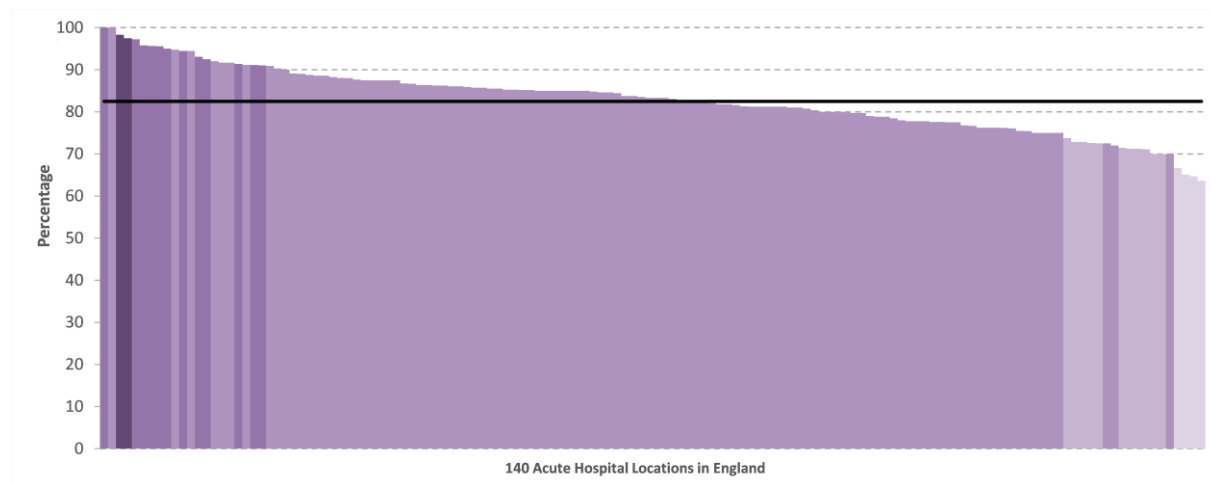
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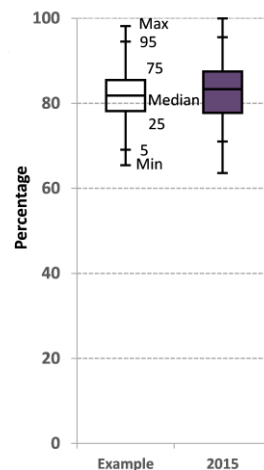
n = 140 acute hospital sites in England. Please refer to the metadata guide for further details.

Variation in proportion of all people who died in hospital that had documented evidence of recognition that they would probably die in the coming hours or days by acute hospital trust site (2015)



Introduction

The 1st of the 5 priorities of care for the dying person as set out in 'One Chance to Get it Right'¹ is that 'the possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's need and wishes, and these are regularly reviewed and decisions revised accordingly'. NICE guideline [NG31] provides guidance on recognising when a person may be in the last days of life². NICE quality standard [QS144] defines how documented evidence of the recognition that a patient was in the last days of life should be measured³. The Royal College of Physicians (RCP) End of life care audit – dying in hospital⁴ collected data on this measure from hospital sites across England.



Max - Min (Range)		36.4
95th - 5th Percentile		24.5
75th - 25th Percentile		9.8
Median		83.3

Magnitude of variation

The map and column chart display the latest period (2015), during which hospital values ranged from 63.6% to 100.0%, which is a 1.6-fold difference between acute hospital sites. The England value for 2015 was 82.5% while the median value by acute hospital site was 83.3%.

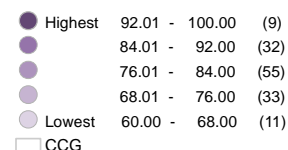
Local considerations

Local commissioners and providers should review this map alongside the other audit maps (16,17 and 18), the RCP End of life care audit – dying in hospital national report⁴, and data on local arrangements and systems to enhance the recognition of adults entering the last days of life so that timely conversations and individualised care planning takes place.

SECTION 2: THE ROLE OF HOSPITALS IN PALLIATIVE AND END OF LIFE CARE

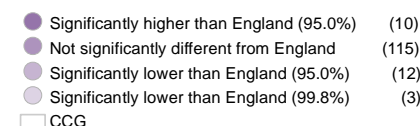
Map 16: Variation in the proportion of all people who had documented evidence that a health professional had recognised during the last episode of care the person was dying and had discussed this with a nominated person(s) important to the dying person by acute hospital trust site (2015)

Equal-sized quintiles by value



LONDON

Significance level compared with England



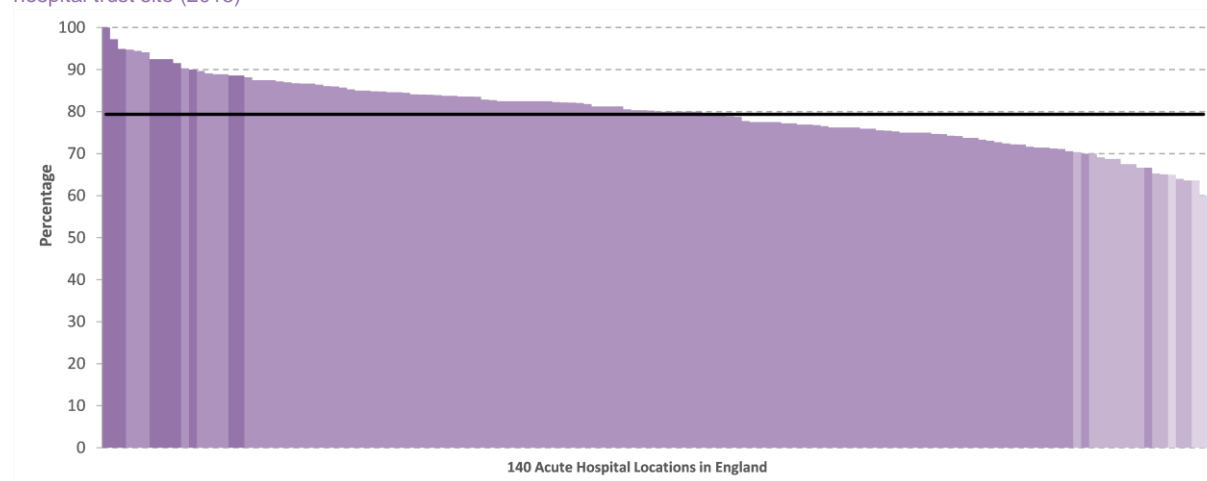
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n = 140 acute hospital sites in England. Please refer to the metadata guide for further details.

Variation in the proportion of all people who had documented evidence that a health professional had recognised during the last episode of care the person was dying and had discussed this with a nominated person(s) important to the dying person by acute hospital trust site (2015)



Introduction

The 2nd of the 5 priorities of care for the dying person in 'One Chance to Get it Right'¹ is that 'sensitive communication takes place between staff and the dying person, and those identified as important to them'. NICE guideline [NG31] provides guidance on establishing and responding to the communication needs of dying patients and those important to them². This indicator reports on data from acute hospital sites collected by the Royal College of Physicians (RCP) End of life care audit – dying in hospital³.

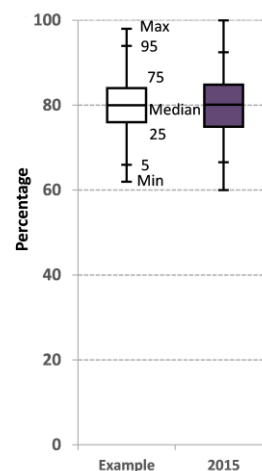
Magnitude of variation

In 2015 for 79.4% of patients audited (and a median by acute hospital sites of 80.1%) there was documented evidence within the last episode of care that health professional recognition that the patient would probably die in the coming hours or days (imminent death) had

been discussed with a nominated person(s) important to the patient. The variation between acute hospital sites was 60.0% to 100.0%, which is a 1.7-fold difference. Analysis presented in the full audit report showed that when sudden/unexpected deaths were excluded, and analysis was restricted to those where there was recognition that the patient was imminently dying, the proportion of patients with documented evidence increased (95%)³.

Local considerations

Local commissioners and providers should review this map alongside the other audit maps (15,17 and 18), the RCP End of life care audit – dying in hospital national report³, and data on local arrangements and systems to ensure appropriate communication about recognition that a patient is thought to be imminently dying. Training on 'breaking bad news' is key to improving the quality and frequency of communication about dying.

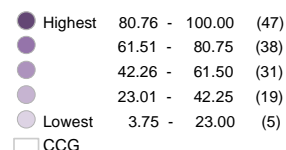


Max - Min (Range)		40.0
95th - 5th Percentile		25.9
75th - 25th Percentile		9.9
Median		80.1

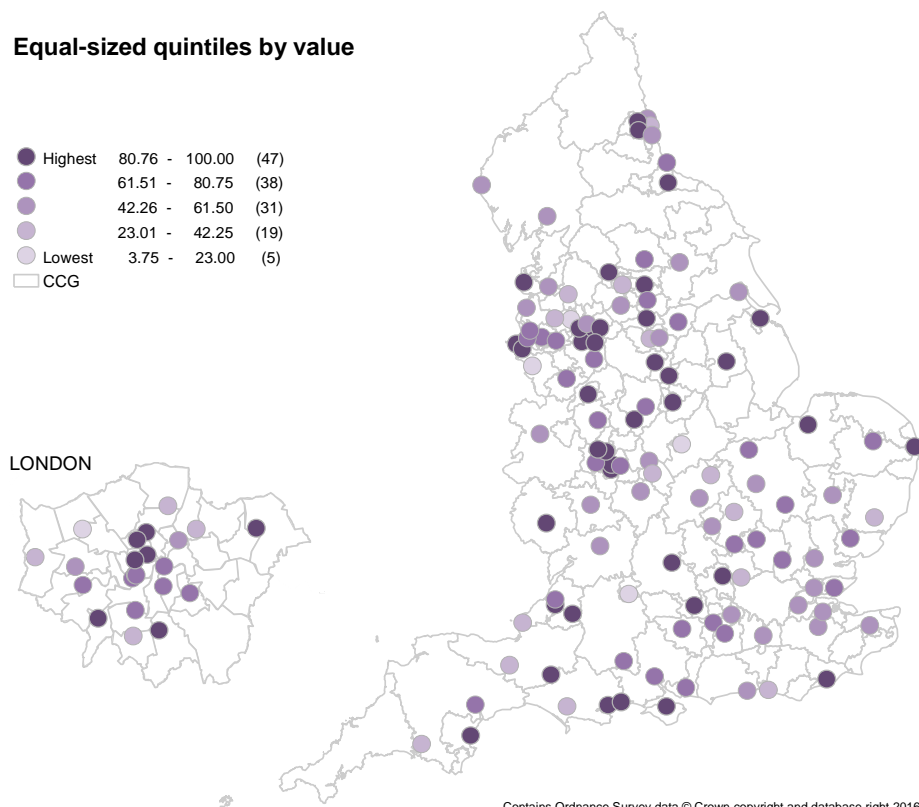
SECTION 2: THE ROLE OF HOSPITALS IN PALLIATIVE AND END OF LIFE CARE

Map 17: Variation in proportion of all people who died in hospital that had documented evidence in the last 24 hours of a holistic assessment of their needs regarding an individual plan of care by acute hospital trust site (2015)

Equal-sized quintiles by value

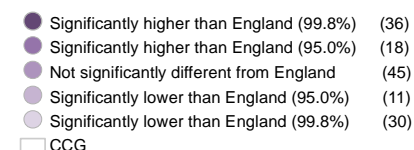


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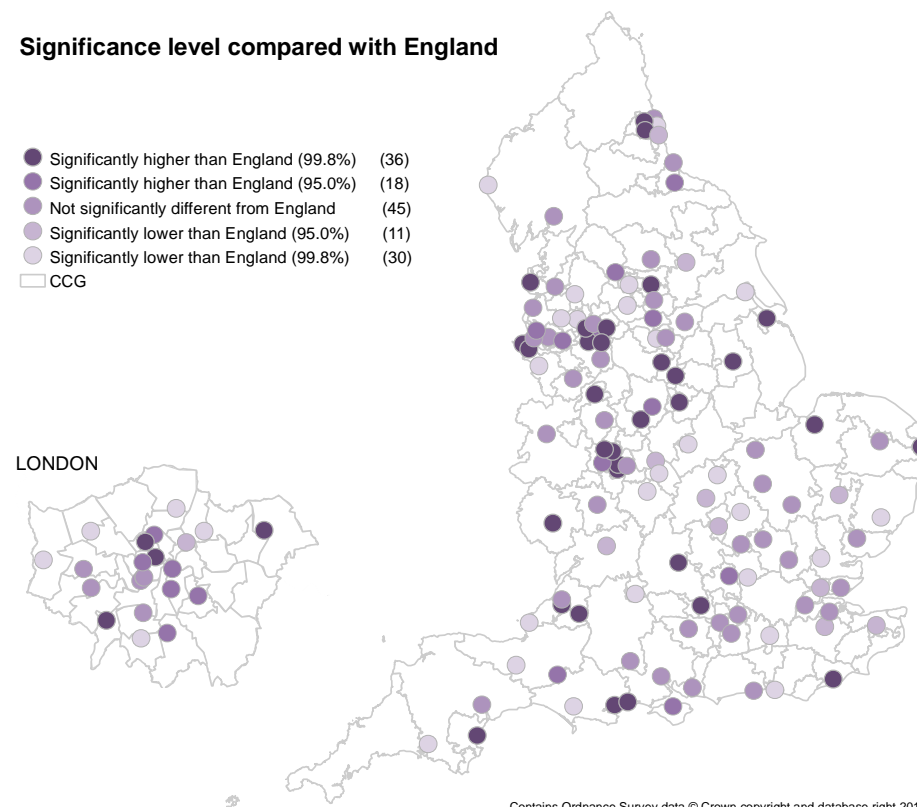


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Significance level compared with England



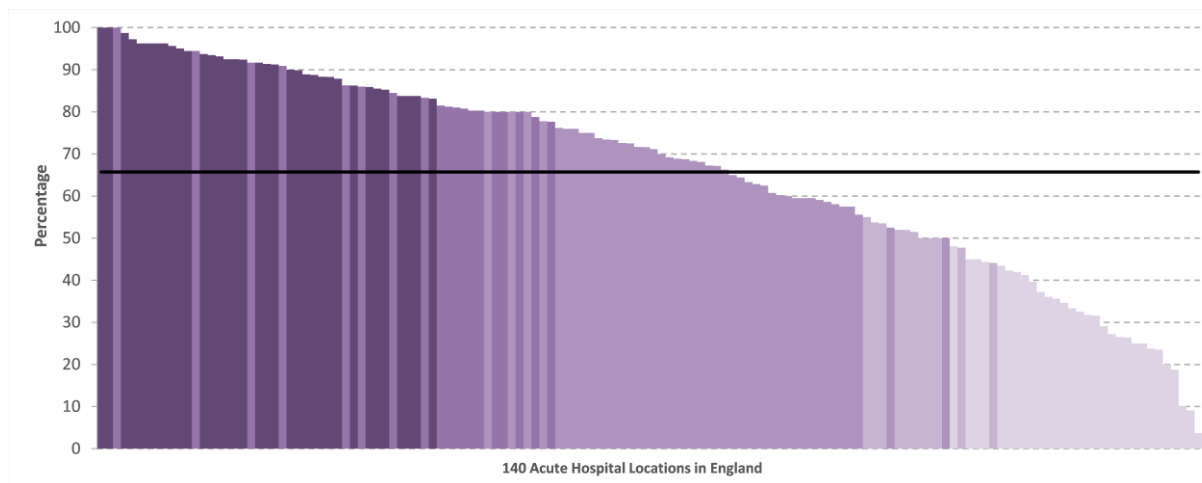
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n = 140 acute hospital sites in England. Please refer to the metadata guide for further details.

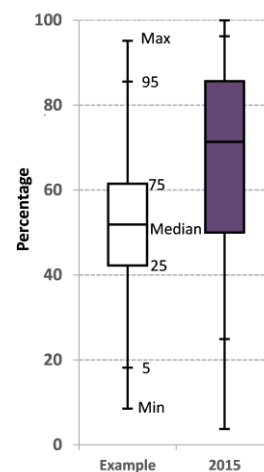
Variation in proportion of all people who died in hospital that had documented evidence in the last 24 hours of a holistic assessment of their needs regarding an individual plan of care by acute hospital trust site (2015)



Introduction

The 5th of the 5 priorities of care for the dying person in 'One Chance to Get it Right'¹ is that 'an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion'. NICE guideline [NG31] provides guidance on how to develop an individualised care plan for a dying patient². NICE quality standard [QS144] defines how to measure whether adults in the last days of life, and the people important to them, are given opportunities to discuss, develop and review an individualised care plan².

This indicator reports on data collected from acute hospital sites across England by the Royal College of Physicians (RCP) End of life care audit – dying in hospital³.



Max - Min (Range)		96.3
95th - 5th Percentile		71.3
75th - 25th Percentile		35.6
Median		71.4

Of the key symptoms that are often present in the last hours or days of life, the audit found documented evidence that pain was controlled in 79%, agitation/delirium in 72%, breathing difficulties in 68%, noisy breathing/death rattle in 62% and nausea/vomiting in 55%³.

Magnitude of variation

In 2015, 65.7% of patients audited in acute hospital sites in England (and a median by acute hospital site of 71.4%) had documented evidence in the last 24 hours of a holistic assessment of their needs regarding an individual plan of care. The variation between acute hospitals was 3.8% to 100.0%, which is a 26.7-fold difference. Data presented in the full audit report shows that when sudden/unexpected deaths were excluded, and analysis was restricted to those with a length of stay of 24 hours or more, the result increased to 73% of patients³.

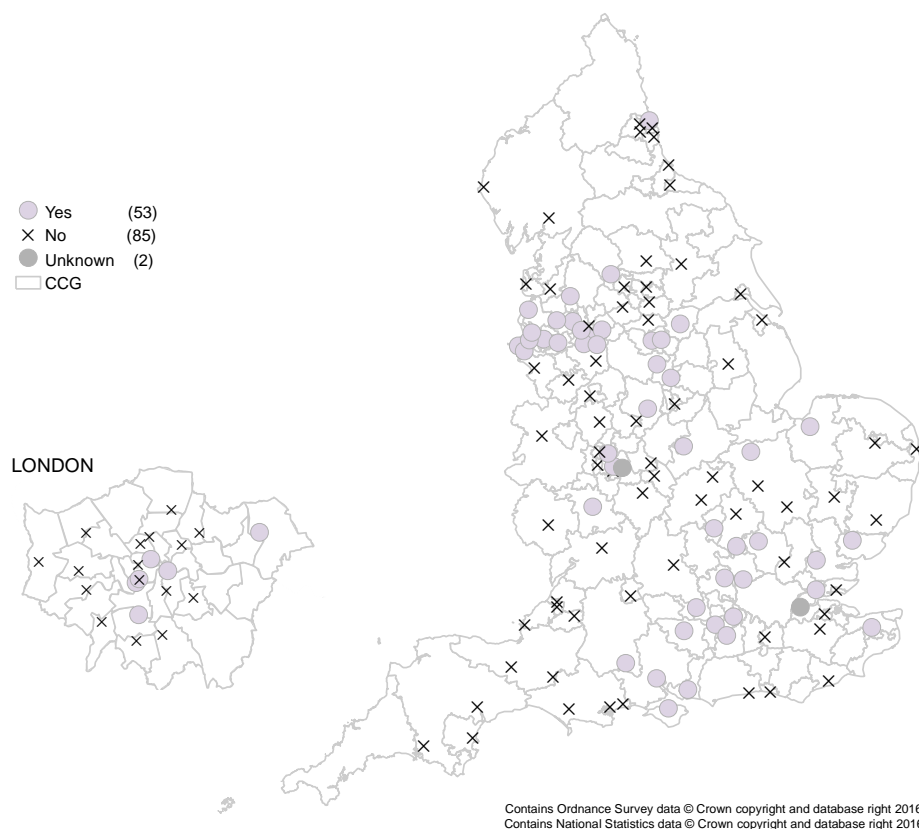
Local considerations

Local commissioners and providers should review this map alongside other audit maps (15, 16 and 18), the RCP End of life care audit – dying in hospital national report³. They should also consider data on local arrangements and systems to ensure that adults in the last days of life have a holistic assessment of their needs and individualised care plans. Opportunities should also be offered to discuss, develop and review these plans.

SECTION 2: THE ROLE OF HOSPITALS IN PALLIATIVE AND END OF LIFE CARE

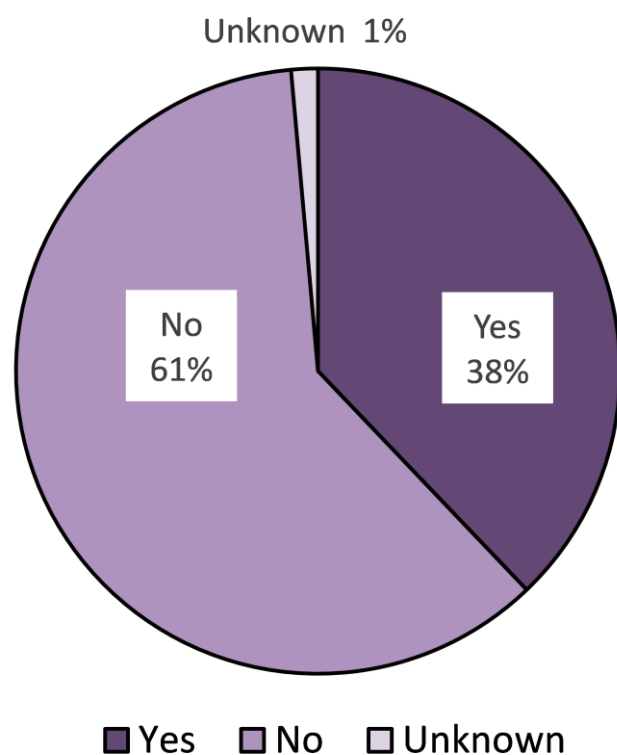
Map 18: Variation in provision of face-to-face access to specialist palliative care at least 9am to 5pm, Monday to Sunday by acute hospital trust site (2015)

Presence of provision



n =140 acute hospital sites in England. Please refer to the metadata guide for further details.

Variation in provision of face-to-face access to specialist palliative care at least 9am to 5pm, Monday to Sunday by acute hospital trust site (2015)



Introduction

The 5th of the 5 priorities of care for the dying person in 'One Chance to Get it Right'¹ set out the requirement for an individual care plan (map 17). The accompanying implementation guidance for service providers and commissioners states that 'there must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this' and that 'service providers and commissioners are expected to ensure provision for specialist palliative medical and nursing cover routinely 9am to 5pm 7 days a week and a 24 hour telephone advice service'.

This map reports on data from acute hospital sites across England collected by the Royal College of Physicians (RCP) End of life care audit – dying in hospital². The map and pie chart describes the analysis of this audit data.

Magnitude of variation

The RCP End of life care audit – dying in hospital, conducted in 2015 asked providers - 'Was there face-to-face access to specialist palliative care for at least 9am to 5pm, Monday to Sunday?'. Of the 140 acute hospital sites included in our analysis, 38% replied yes, 61% replied no and 1% did not reply.

The full audit report provides more data on specialist palliative care telephone advice provided by hospitals. 11% of trusts offered a 24/7 service, 39% offered only a Monday to Friday, 9am to 5pm service, and 49% offered a service covering more than Monday to Friday 9am to 5pm but less than 24/7².

Local considerations

Local commissioners and providers should review this map alongside the other audit maps (15, 16, 17), the RCP End of life care – dying in hospital national report². They should also look at data on local arrangements and systems to ensure access to specialist palliative medical and nursing cover - 9am - 5pm 7 days a week and a 24 hour telephone advice service. Additional guidance is provided in 'Specialist Level Palliative Care: Information for commissioners'³.

SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 19: Variation in the number of patients in need of palliative care/support, as recorded on GP disease registers per 100 deaths by CCG (2015/16)

Equal-sized quintiles by value

Highest	95.04 - 115.50	(2)
	74.56 - 95.03	(10)
	54.09 - 74.55	(28)
	33.62 - 54.08	(79)
Lowest	13.14 - 33.61	(90)

LONDON

Significance level compared with England

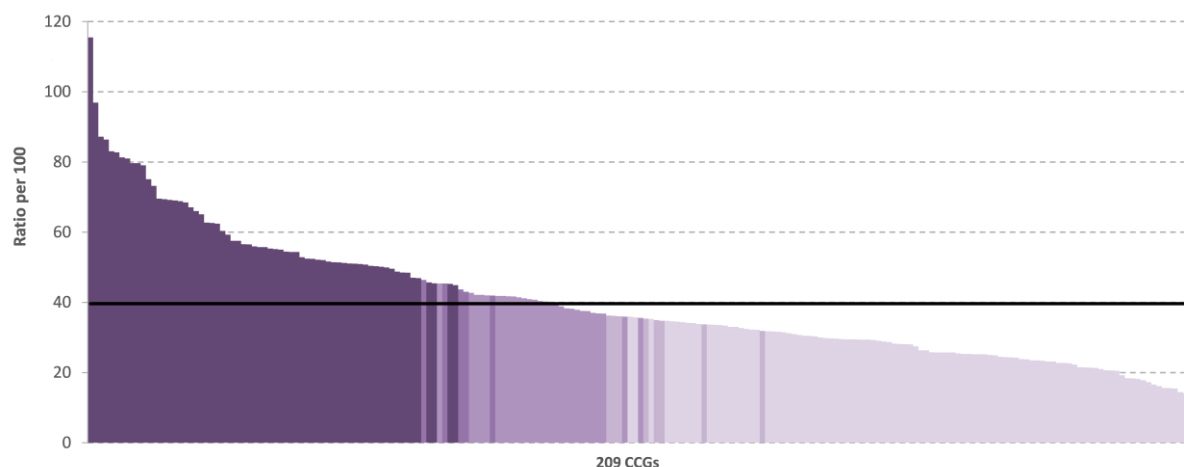
Significantly higher than England (99.8%)	(67)
Significantly higher than England (95.0%)	(5)
Not significantly different from England	(28)
Significantly lower than England (95.0%)	(8)
Significantly lower than England (99.8%)	(101)

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Variation in the number of patients in need of palliative care/support, as recorded on GP disease registers per 100 deaths by CCG (2015/16)



Introduction

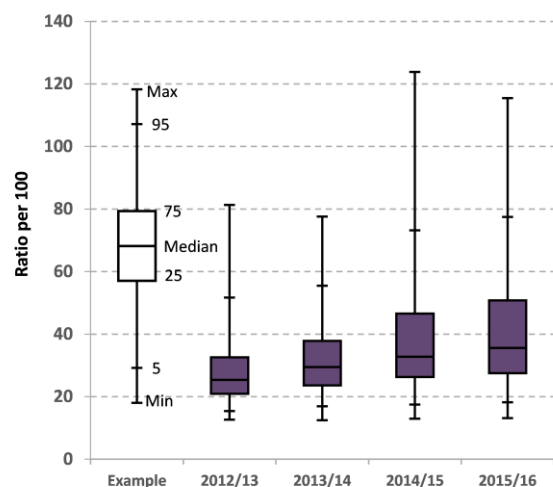
This indicator is a proxy indicator of the extent to which patients are being recognised by their general practitioner (GP) as approaching the end of life and discussions are being held to consider care options and plans. High values suggest a comprehensive approach to identifying patients. A low value could impact on the ability to co-ordinate care and enable people to be cared for and die in their place of choosing. Approximately 75% of deaths are expected¹.

Trends and magnitude of variation

In England 2015/16 the number of patients in need of palliative care/support recorded on GP disease registers was 39.6 per 100 deaths. The variation was between 13.1 per 100 deaths and 115.5 per 100 deaths by CCG, an 8.8-fold difference. (The maximum value of 115.5 per 100 deaths indicates there is a CCG with more patients in need of palliative care/support recorded on GP disease registers than died in a single year). The median by CCG increased significantly from 25.4 per 100 deaths in 2012/13 to 35.6 per 100 deaths in 2015/16. The 75th to 25th percentile gap widened significantly between 2012/13 and 2015/16.

Local considerations

Commissioners and providers should review this map and underlying data in combination with other maps in particular map 23, the proportion of deaths in usual place of residence and maps 24 and 25, deaths at home and in a care home. Data for this Quality Outcome Framework (QOF) measure is provided at general practice level on the National General Practice profiles².



Max - Min (Range)		68.7	65.1	110.9	102.4	No significant change
95th - 5th Percentile		36.3	38.5	55.7	59.2	No significant change
75th - 25th Percentile		11.7	14.3	20.3	23.3	WIDENING Significant
Median		25.4	29.5	32.7	35.6	INCREASING Significant

SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 20: Variation in the proportion of all people who died in a hospice by CCG (2015)**Equal-sized quintiles by value**

Highest	10.66 - 13.26	(5)
	8.04 - 10.65	(34)
	5.43 - 8.03	(74)
	2.82 - 5.42	(75)
Lowest	0.19 - 2.81	(17)
No data		(4)

LONDON

Significance level compared with England

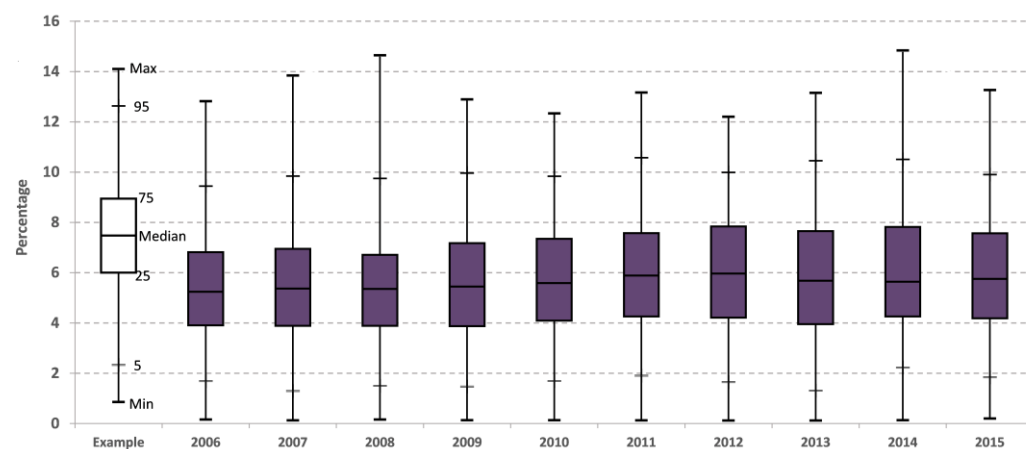
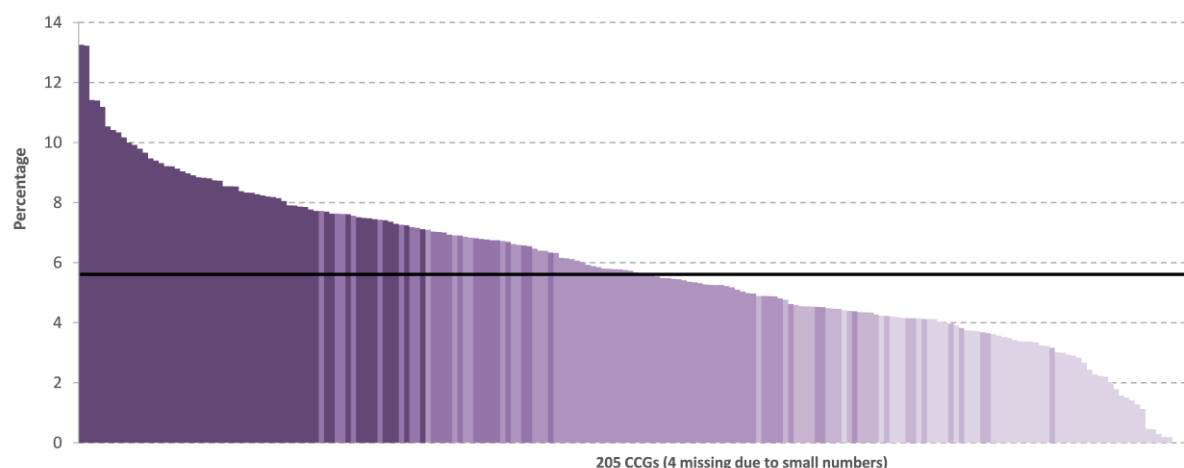
Significantly higher than England (99.8%)	(57)
Significantly higher than England (95.0%)	(22)
Not significantly different from England	(56)
Significantly lower than England (95.0%)	(23)
Significantly lower than England (99.8%)	(47)
No data	(4)

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Variation in the proportion of all people who died in a hospice by CCG (2015)



Max - Min (Range)		2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
95th - 5th Percentile		7.8	8.5	8.3	8.5	8.1	8.7	8.3	9.1	8.3	8.1	No significant change
75th - 25th Percentile		2.9	3.1	2.8	3.3	3.3	3.3	3.6	3.7	3.6	3.4	WIDENING Significant
Median		5.2	5.4	5.4	5.4	5.6	5.9	6.0	5.7	5.6	5.8	INCREASING Significant

Introduction

In a national survey, 8% of bereaved people believed the deceased wanted to die in a hospice¹. This is more than the percentage of deaths that actually occur there. In a few areas in England a hospice is located on the site of an acute hospital and deaths in these hospices are attributed to the hospital. In other parts of the country the hospice provides care in the community and at home rather than in a hospice building. There is no routine data available to accurately show the number of patients who die at home supported by a hospice but specialist palliative and hospice care is estimated to reach over a third of dying people². Hospices also provide some support to care homes mainly in the form of training and education and varying levels of clinical support³.

Trends and magnitude of variation

In England (2015), the proportion of deaths in a hospice was on average 5.6%, varying by CCG up to 13.3%. The CCG median increased significantly from 5.2% in 2006 to 5.8% in 2015 and the 75th to 25th percentile gap widened significantly.

Local considerations

Commissioners and providers should review this map and underlying data in combination with map 21, the proportion of deaths in hospice with a recorded cause of death as cancer. They should also consider local data on specialist palliative care provision – both inpatient and community. Additional guidance is provided in ‘Specialist Level Palliative Care: Information for commissioners’⁴.

SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 21: Variation in the proportion of all people that died in a hospice with a recorded cause of death as cancer by STP (2015)

Equal-sized quintiles by value

Highest	90.92 - 94.27	(9)
	87.55 - 90.91	(13)
	84.18 - 87.54	(16)
	80.81 - 84.17	(3)
Lowest	77.43 - 80.80	(3)

LONDON

Significance level compared with England

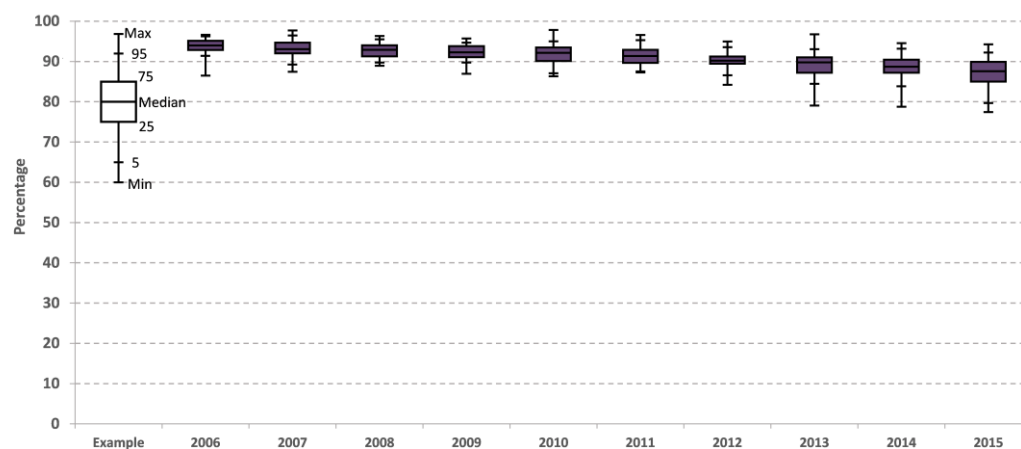
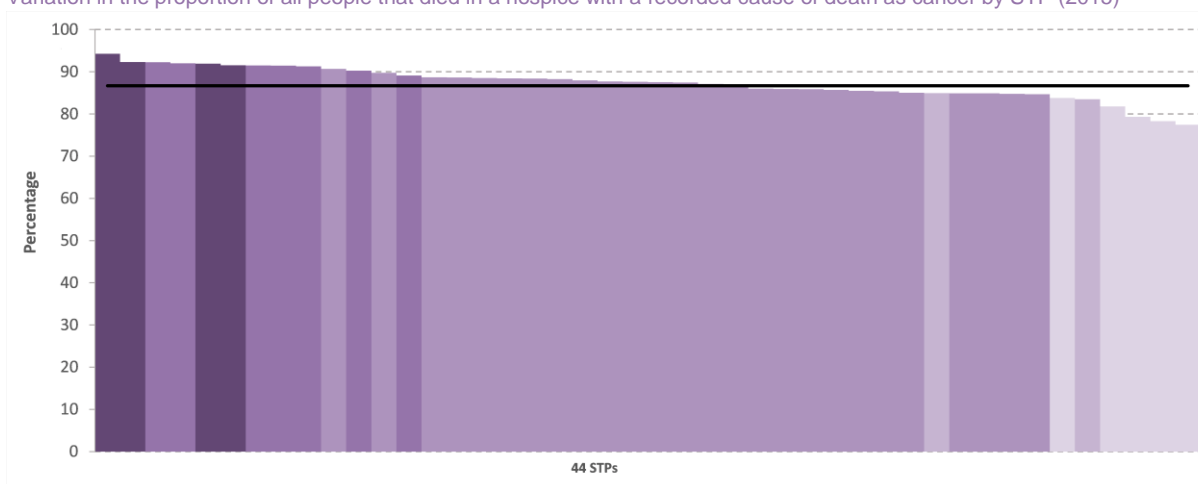
Significantly higher than England (99.8%)	(4)
Significantly higher than England (95.0%)	(7)
Not significantly different from England	(26)
Significantly lower than England (95.0%)	(2)
Significantly lower than England (99.8%)	(5)

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Variation in the proportion of all people that died in a hospice with a recorded cause of death as cancer by STP (2015)



	Example	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
Max - Min (Range)		10.1	10.3	7.4	8.8	11.5	9.3	10.7	17.7	15.8	16.8	WIDENING Significant
95th - 5th Percentile		4.9	7.2	5.8	5.0	7.9	7.8	7.0	8.6	9.3	12.5	WIDENING Significant
75th - 25th Percentile		2.3	2.7	2.7	2.7	3.4	3.3	1.8	3.8	3.2	4.9	WIDENING Significant
Median		94.0	93.1	92.9	92.3	92.1	91.4	90.2	89.8	88.7	87.6	DECREASING Significant

Introduction

Traditionally hospices have predominantly cared for people with cancer and currently about 9 in 10 of deaths in hospice have a recorded cause of cancer. Hospices also provide outreach care for people in their own home and in care homes, again mostly supporting cancer patients. The Care Quality Commission (CQC) encourages specialist palliative care services to take a proactive approach to meeting the needs of people with non-cancer conditions¹.

Trends and magnitude of variation

In England (2015), an average of 86.7% of deaths in a hospice had an underlying cause of death of cancer, with a variation by Sustainability and Transformation Partnership (STP) of between 77.4% and 94.3%, a 1.2-fold difference. The STP median decreased significantly from 94.0% in 2006 to 87.6% in 2015 and there has been significant widening of all 3 measures of variation.

Local considerations

Commissioners and providers should review this map and underlying data in combination with other maps in particular the proportion of deaths in hospice (map 20), cause of death (maps 4 to 9), and patients in need of palliative care/support recorded on GP disease registers (map 19). More detailed data on disease distribution at death and place of death are available from the End of life care profiles². In addition, they should consider local data on specialist palliative care provision and support for non-cancer patients, both inpatient and in the wider community.

SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 22: Variation in the proportion of all people who died in their usual place of residence by CCG (2015)

Equal-sized quintiles by value

Highest	51.26 - 56.95	(25)
	45.57 - 51.25	(76)
	39.87 - 45.56	(74)
	34.18 - 39.86	(26)
Lowest	28.47 - 34.17	(8)

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Significance level compared with England

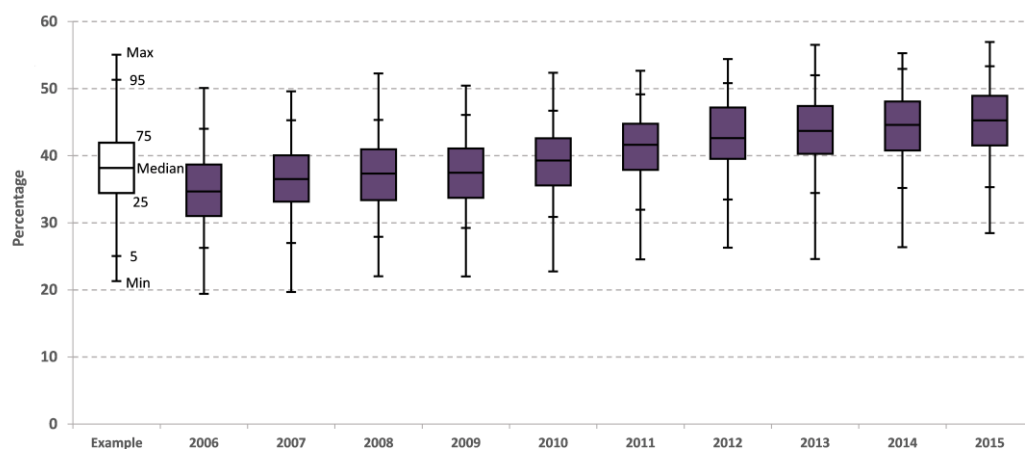
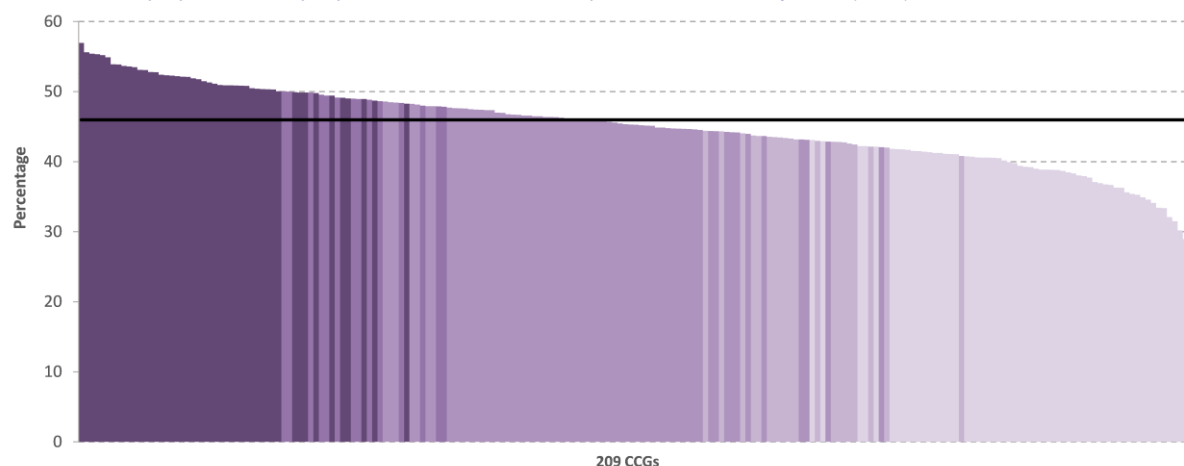
Significantly higher than England (99.8%)	(48)
Significantly higher than England (95.0%)	(14)
Not significantly different from England	(66)
Significantly lower than England (95.0%)	(20)
Significantly lower than England (99.8%)	(61)

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Variation in the proportion of all people who died in their usual place of residence by CCG (2015)



	Example	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
Max - Min (Range)		30.7	29.9	30.2	28.4	29.6	28.1	28.1	31.9	28.9	28.5	No significant change
95th - 5th Percentile		17.7	18.3	17.4	16.8	15.8	17.2	17.3	17.5	17.7	18.0	No significant change
75th - 25th Percentile		7.7	6.9	7.6	7.4	7.0	6.9	7.7	7.1	7.3	7.4	No significant change
Median		34.7	36.5	37.3	37.5	39.3	41.6	42.6	43.7	44.6	45.3	INCREASING Significant

Introduction

Surveys have suggested that many people would prefer to die at home¹. One of the aims of good end of life care is to respect patient choice². The End of life care strategy³ recognised the importance of people's preferences for where they chose to die. This measure was developed as a proxy indicator of patient choice and quality of end of life care and is still produced quarterly to support local planning⁴. It combines death at home with death in a care home. However, recent research shows that a care home is not the permanent home for up to a third of people who die in a care home⁵. Advance care plans and electronic palliative care co-ordination systems (EPaCCS) enable people's choices to be recorded and shared across hospital and community providers facilitating more people to die in their preferred place.

Trends and magnitude of variation

In England 2015, 46.0% of deaths occurred in usual place of residence with a variation by CCG from 28.5% and 56.9%, a 2.0-fold difference. The CCG median increased significantly from 34.7% in 2006 to 45.3% in 2015. There was no significant change in any of the 3 variation measures between 2006 and 2015.

Local considerations

Commissioners and providers should review this map and underlying data in combination with map 19 - patients in need of palliative care/support recorded on GP disease registers, map 28 - permanent care home residents who die in a care home, map 23 deaths at home and map 24 - deaths in a care home. The death in usual place of residence domain on the End of life care profiles⁶ provides detailed data on this measure.

SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 23: Variation in the proportion of people that died at home by CCG (2015)**Equal-sized quintiles by value**

Highest	27.73 - 30.11	(5)
	25.34 - 27.72	(25)
	22.96 - 25.33	(66)
	20.57 - 22.95	(81)
Lowest	18.17 - 20.56	(32)

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Significance level compared with England

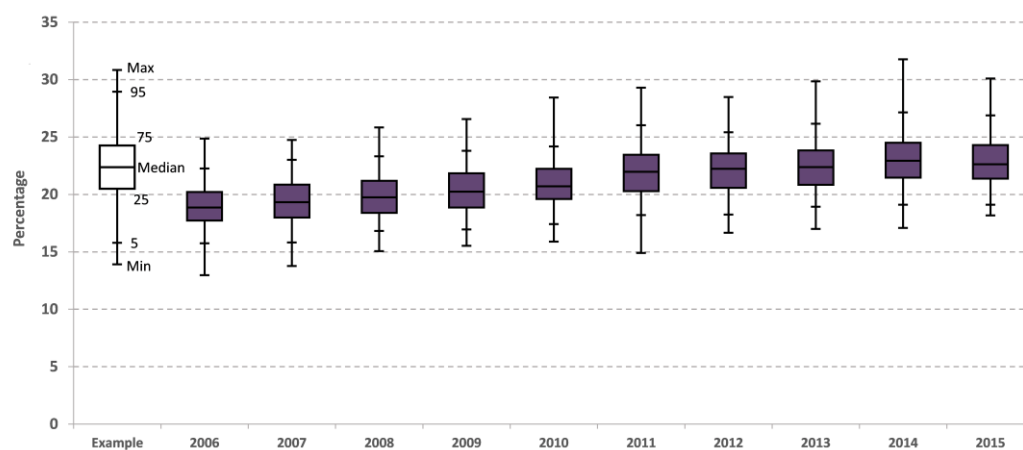
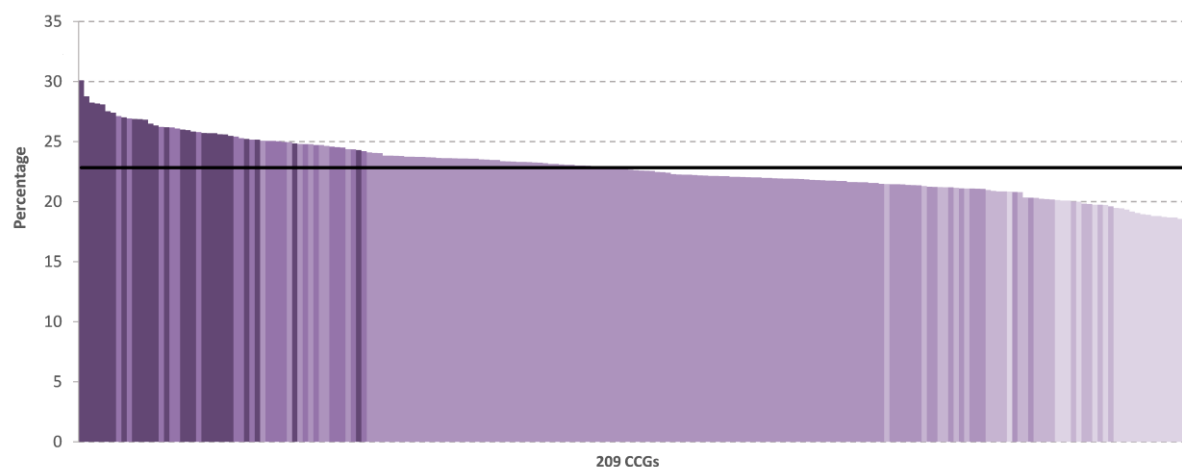
Significantly higher than England (99.8%)	(27)
Significantly higher than England (95.0%)	(20)
Not significantly different from England	(119)
Significantly lower than England (95.0%)	(21)
Significantly lower than England (99.8%)	(22)

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Variation in the proportion of people that died at home by CCG (2015)



Max - Min (Range)		11.9	11.0	10.8	11.0	12.6	14.4	11.8	12.8	14.7	11.9	No significant change
95th - 5th Percentile		6.5	7.2	6.5	6.8	6.8	7.8	7.2	7.2	8.1	7.8	WIDENING Significant
75th - 25th Percentile		2.5	2.9	2.8	3.0	2.6	3.2	3.0	3.0	3.0	2.9	No significant change
Median		18.9	19.3	19.7	20.2	20.7	22.0	22.2	22.4	22.9	22.6	INCREASING Significant

Introduction

A national survey reported that many people would prefer to die at home if they have sufficient support¹. The evidence is not clear that this is the preference of the majority². Indeed some research suggests that the quality of end of life care in the home can be compromised if adequate support services are not available, for example, a national survey of the bereaved reported that pain relief was less effective in the home setting compared with hospitals, care homes and hospice³. The Ambitions framework recommends that good end of life care at home requires co-ordinated access to resources and support of carers⁴.

Trends and magnitude of variation

In England (2015), 22.8% of deaths occurred at home, with a variation by CCG of between 18.2% and 30.1%, a 1.7-fold difference.

The CCG median increased significantly from 18.9% in 2006 to 22.6% in 2015. The 95th to 5th percentile gap widened significantly.

Local considerations

Commissioners and providers should review this map and underlying data in combination with map 19, patients in need of palliative care/support recorded on GP disease registers and demographic data (maps 1 to 3). In addition they should explore local data on community specialist palliative and social care home services.

SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 24: Variation in the proportion of people that died in a care home by CCG (2015)**Equal-sized quintiles by value**

Highest	28.82 - 34.35	(19)
	23.28 - 28.81	(69)
	17.74 - 23.27	(73)
	12.20 - 17.73	(35)
Lowest	6.65 - 12.19	(13)

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Significance level compared with England

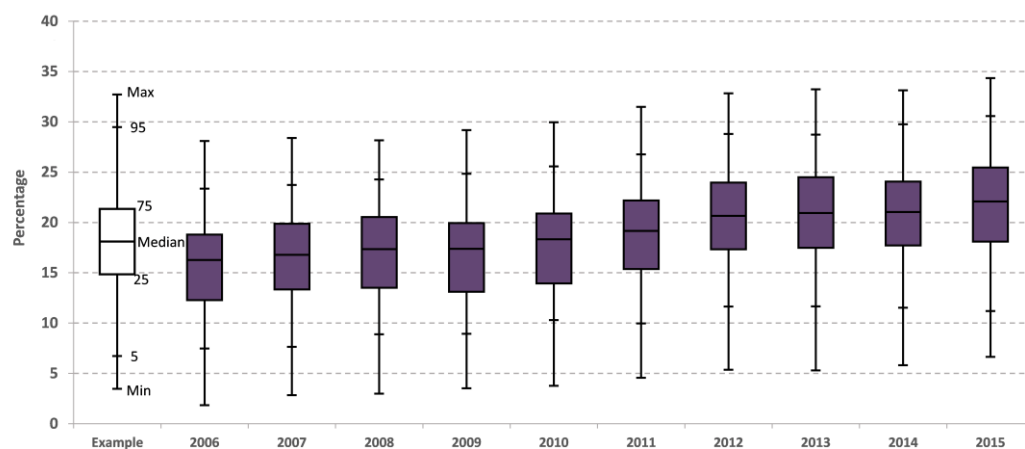
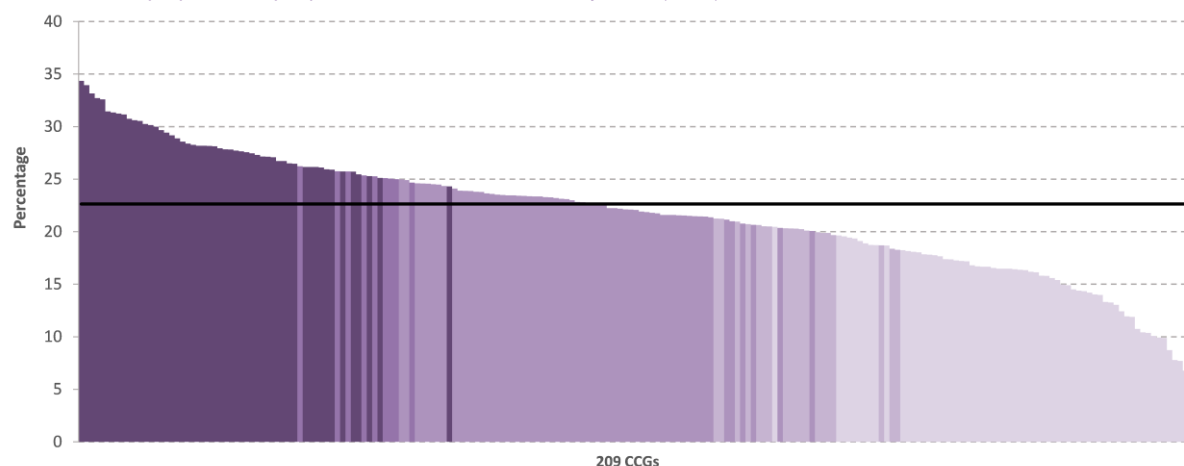
Significantly higher than England (99.8%)	(53)
Significantly higher than England (95.0%)	(9)
Not significantly different from England	(63)
Significantly lower than England (95.0%)	(19)
Significantly lower than England (99.8%)	(65)

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Variation in the proportion of people that died in a care home by CCG (2015)



	Example	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
Max - Min (Range)		26.3	25.6	25.2	25.7	26.2	26.9	27.5	27.9	27.3	27.7	WIDENING Significant
95th - 5th Percentile		15.9	16.1	15.4	15.9	15.3	16.8	17.2	17.1	18.2	19.4	WIDENING Significant
75th - 25th Percentile		6.5	6.5	7.0	6.8	6.9	6.8	6.6	7.0	6.3	7.4	No significant change
Median		16.3	16.8	17.4	17.4	18.3	19.2	20.7	20.9	21.0	22.1	INCREASING Significant

Introduction

Care homes (residential and nursing homes combined) look after some of the most vulnerable in society. Older people are more likely to live and die in this setting¹. It is therefore important that commissioners and planners consider the provision of palliative and end of life care in care homes. There has been concerted effort by improvement programmes² and training from specialist palliative care providers to improve the quality of end of life care in care homes³. More than half of all deaths with dementia recorded as a contributory cause of death occur in a care home. CQC have expressed concern at recent falls in the availability of nursing home beds in the context of increased demands of an ageing population and increasing number of deaths⁴.

Trends and magnitude of variation

In England 2015, an average of 22.6% of deaths occurred in a care home, with a variation of between 6.7% and 34.4% by CCG, a 5.2-fold difference. The CCG median increased significantly from 16.3% in 2006 to 22.1% in 2015. Both the maximum to minimum range and the 95th to 5th percentile gap widened significantly.

Local considerations

Commissioners and providers should review this map and underlying data in combination with other maps in particular map 25 the population in care homes, maps 26 and 27 describing the availability of care home/nursing home beds together with maps 29 and 30 which describe the residential status of people who die in care homes. Additional data can be found in the care home domain in the End of life care profiles⁵ and 'The framework for enhanced health in care homes' provides guidance⁶.

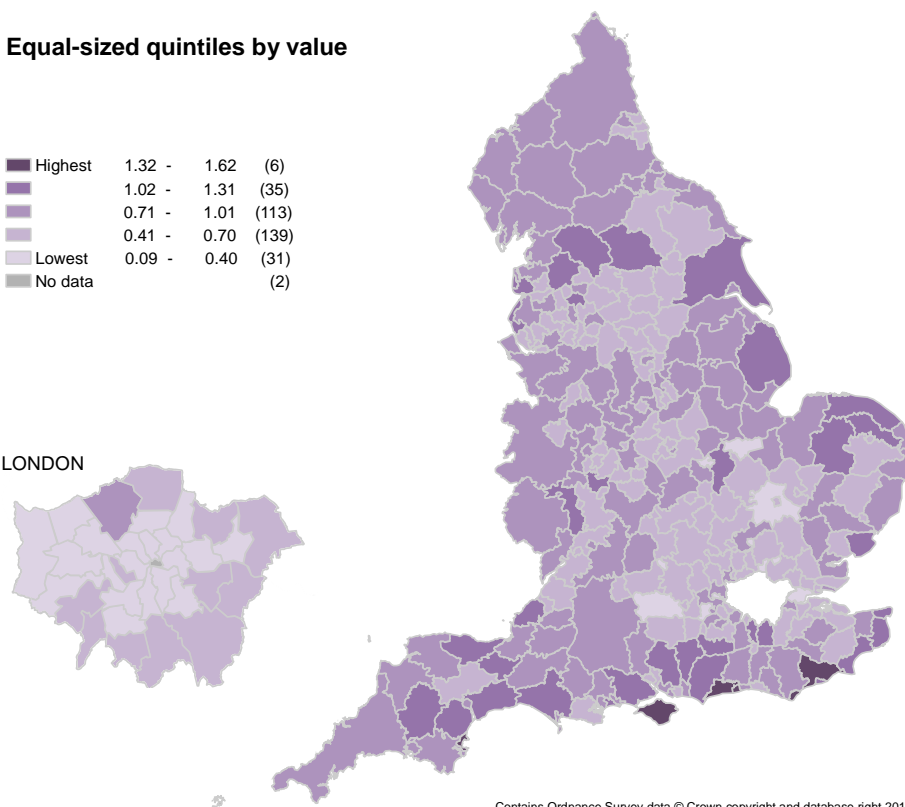
SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 25: Variation in the proportion of the population who are living in a care home by lower tier local authority (2011)

Equal-sized quintiles by value

Highest	1.32 - 1.62	(6)
	1.02 - 1.31	(35)
	0.71 - 1.01	(113)
	0.41 - 0.70	(139)
Lowest	0.09 - 0.40	(31)
No data		(2)

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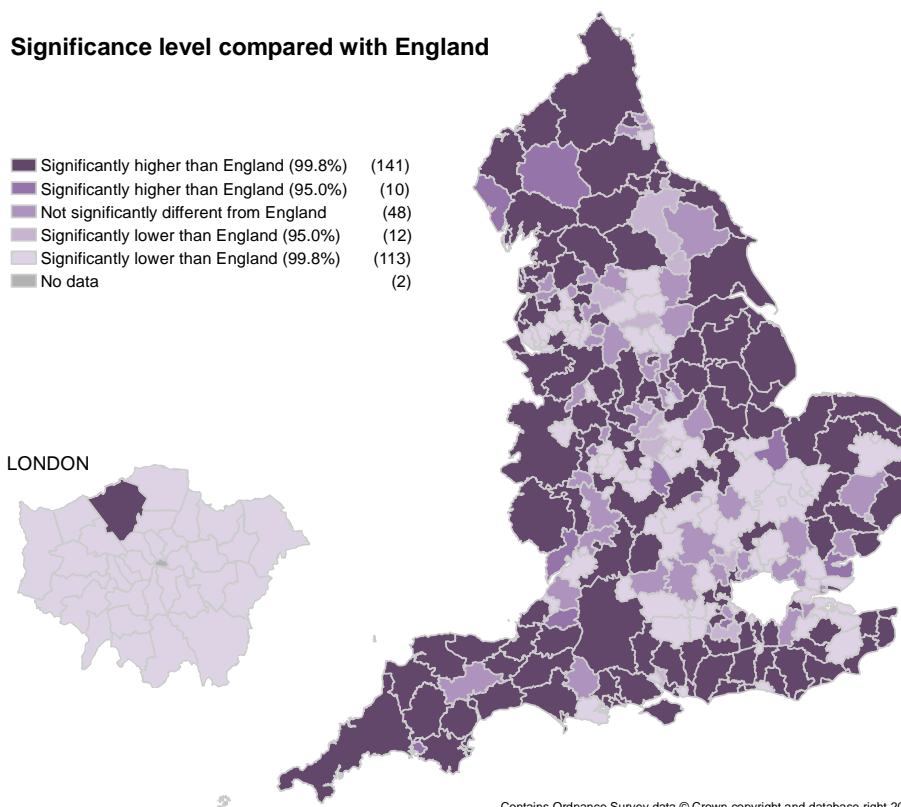


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Significance level compared with England

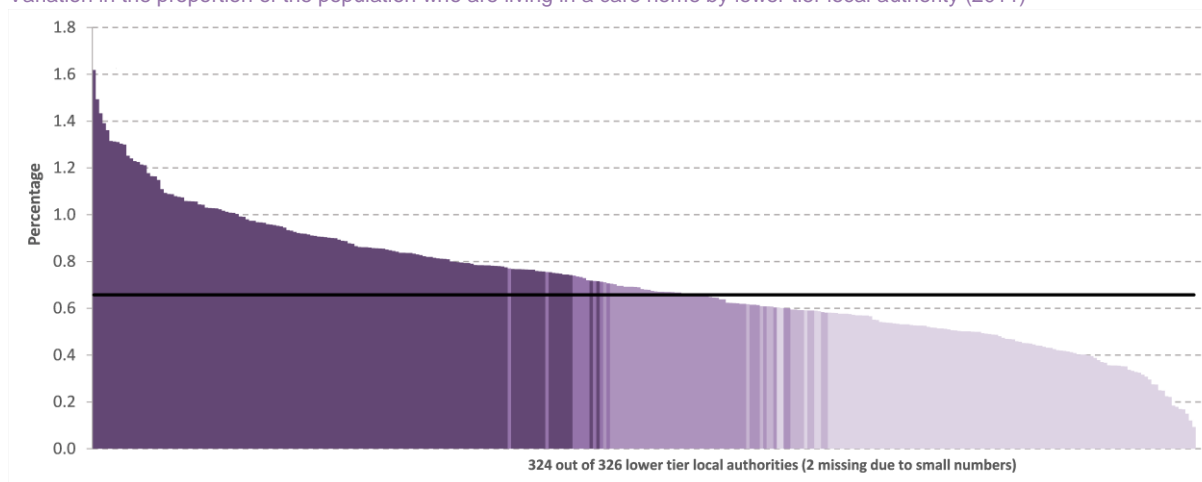
Significantly higher than England (99.8%)	(141)
Significantly higher than England (95.0%)	(10)
Not significantly different from England	(48)
Significantly lower than England (95.0%)	(12)
Significantly lower than England (99.8%)	(113)
No data	(2)

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Variation in the proportion of the population who are living in a care home by lower tier local authority (2011)



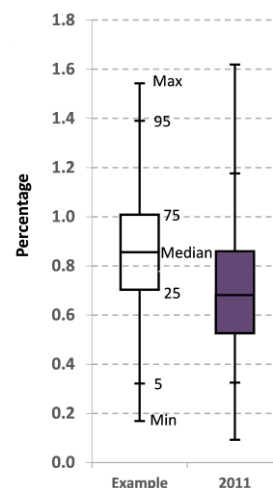
Introduction

Over the past decade the size of the care home population has remained stable¹. This population is ageing, and although most residents are women, the gender gap is closing¹. The number of people who live in care homes will vary, amongst other things, according to the age and health of the local population and the availability of care home places. It is anticipated that the demand for care home beds will increase².

Care Quality Commission (CQC) have expressed concern at recent falls in the availability of nursing home beds in the context of increased demands of an ageing population².

Magnitude of variation

In England (2011), 0.7% of the adult population were living in a care home and aged 65 or older, with a variation of between 0.1% and 1.6% by local authority, a 17.5-fold difference. The median value by local authority was 0.7%.



Max - Min (Range)		1.5
95th - 5th Percentile		0.9
75th - 25th Percentile		0.3
Median		0.7

Local considerations

Commissioners and providers should review this map and underlying data in combination with care homes map (24-29), demographics data (maps 1, 2 and 10), deaths with dementia (map 5) and appendix 2 projected deaths for 2030. Additional data is also available from PHE's suite of analytical resources describing the role of care homes in end of life care³.

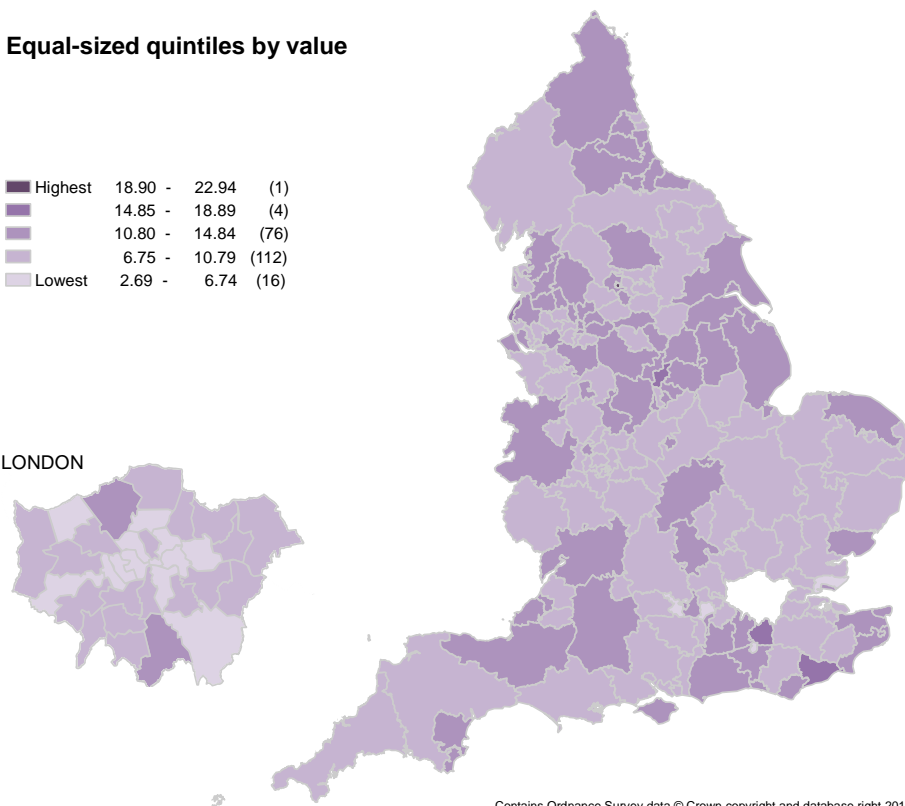
SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 26: Variation in the number of care home beds per 100 people living who are aged 75 years or older by CCG (2017)

Equal-sized quintiles by value

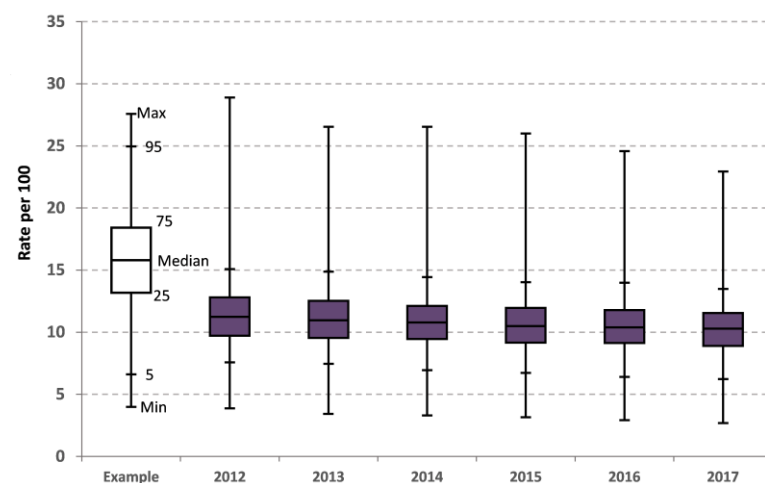
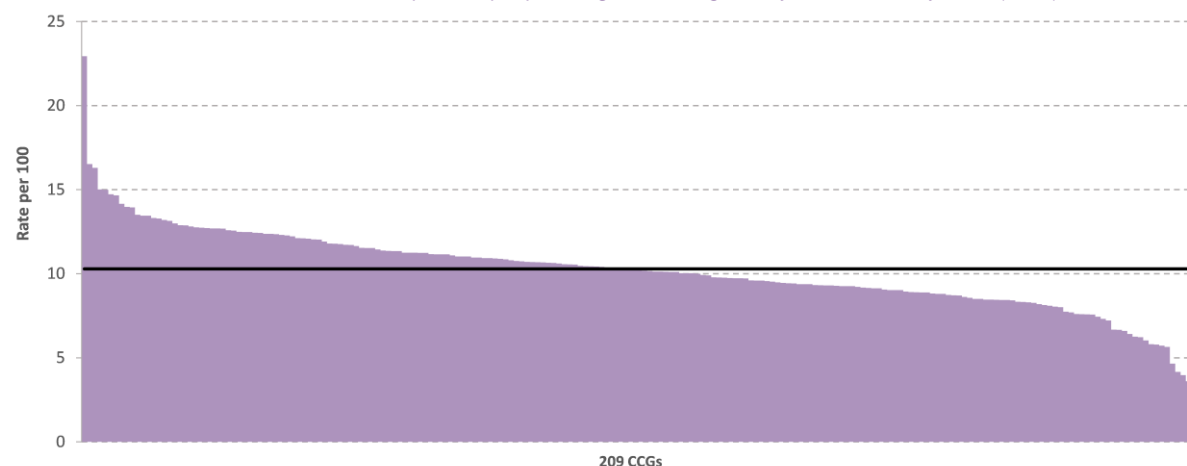
Highest	18.90 - 22.94	(1)
	14.85 - 18.89	(4)
	10.80 - 14.84	(76)
	6.75 - 10.79	(112)
Lowest	2.69 - 6.74	(16)

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Variation in the number of care home beds per 100 people living who are aged 75 years or older by CCG (2017)



Max - Min (Range)		25.0	23.1	23.2	22.8	21.7	20.3	NARROWING Significant
95th - 5th Percentile		7.5	7.4	7.5	7.3	7.6	7.2	No significant change
75th - 25th Percentile		3.1	3.0	2.7	2.8	2.7	2.6	NARROWING Significant
Median		11.2	11.0	10.8	10.5	10.4	10.3	DECREASING Significant

Introduction

It has been estimated that demographic factors may increase demand for care home beds by as much as 71,000 by 2025¹. This indicator uses data from Care Quality Commission (CQC) to describe the availability of care home beds (residential and nursing homes) in comparison with the size of the older population. This gives a crude measure of care home bed availability. The total beds available have remained broadly stable since 2010². Many factors determine the number of care home beds, not only need but local policy too. In recent years some localities placed more emphasis on providing care in people's own homes. There are also complex economic and staffing dynamics which affect the relationship between residential and nursing home beds.

Trends and magnitude of variation

In England (2017) there were 10.3 care home beds for every 100 people aged 75 years or older with a variation by CCG of between 2.7 to 22.9, an 8.5-fold difference.

The CCG median decreased significantly from 11.2 in 2012 to 10.3 in 2017. Both the maximum to minimum range and the 75th to 25th percentile gap narrowed significantly.

Local considerations

Commissioners and providers should review this map and underlying data in combination with map 25 the population living in care homes and map 1 deaths aged 75 and older. Data on care homes is available in the care home domain on the End of life care profiles³. Additional data is also available from PHE's suite of analytical resources describing the role of care homes in end of life care⁴.

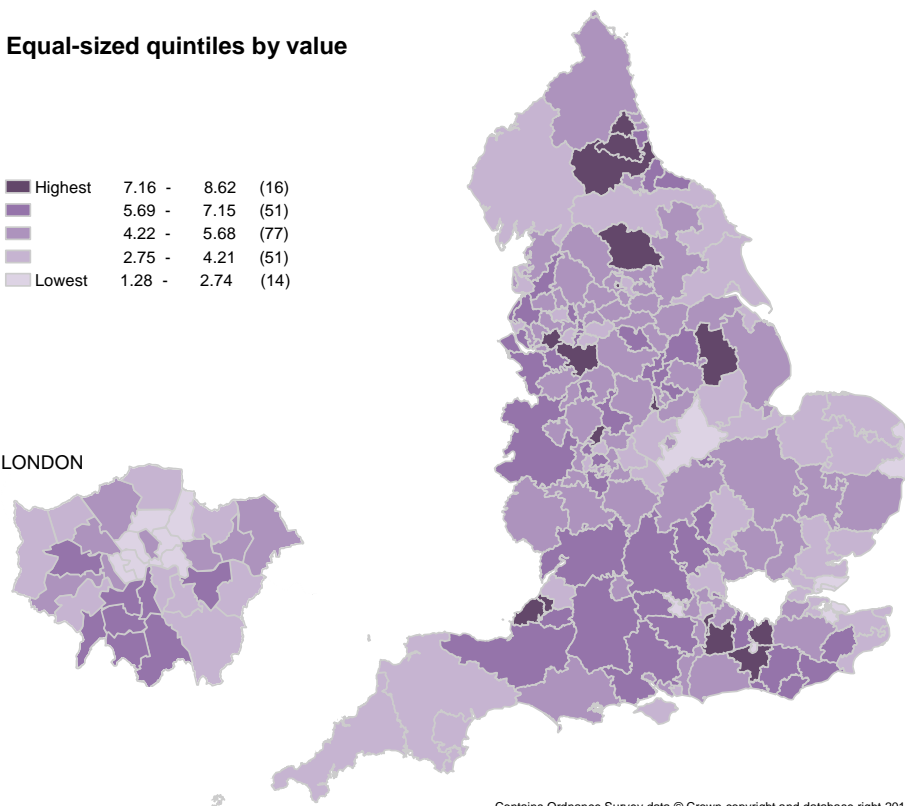
SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 27: Variation in the number of nursing home beds per 100 people living who are aged 75 years or older by CCG (2017)

Equal-sized quintiles by value

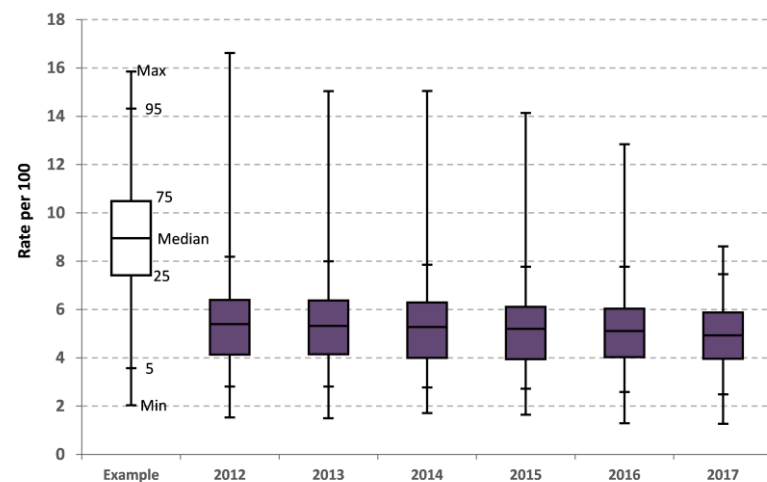
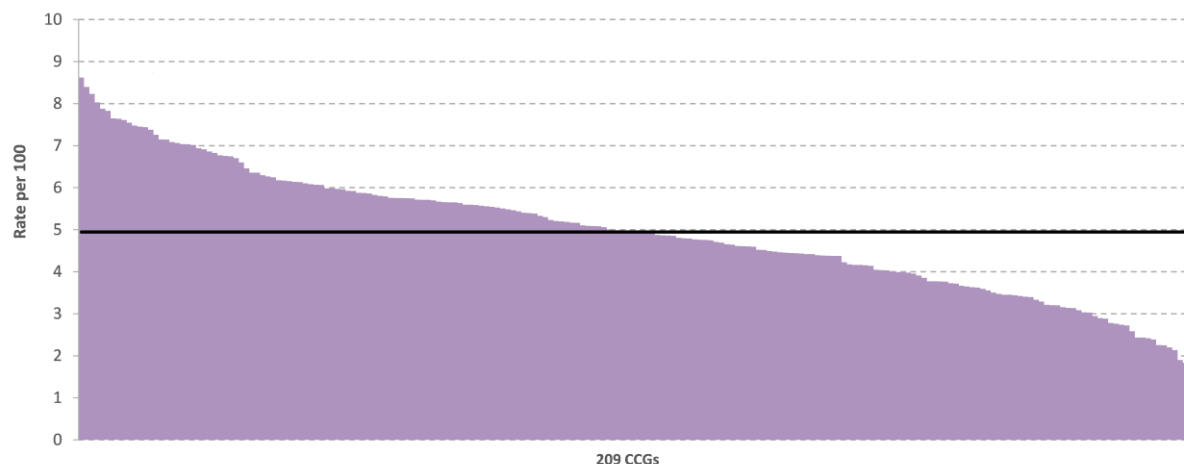
Highest	7.16 - 8.62	(16)
	5.69 - 7.15	(51)
	4.22 - 5.68	(77)
	2.75 - 4.21	(51)
Lowest	1.28 - 2.74	(14)

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Variation in the number of nursing home beds per 100 people living who are aged 75 years or older by CCG (2017)



Max - Min (Range)		15.1	13.5	13.3	12.5	11.5	7.3	NARROWING Significant
95th - 5th Percentile		5.4	5.2	5.1	5.0	5.2	5.0	No significant change
75th - 25th Percentile		2.3	2.2	2.3	2.2	2.0	1.9	NARROWING Significant
Median		5.4	5.3	5.3	5.2	5.1	4.9	DECREASING Significant

Introduction

This indicator uses data from the Care Quality Commission (CQC) to describe the availability of nursing home beds in comparison with the size of the older population to give a measure of nursing home bed availability. The underlying total of nursing home beds available has increased since 2010 although this trend came to a halt in 2015 and in 2017 the total had fallen back to the number of beds available in 2014¹. CQC reported concern in 2017 that although 67% of nursing homes were rated as good and 1% as outstanding, 29% were rated as requires improvement and 3% as inadequate. Considerable regional variation in care quality was also identified¹. This comes at a time of considerable financial stress for care homes in general and questioning of many homes' continuing viability².

Trend and magnitude of variation

In England (2017), there was on average 4.9 beds in nursing homes for every 100 people aged 75 or older. Variation by CCG was between 1.3 and 8.6, a 6.8-fold difference.

The CCG median decreased significantly from 5.4 in 2012 to 4.9 in 2017. Both the maximum to minimum range and the 75th to 25th percentile gap narrowed significantly.

Local considerations

Commissioners and providers should review this map and underlying data in combination with other maps in particular map 25 the population living in care homes, map 26 the care home bed rate and map 1 deaths aged 75 and older. Data on care homes is available in the care home domain on the End of life care profiles³. Additional data is also available from PHE's suite of analytical resources describing the role of care homes in end of life care⁴.

SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 28: Variation in the proportion of care home residents that died in a care home by CCG (2015)

Equal-sized quintiles by value

Highest	75.93 - 83.78	(39)
	68.08 - 75.92	(91)
	60.22 - 68.07	(61)
	52.37 - 60.21	(15)
Lowest	44.50 - 52.36	(3)

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Significance level compared with England

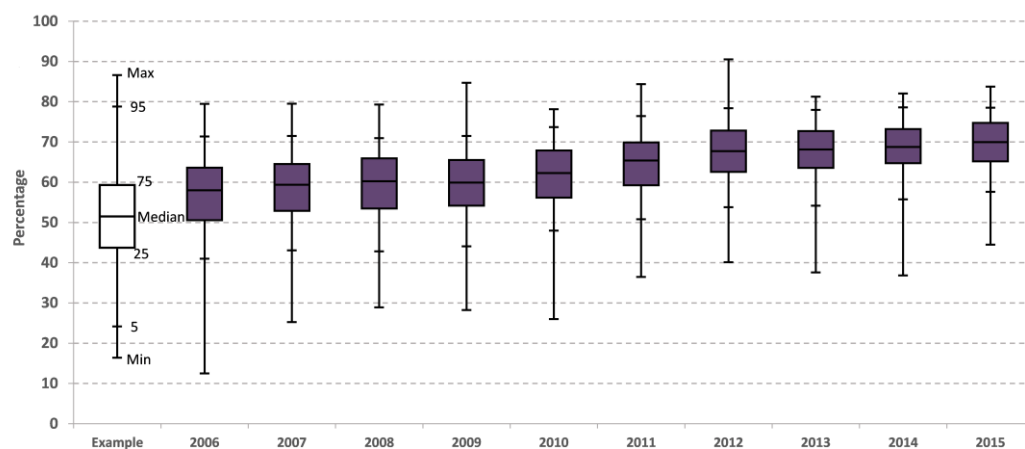
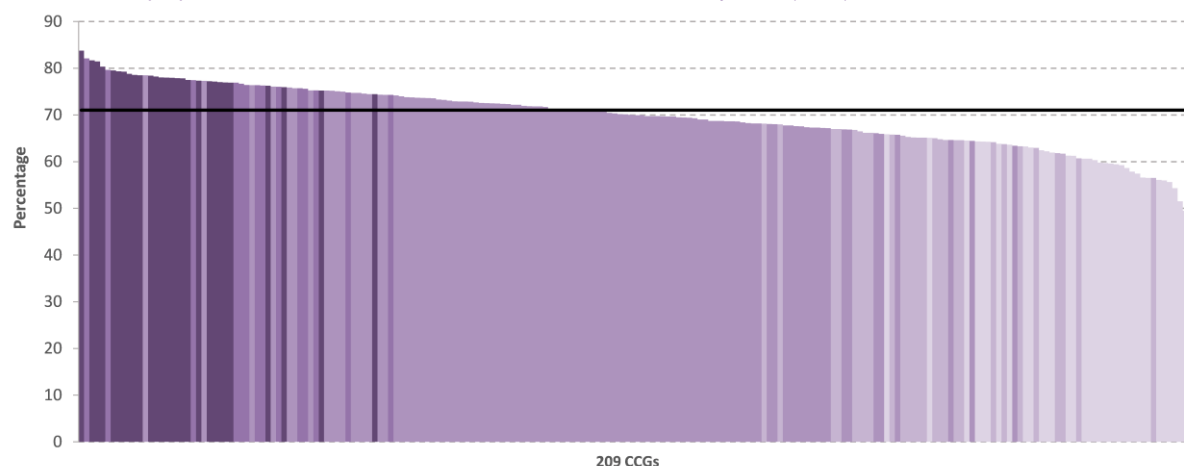
Significantly higher than England (99.8%)	(28)
Significantly higher than England (95.0%)	(14)
Not significantly different from England	(105)
Significantly lower than England (95.0%)	(27)
Significantly lower than England (99.8%)	(35)

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Variation in the proportion of care home residents that died in a care home by CCG (2015)



	Example	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
Max - Min (Range)		67.0	54.2	50.4	56.5	52.2	47.9	50.4	43.7	45.2	39.3	NARROWING Significant
95th - 5th Percentile		30.4	28.4	28.1	27.4	25.7	25.6	24.6	23.8	22.9	20.9	NARROWING Significant
75th - 25th Percentile		13.0	11.6	12.5	11.3	11.7	10.6	10.3	9.2	8.5	9.5	NARROWING Significant
Median		58.0	59.4	60.2	59.9	62.3	65.4	67.7	68.1	68.8	70.0	INCREASING Significant

Introduction

Good advance care planning in care homes will include acknowledgement of the likelihood of death, opportunities to discuss and record the preferences of residents approaching end of life, ongoing review of a resident's needs, access to staff training¹, and enhanced collaboration with GPs and palliative care specialists². These initiatives should reduce hospital admissions and hospital deaths³. A higher value is likely in areas with consistently good quality palliative and end of life care in care homes.

Trends and magnitude of variation

In England (2015), an average of 71.0% of the deaths of permanent care home residents occurred in a care home, with a variation of between 44.5% and 83.8% by CCG, a 1.9-fold difference.

The CCG median increased significantly from 58.0% in 2006 to 70.0% in 2015. There has been significant narrowing of all 3 measures of variation.

Local considerations

Commissioners and providers should review this map and underlying data in combination with other maps in particular 3 or more emergency hospital admissions (map 13), the population living in care homes (map 25) and the proportion of deaths in care homes (map 24) together with the care home bed rate (map 26). Additional data on care homes is available in the care home domain on the End of life care profiles⁴. PHE have published a suite of analytical resources describing the role of care homes in end of life care⁵.

SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 29: Variation in the proportion of people who died in a care home who were temporary residents by CCG (2015)

Equal-sized quintiles by value

Highest	57.47 - 67.39	(1)
	47.54 - 57.46	(8)
	37.61 - 47.53	(45)
	27.67 - 37.60	(114)
Lowest	17.73 - 27.66	(41)

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Significance level compared with England

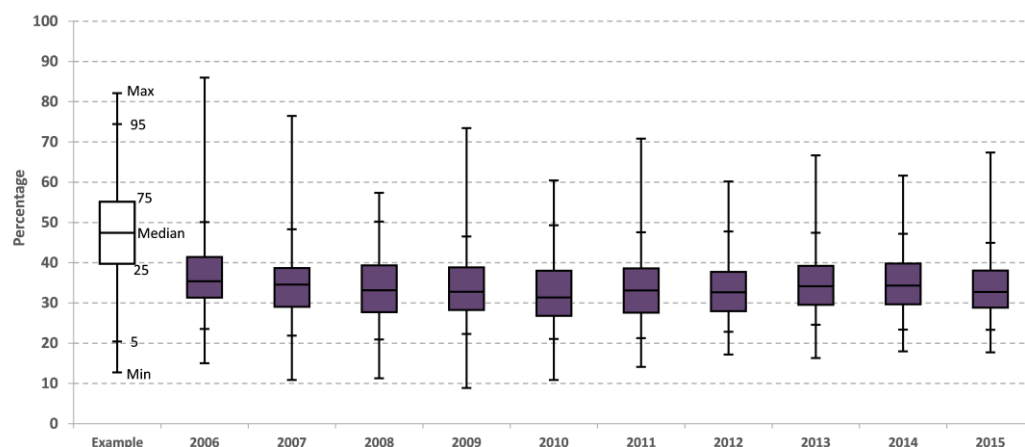
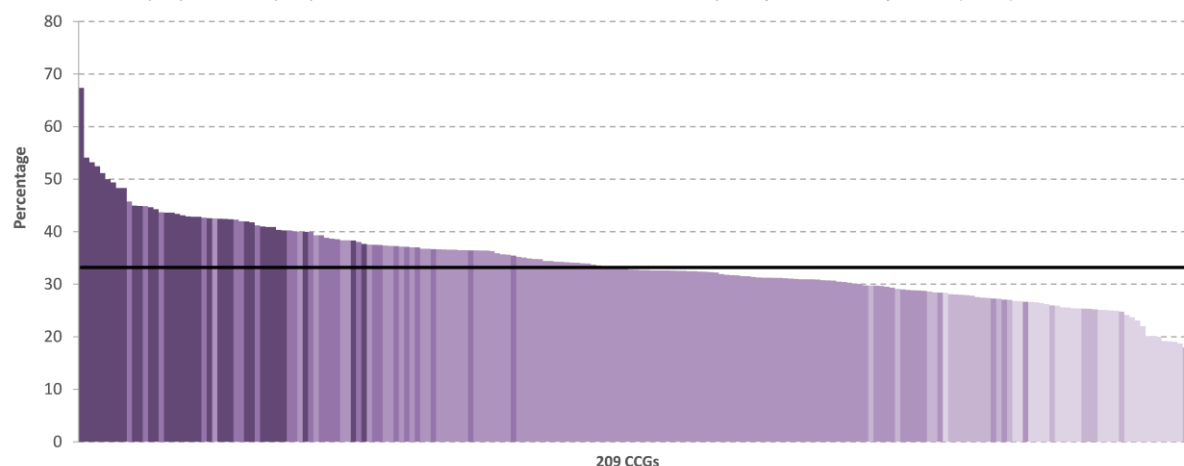
Significantly higher than England (99.8%)	(34)
Significantly higher than England (95.0%)	(23)
Not significantly different from England	(104)
Significantly lower than England (95.0%)	(20)
Significantly lower than England (99.8%)	(28)

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Variation in the proportion of people who died in a care home who were temporary residents by CCG (2015)



	Example	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	
Max - Min (Range)		70.9	65.6	46.0	64.6	49.5	56.7	43.0	50.3	43.7	49.7	NARROWING Significant
95th - 5th Percentile		26.6	26.4	29.3	24.2	28.2	26.3	24.9	22.9	23.8	21.6	NARROWING Significant
75th - 25th Percentile		10.1	9.7	11.6	10.6	11.2	11.0	9.8	9.7	10.1	9.2	No significant change
Median		35.4	34.6	33.2	32.8	31.4	33.1	32.6	34.1	34.3	32.7	No significant change

Introduction

Not everyone who dies in a care home is a permanent resident of that care home – referred to as ‘temporary care home residents’. Temporary admission to a care home may occur following discharge from hospital during a terminal illness, when someone needs short term support recuperating from an illness or for a trial period to decide whether they want to live permanently in a care home. About a third of people who die in care homes are temporary residents and they differ from the permanent residents. They are younger and more likely to have a cancer diagnosis¹.

Trends and magnitude of variation

In England (2015), 33.2% of deaths in care homes were temporary residents with a variation by CCG of between 17.7% and 67.4%, a 3.8-fold difference.

The CCG median in 2015 was 32.7% and the maximum to minimum range and the 95th to 5th percentile gap narrowed significantly between 2006 and 2015.

Local considerations

Commissioners and providers should review this map and underlying data in combination with other maps in particular map 24 the proportion of deaths in a care home and map 25 the care home population. They should review their hospital discharge policies to care homes and the impact of quality of end of life care. Additional data on care homes is available in the care home domain on the End of life care profiles². PHE have published a suite of analytical resources describing the role of care homes in end of life care³.

The map references

SECTION 1: NEED FOR PALLIATIVE AND END OF LIFE CARE

Map 1: Variation in the proportion of all people who died who were aged 75 years and older by CCG (2015)

None.

Map 2: Variation in the proportion of adults who are aged 65 years or older and who are living alone by lower tier local authority (2011)

¹ Age UK Information and advice [Loneliness](#) [Accessed August 2018]

² British Red Cross [Action on Loneliness](#) [Accessed August 2018]

³ [Campaign to End Loneliness](#) [Accessed August 2018]

⁴ NHS England [Social prescribing](#) [Accessed 2018]

Map 3: Variation in the proportion of the population aged 16 years or older who are unpaid carers by CCG (2011)

¹ Schonegevel L (2013) [Macmillan Briefing on Carers Issues](#) [Accessed August 2018]

² NHS England & NHS Improving Quality (2014) [Commitment for Carers: Report of the findings and outcomes](#) [Accessed August 2018]

³ NHS [Your guide to care and support](#) [Accessed August 2018]

Map 4: Variation in the proportion of all people who died with an underlying cause of cancer by CCG (2015)

¹ National Institute for Health and Care Excellence (NICE) Conditions and diseases: [Cancer](#) [Accessed August 2018]

² National Cancer Registration and Analysis Service (2015) [Older People and Cancer report](#) [Accessed August 2018]

³ Pinder RJ, Ferguson J, Moller, H (2016) [Minority ethnicity patient satisfaction and experience: results of the National Cancer Patient Experience Survey in England](#) [Accessed August 2018]

⁴ PHE [End of Life Care Profiles](#) [Accessed August 2018]

Map 5: Variation in the proportion of all people who died with an underlying or contributory cause of dementia by CCG (2015)

¹ National Institute for Health and Care Excellence (NICE) (2018) [Dementia: assessment, management and support for people living with dementia and their carers](#) Guideline NG27 [Accessed August 2018]

² NHS England (2017) [Implementation guide and resource pack for dementia care](#) [Accessed August 2018]

³ PHE [Dementia Profile](#) [Accessed August 2018]

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⁵ PHE [End of Life Care Profiles](#) [Accessed August 2018]

⁶ National Institute for Health and Care Excellence (NICE) (2010) [Dementia: support in health and social care](#) QS1 [Accessed August 2018]

Map 6: Variation in the proportion of all people who died with an underlying cause of chronic heart disease by CCG (2015)

- ¹ Buetow SA, Coster GD (2001) [Do general practice patients with heart failure understand its nature and seriousness, and want improved information?](#) Patient Education and Counseling 45:181-185 [Accessed August 2018]
- ² Hospice UK (2017) [Heart failure and hospice care](#) [Accessed August 2018]
- ³ Cheang MH, Rose G, and others (2015) [Current challenges in palliative care provision for heart failure in the UK: a survey on the perspectives of palliative care professionals](#) Open Heart 2015;15;2(1):e000188. doi: 10.1136/openhrt-2014-000188. eCollection [Accessed August 2018]
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- ⁵ Johnson MJ, Nunn A, Hawkes T and others (2012) [Planning for end of life care in people with heart failure: experience of two integrated cardiology-palliative care teams](#) British Journal of Cardiology; 19(2):71-5 [Accessed August 2018]
- ⁶ Bränström M, Boman K (2014) [Effects of person centred and integrated chronic heart failure and palliative home care. PREFER: a randomised controlled study](#) Eur J Heart Fail 16: 1142–115 [Accessed August 2018]
- ⁷ National Institute of Health and Care Excellence (NICE) (2018) [Chronic heart failure in adults: diagnosis and management. Draft guidelines for consultation](#) [Accessed August 2018]
- ⁸ Resuscitation Council (UK) the British Cardiovascular Society and the National Council for Palliative Care (2015) [Deactivation of implantable cardioverter-defibrillators towards the end of life](#) [Accessed August 2018]
- ⁹ PHE National Cardiovascular Intelligence Network (NCVIN) [Cardiovascular disease data and analysis: guide for health professionals](#) [Accessed August 2018]

Map 7: Variation in the proportion of all people who died with an underlying or contributory cause of chronic obstructive pulmonary disease (COPD) by CCG (2015)

- ¹ Edmonds P, Karlsen S, Khan S and others (2001) [A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer](#) Palliat Med Jul;15(4):287-95. [Accessed August 2018]
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- ³ Hayles C, Coventry PA, Gomm S and others (2009) [Understanding the experience of patients with chronic obstructive pulmonary disease who access specialist palliative care: A qualitative study](#) [Accessed August 2018]
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- ⁶ Higginson IJ, Reilly CC, Bajwah S and others on behalf of the GUIDE_Care project (2017) [Which patients with advanced respiratory disease die in hospital? A 14-year population-based study of trends and associated factors](#) BMC Medicine 15:19 [Accessed August 2018]
- ⁷ PHE [Interactive Health Atlas of Lung conditions in England](#) [Accessed August 2018]

Map 8: Variation in the proportion of people who died with an underlying cause of stroke by CCG (2015)

- ¹ Intercollegiate Stroke Working Party (2016) [Sentinel Stroke National Audit Programme Annual Results Portfolio](#) London [Accessed August 2018]
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- ³ Royal College of Physicians (2016) [National Clinical Guideline for Stroke 2016 Fifth Edition](#) [Accessed August 2018]
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- ⁵ PHE [Cardiovascular disease profiles](#) [Accessed August 2018]
- ⁶ PHE and NHS RightCare (2017) [The 2nd Atlas of Variation in NHS Diagnostic Services in England](#) [Accessed August 2018]

Map 9: Variation in the proportion of all people who died with an underlying cause of liver disease by CCG (2015)

- ¹ PHE and NHS RightCare (2017) [The 2nd Atlas of Variation in risk factors and healthcare for liver disease in England](#) [Accessed August 2018]
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- ³ The Lancet (2015) [Implementation of the Lancet Standing Commission on Liver Disease in the UK](#) [Accessed August 2018]
- ⁴ PHE [Liver disease profiles](#) [Accessed August 2018]

Map 10: Variation in the percentage change in the annual number of people dying between 2014 and 2030 by lower-tier local authority

- ¹ Etkind SN, Bone A, Gomes B and others (2017) [How many people will need palliative care in 2040? Past trends, future projections and implications for services](#) BMC Medicine 15:102 [Accessed August 2018]

SECTION 2: THE ROLE OF HOSPITALS IN PALLIATIVE AND END OF LIFE CARE

Map 11: Variation in the proportion of all people who died in hospital by CCG (2015)

- ¹ Department of Health and Social Care (2008) [End of life care strategy: promoting high quality care for adults at the end of their life](#) [Accessed August 2018]
- ² National Institute for Health and Care Excellence (NICE) (2015) [Care of dying adults in the last days of life \[NG31\]](#) NICE Guideline [NG31] [Accessed August 2018]
- ³ Leadership Alliance for the Care of Dying People (2014) [One chance to get it right – Improving people's experience of care in the last few days and hours of life](#) [Accessed August 2018]
- ⁴ NHS England (2015) [Transforming end of life care in acute hospitals: the route to success 'how to' guide](#) [Accessed August 2018]

Map 12: Variation in the proportion of all people admitted into hospital during the last 90 days of their life by CCG (2015)

- ¹ NHS England (2015) [Transforming end of life care in acute hospitals: the route to success 'how to' guide](#) [Accessed August 2018]
- ² Leadership Alliance for the Care of Dying People (2014) [One chance to get it right – Improving people's experience of care in the last few days and hours of life](#) [Accessed August 2018]
- ³ National Institute of Health and Care Excellence (NICE) Guideline [NG27] (2015) [Transition between inpatient hospital settings and community or care home settings for adults with social care needs](#) [Accessed August 2018]

Map 13: Variation in the proportion of people who have 3 or more emergency hospital admissions during the last 90 days of life by CCG (2015)

- ¹ Department of Health and Social Care (2008) [End of life care strategy: promoting high quality care for adults at the end of their life](#) [Accessed August 2018]
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Map 14: Variation in the proportion of hospital admissions ending in death in hospital which are 8 days or longer by CCG (2015)

- ¹ Office for National Statistics (ONS) (2016) [National Survey of Bereaved People \(VOICES\): England, 2015](#) [Accessed August 2018]
- ² National Institute of Health and Care Excellence (NICE) (2015) [Transition between inpatient hospital settings and community or care home settings for adults with social care needs](#) Guideline [NG27] [Accessed August 2018]
- ³ NHS England [Delayed Transfers of Care](#) [Accessed August 2018]

Map 15: Variation in proportion of all people who died in hospital that had documented evidence of recognition that they would probably die in the coming hours or days by acute hospital trust site (2015)

- ¹ Leadership Alliance for the Care of Dying People (2014) [One chance to get it right – Improving people's experience of care in the last few days and hours of life](#) [Accessed August 2018]
- ² National Institute for Health and Care Excellence (NICE) (2015) [Care of dying adults in the last days of life \[NG31\]](#) NICE Guideline [NG31] [Accessed August 2018]
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- ⁴ Royal College of Physicians (2016) [End of Life Care Audit – Dying in Hospital: National report for England 2016](#) [Accessed August 2018]

Map 16: Variation in the proportion of all people who had documented evidence that a health professional had recognised during the last episode of care the person was dying and had discussed this with a nominated person(s) important to the dying person by acute hospital trust site (2015)

- ¹ Leadership Alliance for the Care of Dying People (2014) [One chance to get it right – Improving people's experience of care in the last few days and hours of life](#) [Accessed August 2018]
- ² National Institute for Health and Care Excellence (NICE) (2015) [Care of dying adults in the last days of life \[NG31\]](#) NICE Guideline [NG31] [Accessed August 2018]
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Map 17: Variation in proportion of all people who died in hospital that had documented evidence in the last 24 hours of a holistic assessment of their needs regarding an individual plan of care by acute hospital trust site (2015)

- ¹ Leadership Alliance for the Care of Dying People (2014) [One chance to get it right – Improving people's experience of care in the last few days and hours of life](#) [Accessed August 2018]
- ² National Institute for Health and Care Excellence (NICE) (2015) [Care of dying adults in the last days of life \[NG31\]](#) NICE Guideline [NG31] [Accessed August 2018]
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Map 18: Variation in proportion of all people who died in hospital that had documented evidence in the last 24 hours of a holistic assessment of their needs regarding an individual plan of care by acute hospital trust site (2015)

- ¹ Leadership Alliance for the Care of Dying People (2014) [One chance to get it right – Improving people's experience of care in the last few days and hours of life](#) [Accessed August 2018]
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SECTION 3: PALLIATIVE AND END OF LIFE CARE IN THE COMMUNITY

Map 19: Variation in the number of patients in need of palliative care/support, as recorded on GP disease registers per 100 deaths by CCG (2015/16)

- ¹ PHE National End of Life Care Intelligence Network (2011) [Predicting Death: Estimating the proportion of deaths that are 'unexpected'](#) [Accessed August 2018]
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Map 20: Variation in the proportion of all people who died in a hospice by CCG (2015)

- ¹ Office for National Statistics (ONS) (2016) [National Survey of Bereaved People \(VOICES\): England, 2015](#) [Accessed August 2018]
- ² National Council for Palliative Care [Minimum Data Set reports 2014/15](#) [Accessed August 2018]
- ³ Marie Curie Palliative Care Research Centre, Cardiff University, Public Health England and Hospice UK (2017) [Results of a national survey of support to adult care homes in England: A specialist palliative care provider perspective](#) [Accessed August 2018]
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Map 21: Variation in the proportion of all people that died in a hospice with a recorded cause of death as cancer by STP (2015)

- ¹ Care Quality Commission (CQC) (2016) [A different ending: People with conditions other than cancer](#) [Accessed August 2018]
- ² PHE [End of Life Care Profiles](#) [Accessed August 2018]

Map 22: Variation in the proportion of all people who died in their usual place of residence by CCG (2015)

- ¹ Gomes B, Calanzani N, Higginson IJ (2010) [Local preferences and place of death in regions within England 2010](#) Cicely Saunders International [Accessed August 2018]
- ² The Choice in End of Life Care Programme Board (2015) [What's important to me. A Review of Choice in End of Life](#) [Accessed August 2018]
- ³ Department of Health and Social Care (2012) [End of Life Care Strategy: fourth annual report](#) [Accessed August 2018]
- ⁴ PHE National End of Life Care Intelligence Network [Number and proportion of deaths by place of occurrence](#) [Accessed August 2018]
- ⁵ PHE National End of Life Care Intelligence Network (2017) [Briefing 2 - Place and cause of death for permanent and temporary residents of care homes](#) [Accessed August 2018]
- ⁶ PHE [End of Life Care Profiles](#) [Accessed August 2018]

Map 23: Variation in the proportion of people that died at home by CCG (2015)

- ¹ Gomes B, Calanzani N, Higginson IJ (2010) [Local preferences and place of death in regions within England 2010](#) Cicely Saunders International [Accessed August 2018]
- ² Hoare S, Slote Morris Z and others (2015) [Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death](#) [Accessed August 2018]
- ³ Office for National Statistics (ONS) (2016) [National Survey of Bereaved People \(VOICES\): England, 2015](#) [Accessed August 2018]
- ⁴ National Palliative and End of Life Care Partnership (2018) [A National framework for local action 2015-2020. National Palliative and End of Life Care Partnership](#) [Accessed August 2018]

Map 24: Variation in the proportion of people that died in a care home by CCG (2015)

- ¹ PHE National End of Life Care Intelligence Network (2017) [Briefing 2 - Place and cause of death for permanent and temporary residents of care homes](#) [Accessed August 2018]
- ² Gold Standards Framework [Accreditation](#) [Accessed August 2018]

- ³ Marie Curie Palliative Care Research Centre, Cardiff University, PHE and Hospice UK (2017) [Results of a national survey of support to adult care homes in England: A specialist palliative care provider perspective](#) [Accessed August 2018]
- ⁴ Care Quality Commission (CQC) (2017) [The state of adult social care services 2014 to 2017](#) [Accessed August 2018]
- ⁵ PHE [End of Life Care Profiles](#) [Accessed August 2018]
- ⁶ NHS (2016) [The framework for enhanced health in care homes](#) [Accessed August 2018]

Map 25: Variation in the proportion of the population who are living in a care home by lower tier local authority (2011)

- ¹ Office for National Statistics (ONS) (2014) [Changes in the Older Resident Care Home Population between 2001 and 2011](#) [Accessed August 2018]
- ² Care Quality Commission (CQC) (2017) [The state of adult social care services 2014 to 2017](#) [Accessed August 2018]
- ³ PHE National End of Life Care Intelligence Network (2017) [The role of care homes in end of life care](#) [Accessed August 2018]

Map 26: Variation in the number of care home beds per 100 people living who are aged 75 years or older by CCG (2017)

- ¹ Kingston A, Wohland P, Wittenberg R and others (2017) [Is late-life dependency increasing or not? A comparison of the Cognitive Function and Ageing Studies](#) (CFAS), The Lancet Volume 390, No. 10103, p1676–1684 [Accessed August 2018]
- ² Care Quality Commission (CQC) (2017) [The state of adult social care services 2014 to 2017](#) [Accessed August 2018]
- ³ PHE [End of Life Care Profiles](#) [Accessed August 2018]
- ⁴ PHE National End of Life Care Intelligence Network (2017) [The role of care homes in end of life care](#) [Accessed August 2018]

Map 27: Variation in the number of nursing home beds per 100 people living who are aged 75 years or older by CCG (2017)

- ¹ Care Quality Commission (CQC) (2017) [The state of adult social care services 2014 to 2017](#) [Accessed August 2018]
- ² Competition and Markets Authority (2017) [Care Homes Market Study](#) [Accessed August 2018]
- ³ PHE [End of Life Care Profiles](#) [Accessed August 2018]
- ⁴ PHE National End of Life Care Intelligence Network (2017) [The role of care homes in end of life care](#) [Accessed August 2018]

Map 28: Variation in the proportion of care home residents that died in a care home by CCG (2015)

- ¹ Department of Health (2009) [End of life care strategy: quality markers and measures for end of life care](#) (The National Archives) [Accessed August 2018]
- ² Badger F, Thomas K, Clifford C (2007) [Raising standards for elderly people dying in care homes](#) European Journal of Palliative Care [Accessed August 2018]
- ³ The University of York, Centre for Reviews and Dissemination (2014) [Interventions to reduce unplanned admissions from care home settings](#) [Accessed August 2018]
- ⁴ PHE [End of Life Care Profiles](#) [Accessed August 2018]
- ⁵ PHE National End of Life Care Intelligence Network (2017) [The role of care homes in end of life care](#) [Accessed August 2018]

Map 29: Variation in the proportion of people who died in a care home who were temporary residents by CCG (2015)

- ¹ PHE National End of Life Care Intelligence Network (2017) [Briefing 2 - Place and cause of death for permanent and temporary residents of care homes](#) [Accessed August 2018]
- ² PHE [End of Life Care Profiles](#) [Accessed August 2018]
- ³ PHE National End of Life Care Intelligence Network (2017) [The role of care homes in end of life care](#) [Accessed August 2018]

Palliative and end of life care resources

This section provides links to key resources on end of life care. These resources have been selected to assist stakeholders in their interpretation of the data presented in the Atlas of variation for palliative and end of life care. This compendium of resources can be used by service providers, commissioners and policy makers in facilitating, scoping and implementing their local responses to the findings presented in this Atlas. The resources have been organised in 5 thematically domains:

1. General
2. Commissioning and contracting
3. Condition specific
4. Data and intelligence
5. Learning and training

1. General

Department of Health and Social Care (2008) End of life care strategy: promoting high quality care for adults at the end of their life www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life [Accessed August 2018]

Department of Health and Social Care (2015) Improvements to care in the last days and hours of life www.gov.uk/government/publications/improvements-to-care-in-the-last-days-and-hours-of-life [Accessed August 2018]

General Medical Council (2010) Treatment and care towards the end of life: good practice in decision making www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp [Accessed August 2018]

The King's Fund (2014) Making our health and care systems fit for an ageing population www.kingsfund.org.uk/publications/making-our-health-and-care-systems-fit-ageing-population [Accessed August 2018]

The Leadership Alliance for the Care of Dying People (2014) One chance to get it right - Improving people's experience of care in the last few days and hours of life (Liverpool Care Pathway Review) www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf [Accessed August 2018]

NHS England. End of life care www.england.nhs.uk/ourwork/ltc-op-eolc/improving-eolc [Accessed August 2018]

1.1 Ambitions for palliative and end of life care

National Palliative and End of Life Care Partnership (2018) Ambitions for palliative and end of life website <http://endoflifecareambitions.org.uk/> [Accessed August 2018]

National Palliative and End of Life Care Partnership (2015) Ambitions for palliative and end of life: A national framework for local action 2015-2020 <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/A-Presentation-of-the-Ambitions-for-Palliative-and-End-of-Life-Care1.pdf> [Accessed August 2018]

1.2 Carers

Carers UK Caring and family finances Inquiry (2014) www.carersuk.org/for-professionals/policy/policy-library/caring-family-finances-inquiry [Accessed August 2018]

Carers UK Facts about carers: Policy briefing (2015) www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2015 [Accessed August 2018]

Carers UK State of Caring (2017) www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-report-2017 [Accessed August 2018]

Office for National Statistics (2017) Unpaid carers provide social care worth £57 billion
<https://visual.ons.gov.uk/unpaid-carers-provide-social-care-worth-57-billion/> [Accessed August 2018]

NHS Your guide to care and support www.nhs.uk/conditions/social-care-and-support/carers-assessment/
 [Accessed August 2018]

1.3 Choice in end of life care review

The Choice in End of Life Care Programme Board (2015) What's important to me. A review of choice in end of life care
www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf [Accessed August 2018]

Department of Health and Social Care (2016) Our commitment to you for end of life care: The government response to the review of choice in end of life care www.gov.uk/government/publications/choice-in-end-of-life-care-government-response [Accessed August 2018]

1.4 Electronic palliative care co-ordination systems (EPaCCS)

Public Health England. National End of Life Care Intelligence Network (2013) Electronic palliative care co-ordination systems (EPaCCS) in England: survey of clinical commissioning groups www.endoflifecare-intelligence.org.uk/resources/publications/epaccs_in_england [Accessed August 2018]

NHS Digital (2015) Palliative Care Co-ordination: Core Content (SCCI1580)
<http://content.digital.nhs.uk/isce/publication/SCCI1580> [Accessed August 2018]

NHS Improving Quality (2014) Lessons learned – implementing an Electronic Palliative Care Co-ordination System (EPaCCS) www.england.nhs.uk/improvement-hub/publication/lessons-learned-implementing-an-electronic-palliative-care-co-ordination-system-epaccs [Accessed August 2018]

1.5 Hospital setting specific

Royal College of Physicians (2016) End of Life Care Audit – Dying in Hospital: National Report for England 2016 [Accessed August 2018] <https://www.rcplondon.ac.uk/projects/outputs/end-life-care-audit-dying-hospital-national-report-england-2016>

NHS Benchmarking Network (2018) National audit of care at the end of life (NACEL)
www.nhsbenchmarking.nhs.uk/nacel [Accessed August 2018]

NHS England (2015) Transforming end of life care in acute hospitals: the route to success 'how to' guide
www.england.nhs.uk/wp-content/uploads/2016/01/transforming-end-of-life-care-acute-hospitals.pdf
 [Accessed August 2018]

1.6 Inequalities

Care Quality Commission (2016) A different ending: End of life care review
www.cqc.org.uk/publications/themed-work/different-ending-end-life-care-review [Accessed August 2018]

NHS England and the Palliative Care for People with Learning Disabilities Network (2017) Delivering high quality end of life care for people who have a learning disability www.england.nhs.uk/publication/delivering-high-quality-end-of-life-care-for-people-who-have-a-learning-disability [Accessed August 2018]

Marie Curie (2016) "Hiding who I am" The reality of end of life care for LGBT people
www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf [Accessed August 2018]

St Mungos and Marie Curie Cancer Care (2017) Homelessness and end of life care. Practical information and tools to support the needs of homeless people who are approaching the end of life and those who are bereaved www.mungos.org/publication/homelessness-palliative-care [Accessed August 2018]

1.7 National institute of health and care excellence (NICE) guidance

NICE (2015) Care of dying adults in the last days of life [NG31] www.nice.org.uk/guidance/ng31 [Accessed August 2018]

NICE (2017) Care of dying adults in the last days of life [QS144] www.nice.org.uk/guidance/qs144 [Accessed August 2018]

NICE (2011) End of life care for adults [QS13] www.nice.org.uk/guidance/qs13 [Accessed August 2018]

NICE (2018) End of life care for adults in the last year of life: service delivery. In development [GID-CGWAVE0799] www.nice.org.uk/guidance/indevelopment/gid-cgwave0799 [Accessed August 2018]

1.8 Public health approaches to end of life care

Hospice UK and Dying Matters. Dying matters www.dyingmatters.org [Accessed August 2018]

Kellehear A (2005) Compassionate cities: public health and end of life care

Murray Hall Community Trust and The National Council for Palliative Care Dying Matters (2013) An overview of compassionate communities in England
www.compassionatecommunities.org.uk/files/PDF/CC_Report_Final_July_2013-2.pdf [Accessed August 2018]

The National Council for Palliative Care (2016) Dying well community charter pathfinder project: evaluation report www.ncpc.org.uk/sites/default/files/J1448%20ncpc_Pathfinder%20Evaluation_05.pdf [Accessed August 2018]

The National Council for Palliative Care. The dying well community charter principles of care and support (2014) www.ncpc.org.uk/sites/default/files/Dying_Well_Community_Charter.pdf [Accessed August 2018]

The National Council for Palliative Care (2016) Each community is prepared to help: community development in end of life care – guidance on ambition six http://endoflifecareambitions.org.uk/wp-content/uploads/2016/09/Ambition_6_booklet.pdf [Accessed August 2018]

Public Health England and The National Council for Palliative Care. Public health approaches to end of life care www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf [Accessed August 2018]

1.9 Social care setting specific

Association of Directors of Adult Social Services (2018) End of life care policy page www.adass.org.uk/end-of-life-care [Accessed August 2018]

Association of Palliative Care Social Workers (2016) The role of social workers in palliative, end of life and bereavement care www.apcsw.org.uk/resources/social-work-role-eol.pdf [Accessed August 2018]

NHS (2016) The framework for enhanced health in care homes www.england.nhs.uk/wp-content/uploads/2016/09/ehch-framework-v2.pdf [Accessed August 2018]

1.10 Specialist palliative care

Macmillan Cancer Support www.macmillan.org.uk [Accessed August 2018]

Marie Curie www.mariecurie.org.uk [Accessed August 2018]

Hospice UK www.hospiceuk.org [Accessed August 2018]

Hospice UK Resources for rehabilitative palliative care www.hospiceuk.org/what-we-offer/clinical-and-care-support/rehabilitative-palliative-care/resources-for-rehabilitative-palliative-care [Accessed August 2018]

Sue Ryder www.sueryder.org [Accessed August 2018]

1.11 Vanguard

NHS England. Enhanced health in care homes vanguards www.england.nhs.uk/new-care-models/vanguards/care-models/care-homes-sites [Accessed August 2018]

NHS England (2016) New care models: Vanguards – developing a blueprint for the future of NHS and care services www.england.nhs.uk/wp-content/uploads/2015/11/new_care_models.pdf [Accessed August 2018]

2. Commissioning and contracting

Gold Standards Framework (2015) Commissioning end of life care using the gold standards framework www.goldstandardsframework.org.uk/how-to-commission [Accessed August 2018]

Hospice UK. Commissioning support resources www.hospiceuk.org/what-we-offer/commissioning-support/resources [Accessed August 2018]

Marie Curie Healthcare professionals: Commissioning www.mariecurie.org.uk/professionals/commissioning-our-services [Accessed August 2018]

The National Council for Palliative Care (2015) Getting serious about prevention: enabling people to stay out of hospital at the end of life www.ncpc.org.uk/publication/getting-serious-about-prevention-enabling-people-stay-out-hospital-end-life [Accessed August 2018]

The National Council for Palliative Care (2017) Best Practice in care coordination for palliative and end of life care services: information for commissioners <http://endoflifecareambitions.org.uk/wp-content/uploads/2017/06/Care-Coordination-Quick-Guide-for-Commissioners.pdf> [Accessed August 2018]

The National Council for Palliative Care (2012) Commissioning guidance for specialist palliative care: helping to deliver commissioning objectives www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf [Accessed August 2018]

NHS England (2018) CCG improvement and assessment www.england.nhs.uk/commissioning/ccg-assess [Accessed August 2018]

NHS England (2014) Commissioning for carers www.england.nhs.uk/commissioning/comm-carers [Accessed August 2018]

NHS England (2016) Commissioning person centred end of life care: A toolkit for health and social care www.england.nhs.uk/publication/commissioning-person-centred-end-of-life-care-a-toolkit-for-health-and-social-care [Accessed August 2018]

NHS England (2017) Palliative care development currency www.england.nhs.uk/resources/pay-syst/development/palliative-care-development-currency [Accessed August 2018]

NHS England. Personal health budgets in end of life care www.england.nhs.uk/personal-health-budgets/personal-health-budgets-in-end-of-life-care [Accessed August 2018]

NHS England (2016) Specialist level palliative care: information for commissioner www.england.nhs.uk/wp-content/uploads/2016/04/specilst-palliatv-care-comms-guid.pdf [Accessed August 2018]

North West Coast Strategic Clinical Networks. Self assessment ambitions framework. www.nwscnsenate.nhs.uk/files/5214/7705/5296/Final_Ambitions_for_Palliative_and_End_of_Life_Care-self_assessment_toolV1.1.xlsx [Accessed August 2018]

Public Health England National End of Life Care Intelligence Network (2017) Cost-effective commissioning of end of life care www.endoflifecare-intelligence.org.uk/resources/publications/costeffectivecomm [Accessed August 2018]

Royal College of General Practitioners (2013) Commissioning Guidance in End of Life Care www.rcgp.org.uk/clinical-and-research/toolkits/-/media/061D4183F04E42EA84B4830D4C8FC7E7.ashx [Accessed August 2018]

2.1 Sustainability and transformation partnerships (STPs)

Hospice UK (2017) Achieving excellent end of life care locally www.hospiceuk.org/docs/default-source/Policy-and-Campaigns/achieving_excellent_eolc_locally_final.pdf?sfvrsn=0 [Accessed August 2018]

Public Health England, Care Quality Commission & NHS England (2017) End of life care: Sustainability and Transformation Partnership support tools. Tools for each of the 44 STP areas. <https://future.nhs.uk/connect.ti/system/login?nextURL=%2Fconnect%2Eti%2FNHSTransformation%2Fview%3FobjectId%3D10178512> (requires password) [Accessed August 2018]

Example of the STP support tools:

Public Health England, Care Quality Commission & NHS England (2017) End of life care: Sustainability and Transformation Partnership support tool – Lincolnshire www.eolc.co.uk/educational/end-of-life-care-stp-sustainability-and-transformation-partnership-support-tool-lincolnshire [Accessed August 2018]

3. Condition specific

3.1 Cancer

Cancer Research. UK Dying with cancer www.cancerresearchuk.org/about-cancer/coping/dying-with-cancer [Accessed August 2018]

Cancer Research UK. Cancer mortality statistics www.cancerresearchuk.org/health-professional/cancer-statistics/mortality [Accessed August 2018]

Independent Cancer Taskforce (2015) Achieving world-class cancer outcomes. A strategy for England 2015-2020 www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf [Accessed August 2018]

NHS Rightcare (2018) Long Term Condition scenarios: colorectal cancer. NHS England www.england.nhs.uk/rightcare/products/ltc [Accessed August 2018]

NICE (2004) Improving supportive and palliative care for adults with cancer. Cancer service guideline [CSG4] www.nice.org.uk/guidance/csg4 [Accessed August 2018]

Public Health England. National cancer registration and analysis service www.ncin.org.uk/home [Accessed August 2018]

3.2 Dementia

Alzheimer's Society (2017) End of life care www.alzheimers.org.uk/info/20046/help_with_dementia_care/80/end_of_life_care/2 [Accessed August 2018]

Alzheimer's Society, Alzheimer's Research UK and Marie Curie (2017) Caring for someone with dementia at the end of life www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/condition-specific-short-guides/dementia [Accessed August 2018]

Dementia Friends www.dementiafriends.org.uk [Accessed August 2018]

Dementia Partnerships <http://dementiapartnerships.com/> [Accessed August 2018]

Department of Health and Social Care (2015) Prime Minister's challenge on dementia 2020 www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020 [Accessed August 2018]

NICE (2006) Dementia: supporting people with dementia and their carers in health and social care [CG42] www.nice.org.uk/guidance/cg42 [Accessed August 2018]

NICE (2010) Dementia: support in health and social care QS1

www.nice.org.uk/guidance/qs1/chapter/Quality-statement-9-Palliative-care-needs [Accessed August 2018]

Public Health England. National Mental Health, Dementia and Neurology Intelligence Network. Dementia data and analysis: a guide for health professionals www.gov.uk/guidance/dementia-data-and-analysis-a-guide-for-health-professionals [Accessed August 2018]

Public Health England. National Mental Health, Dementia and Neurology Intelligence Network. Dementia profiles <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia> [Accessed August 2018]

Public Health England. National Mental Health, Dementia and Neurology Intelligence Network and National End of Life Care Intelligence Network (2016) Dying with dementia. Data briefing www.gov.uk/government/publications/dying-with-dementia-data-briefing [Accessed August 2018]

Public Health England, Strategic Health Asset Planning and Evaluation (SHAPE): Dementia Atlas <https://shapeatlas.net/dementia/#6/52.945/-2.147/l-p65> [Accessed August 2018]

3.3 Chronic heart disease

British Heart Foundation (2014) Difficult conversations - talking to people with heart failure about the end of life www.bhf.org.uk/publications/living-with-a-heart-condition/difficult-conversations---talking-to-people-with-heart-failure-about-the-end-of-life [Accessed August 2018]

British Heart Foundation and Marie Curie (2017) Caring for someone with heart failure at the end of life www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/condition-specific-short-guides/heart-failure [Accessed August 2018]

British Society for Heart Failure (2017) National heart failure audit. Report (2015/16) www.ucl.ac.uk/nicor/audits/heartfailure/documents/annualreports/annual-report-2015-6-v8.pdf [Accessed August 2018]

Hospice UK (2017) Heart failure and hospice care: how to make a difference www.hospiceuk.org/docs/default-source/What-We-Offer/Care-Support-Programmes/heart-failure-and-hospice-care_web.pdf?sfvrsn=2 [Accessed August 2018]

3.4 Chronic obstructive pulmonary disease (COPD)

British Lung Foundation, End of life www.blf.org.uk/support-for-you/end-of-life [Accessed August 2018]

British Lung Foundation and Marie Curie (2017) Caring for someone with chronic respiratory diseases at end of life www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/condition-specific-short-guides/respiratory-diseases [Accessed August 2018]

Public Health England. Inhale - Interactive health atlas of lung conditions in England <https://fingertips.phe.org.uk/profile/inhale> [Accessed August 2018]

3.5 Stroke

Department of Health (2013) Improving cardiovascular disease outcomes: strategy www.gov.uk/government/publications/improving-cardiovascular-disease-outcomes-strategy [Accessed August 2018]

Institute of Healthcare Improvement (2008) Global trigger tool for measuring adverse events www.ihl.org/resources/Pages/Tools/IHIGlobalTriggerToolforMeasuringAEs.aspx [Accessed August 2018]

Public Health England. National Cardiovascular Intelligence Network. Cardiovascular disease data and analysis: guide for health professionals www.gov.uk/guidance/cardiovascular-disease-data-and-analysis-a-guide-for-health-professionals [Accessed August 2018]

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Royal College of Physicians. Sentinel Stroke National Audit Programme (SSNAP)
www.strokeaudit.org/results.aspx [Accessed August 2018]

Royal College of Physicians (2006) Stroke peer review scheme www.rcplondon.ac.uk/projects/outputs/stroke-peer-review-scheme [Accessed August 2018]

PHE Cardiovascular disease profiles <https://fingertips.phe.org.uk/profile/cardiovascular> [Accessed August 2018]

3.6 Liver disease

British Society of Gastroenterology (2014) BASL Decompensated Cirrhosis Care Bundle - First 24 Hours.
www.bsg.org.uk/clinical/bsg-guidance/liver-guidance/bsg-basl-decompensated-cirrhosis-care-bundle.html
 [Accessed August 2018]

Public Health England and NHS Rightcare (2017) The 2nd Atlas of variation in risk factors and healthcare for liver disease in England <https://fingertips.phe.org.uk/profile/atlas-of-variation> [Accessed August 2018]

Public Health England. National End of Life Care Intelligence Network (2012) Deaths from liver disease: implications for end of life care in England www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease [Accessed August 2018]

Public Health England. National End of Life Care Programme (2013) Getting it Right: Improving end of life care for people living with liver disease
www.yhln.org.uk/data/documents/2013/NHS%20Liver%20Care,%20Getting%20it%20Right%20-%20Improving%20End%20of%20Life%20Care%20for%20People%20with%20Liver%20Disease.pdf
 [Accessed August 2018]

National Confidential Enquiry into Patient Outcome and Death (2013) Alcohol Related Liver Disease: Measuring the Units www.ncepod.org.uk/2013arld.html [Accessed August 2018]

National Confidential Enquiry into Patient Outcome and Death (2015) Gastrointestinal Haemorrhage: Time to Get Control? www.ncepod.org.uk/2015gih.html [Accessed August 2018]

3.7 Other diseases

NHS RightCare (2018) Long Term Condition scenarios: Parkinson's NHS England
www.england.nhs.uk/rightcare/products/ltc [Accessed August 2018]

Public Health England. Neurology Intelligence Network and National End of Life Care Intelligence Network (2018) Deaths associated with neurological conditions www.gov.uk/government/publications/deaths-associated-with-neurological-conditions [Accessed August 2018]

4. Data and intelligence

Age UK (2015) Briefing: The health and care of older people in England www.cpa.org.uk/cpa/docs/AgeUK-Briefing-TheHealthandCareofOlderPeopleinEngland-2015.pdf [Accessed August 2018]

Age UK (2014) Care in crisis www.ageuk.org.uk/Documents/EN-GB/Campaigns/CIC/Care_in_Crisis_report_2014.pdf?epslanguage=en-GB&dtrk%3Dtrue [Accessed August 2018]

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www.goldstandardsframework.org.uk/cd-content/uploads/files/Library,%20Tools%20%26%20resources/EOLC%20in%20Primary%20Care%20national%20snapshot%20-%20Key%20Findings.pdf [Accessed August 2018]

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Nuffield Trust (2014) Exploring the cost of care at the end of life www.nuffieldtrust.org.uk/files/2017-01/end-of-life-care-web-final.pdf [Accessed August 2018]

Office for National Statistics (2015) National survey of bereaved people (VOICES): England www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015 [Accessed August 2018]

Public Health England. Adult social care profiles <https://fingertips.phe.org.uk/profile/adultsocialcare> [Accessed August 2018]

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Public Health England. National End of Life Care Intelligence Network. End of life care profiles <https://fingertips.phe.org.uk/profile/end-of-life> [Accessed August 2018]

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Sue Ryder (2013) A time and a place. What people want at the end of life www.sueryder.org/~media/files/about-us/a-time-and-a-place-sue-ryder.ashx [Accessed August 2018]

NHS England Delayed Transfers of Care www.england.nhs.uk/statistics/statistical-work-areas/delayed-transfers-of-care/ [Accessed August 2018]

Public Health England. National General Practice Profiles <https://fingertips.phe.org.uk/profile/general-practice> [Accessed August 2018]

5. Learning and training

Derbyshire Alliance for End of Life Care. End of life care toolkit <http://derbyshire.eolcare.uk> [Accessed August 2018]

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The End of Life Partnership. 6 Steps to success programme www.sixsteps.net [Accessed August 2018]

Gold Standards Framework www.goldstandardsframework.org.uk [Accessed August 2018]

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Glossary of terms

Much of the disagreement that occurs during the commissioning or management of services arises because different people use the same term but have a different understanding of its meaning. This Glossary is provided to help develop a shared or common language. If there is a clear, short or memorable definition from the literature, this has been cited and presented in italics; where definitions in the literature do not meet any of these criteria, the PHE Atlas Team have composed and provided a definition. Where definitions have been adapted from the published literature, they are presented with the source acknowledged.

Access to healthcare

Facilitating access is concerned with helping people to access appropriate healthcare resources to preserve or improve their health. Access is a complex concept and there are at least 4 aspects.

1. If services are available in terms of an adequate supply, a population may have theoretical access to healthcare.
2. The extent to which a population gains access to healthcare also depends on 'health literacy', which in turn depends on educational level and language competency. These affect an individual's ability to understand their own needs and to communicate these or to understand, and take action in response to, medical advice. Effective services must be acceptable to the population if they are to make use of them. Acceptability may be influenced by social and cultural norms. Population access may vary due to physical accessibility, in particular, travelling distance. Financial, organisational and social or cultural barriers may also limit utilisation. Thus utilisation is dependent on many factors and not the adequacy of supply. These factors may be unequally distributed across the population and lead to inequalities in access.
3. The services available must be relevant and effective if the population is to gain access to satisfactory health outcomes.
4. The availability of services, and barriers to utilisation, have to be evaluated in the context of differing perspectives, health needs and the material and cultural settings of diverse groups in society.

Equity of access may be measured in terms of the availability, utilisation or outcomes of services. Both horizontal and vertical dimensions of equity require consideration.

Source adapted from: Gulliford M, Figueroa-Munoz J, Morgan M et al. What does 'access to healthcare' mean? J Health Serv Res Policy 2002; 7: 186-188.

Advance care planning (ACP)

ACP is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. An ACP discussion might include:

- the individual's concerns and wishes
- their important values or personal goals for care
- their understanding about their illness and prognosis
- their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these

(Advance Care Planning: A Guide for Health and Social Care Staff NHS End of Life Care Programme, Published February 2017, Revised August 2008).

Source: [One chance to get it right](#) (2014) Leadership Alliance for the Care of Dying People [Accessed August 2018]

Average, see **Mean**

Box and whisker plot

See **Introduction to the data** section.

Cancer

Cancer is a condition where cells in a specific part of the body grow and reproduce uncontrollably. The cancerous cells can invade and destroy surrounding healthy tissue, including organs.

Cancer sometimes begins in one part of the body before spreading to other areas. This process is known as metastasis.

Source: NHS Choices [Cancer](#) [Accessed August 2018]

Cardiovascular disease

Cardiovascular disease (CVD) is a general term for conditions affecting the heart or blood vessels.

It's usually associated with a build-up of fatty deposits inside the arteries – known as atherosclerosis – and an increased risk of blood clots. It can also be associated with damage to arteries in organs such as the brain, heart, kidneys and eyes.

CVD is one of the main causes of death and disability in the UK, but it can often largely be prevented with a healthy lifestyle.

Source: NHS Choices [Cardiovascular disease](#) [Accessed August 2018]

Care home

The definitions used to describe the 2 main types of care home in this report combine the terminology used by the Care Quality Commission 9 (CQC) and understood in community practice. These are:

- nursing home (Care home with nursing)
- residential home (Care home without nursing)

Carer

A carer is a person who is either providing or intending to provide a substantial amount of unpaid care on a regular basis for someone who is disabled, ill or frail. A carer is usually a family member, friend or neighbour and does not include care workers. (Carers (Recognition and Services) Act 1995.)

Note: The main carer will be identified by the individual or the person's GP or key worker if the person lacks capacity to identify one themselves.

Care workers

A care worker is employed to support and supervise vulnerable, infirm or disadvantaged people, or those under the care of the state. They can be volunteers who provide care as part of their work for the voluntary organisation or paid workers who are providing care by virtue of a contract of employment or any other contract.

Chronic obstructive pulmonary disease (COPD)

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions that cause breathing difficulties.

It includes:

- emphysema – damage to the air sacs in the lungs
- chronic bronchitis – long-term inflammation of the airways
- COPD is a common condition that mainly affects middle-aged or older adults who smoke. Many people don't realise they have it

The breathing problems tend to get gradually worse over time and can limit your normal activities, although treatment can help keep the condition under control.

Source: NHS Choices [Chronic obstructive pulmonary disease](#) [Accessed August 2018]

Clinical audit

Clinical audit is a way to find out if healthcare is being provided in line with standards and lets care providers and patients know where their service is doing well, and where there could be improvements.

The aim is to allow quality improvement to take place where it will be most helpful and will improve outcomes for patients. Clinical audits can look at care nationwide (national clinical audits) and local clinical audits can also be performed locally in trusts, hospitals or GP practices anywhere healthcare is provided.

Source: NHS England [Clinical audit](#) [Accessed August 2018]

Clinical guidelines

Systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific circumstances.

Source: Timmermans S, Berg M. The Gold Standard. The challenge of evidence-based medicine and standardization in health care. Temple University Press, Philadelphia: 2003

Commissioner

... to be the advocate for patients and communities, securing a range of appropriate high-quality health care services for people in need [and] to be the custodian of tax-payers' money; this brings a requirement to secure best value in the use of resources.

Source: House of Commons Health Committee (2010) Commissioning [Fourth Report of Session 2009-10. Volume 1](#)

Commissioning

Commissioning in the NHS is the process of ensuring that the health and care services provided effectively meet the needs of the population. It is a complex process with responsibilities ranging from assessing population needs, prioritising health outcomes, procuring products and services, and managing service providers.

Source: Department of Health (2010) [Commissioning](#) [Archived content] [Accessed August 2018]

Confidence intervals

Confidence intervals give the range within which the true size of a treatment effect (which is never precisely known) lies, with a given degree of certainty (usually 95% or 99%).

Source: Evans I, Thornton H, Chalmers I (2006) *Testing Treatments. Better Research for Better Healthcare*. The British Library

Coronary heart disease

Coronary heart disease (CHD) is a major cause of death both in the UK and worldwide. CHD is sometimes called ischaemic heart disease.

Source: NHS Choices [Coronary Heart Disease](#) [Accessed August 2018]

Death in usual place of residence (DiUPR)

This is an indicator for end of life care. It focuses on place of death, namely 'usual place of residence'. 'Usual place of residence' includes deaths that occurred at home, care home or religious establishment.

Dementia

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Alzheimer's disease is the most common cause of dementia, but not the only one. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia.

Source: Alzheimer's Society [What is Dementia?](#) [Accessed August 2018]

Deprivation

See also 'English Indices of Deprivation 2015' Deprivation covers a broad range of issues and refers to unmet needs caused by a lack of resources of all kinds, not just financial.

Source: Ministry of Housing, Communities & Local Government (2015) [English Indices of Deprivation 2015](#) Volume 3, Issue [Accessed August 2018]

Efficiency

... efficiency can be defined as maximising well-being at the least cost to society.

Source: Mitton C, Donaldson C (2004) *Priority setting toolkit*. A guide to the use of economics in healthcare decision making. BMJ Publishing Group.

End of life

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition life-threatening acute conditions caused by sudden catastrophic events

Source: Edited definition from [One chance to get it right](#) (2014) Leadership Alliance for the Care of Dying People [Accessed August 2018]

End of life care (EoLC)

See also ***Palliative care, Specialist palliative care***

Care that helps all those with advanced, progressive and terminal conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both the individual and family to be identified and met through the last phase of life and into bereavement.

It includes the physical care, management of pain and other symptoms and provision of psychological, social care, spiritual and practical support.

Source: [End of life care strategy: promoting high quality care for adults at the end of their life](#) Department of Health (2008)

Electronic palliative care co-ordination systems (EPaCCS)

An initiative enabling advance care planning and improved communication and co-ordination at the end of life—the Electronic Palliative Care Co-ordination Systems. EPaCCS. They take various forms— web-based electronic registers, systems based on sharing care summaries and plans alongside patients' electronic records, patient portals, real-time extractions from the records of participating organisations, etc. They aim to provide up-to-date key information about patients believed to be in the last year of their life in GP practices, emergency telephone services (111 and 999), GP out of hours services, accident and emergency departments, ambulance services, hospitals, community nursing teams, specialist

palliative care services, hospices and care homes. In the UK, each of these settings has their own (electronic or paper) patient record. EPaCCS aim to improve communication and co-ordination and ensure that all those involved in a patient's care are aware of their wishes, preferences and advance care plan.

Source: Petrova M, Riley J, Abel J, Barclay S (2016) [Crash course in EPaCCS \(Electronic Palliative Care Coordination Systems\): 8 years of successes and failure in patient data sharing to learn from](#) [Accessed August 2018]

Emergency admission

An emergency admission is one where a patient is admitted to hospital urgently and unexpectedly (ie the admission is unplanned). Emergency admissions often occur via A&E, but can also occur directly via GPs or consultants in ambulatory clinics.

English Indices of Deprivation 2015

See also **Deprivation**

The English Indices of Deprivation 2015 are based on 37 separate indicators, organised across 7 distinct domains of deprivation which are combined, using appropriate weights, to calculate the Index of multiple deprivation 2015 (IMD 2015). This is an overall measure of multiple deprivation experienced by people living in an area and is calculated for every lower layer super output area (LSOA), or neighbourhood, in England. Every such neighbourhood in England is ranked according to its level of deprivation relative to that of other areas.

Source: Ministry of Housing, Communities and Local Government (2015) [English Indices of Deprivation 2015](#) Statistical Release [Accessed August 2018]

Equity

“Fair” distribution of health/health care resources or opportunities according to population need.

Evidence

Evidence is generally considered to be information from clinical experience that has met some established test of validity, and the appropriate standard is determined according to the requirements of the intervention and clinical circumstance. Processes that involve the development and use of evidence should be accessible and transparent to all stakeholders.

Source: Olsen LA, Goolsby WA, McGinnis JM; Roundtable on Evidence-Based Medicine (2009) [Leadership Commitments to Improve Value in Health Care: Finding Common Ground: Workshop Summary](#) National Academies Press Free to download [Accessed August 2018]

Frailty

Frailty is a loss of resilience that means people living with frailty do not bounce back quickly after a physical or mental illness, an accident or other stressful event.

In clinical terms, frailty is characterised by loss of biological reserves across multiple organ systems and increasing vulnerability to physiological decompensation after a stressor event.

People living with frailty are likely to have a number of different issues or problems, which, taken individually, might not be very serious but when added together have a large impact on health, confidence and wellbeing.

Source: NHS England [Older people living with frailty](#) [Accessed August 2018]

Guidelines/guidance

NICE uses the terms ‘guidance’/‘guidelines’ interchangeably, to refer to evidence-based recommendations on the most effective and cost-effective treatment and care of people with specific diseases and conditions, and recommendations for populations and individuals on interventions that can help prevent disease or improve health.

The professional regulators produce regulatory ‘guidelines’/‘guidance’ on how professional standards should be achieved.

Source: [One chance to get it right](#) (2014) Leadership Alliance for the Care of Dying People [Accessed August 2018]

Health

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The bibliographic citation for this definition is: Preamble to the Constitution of WHO as adopted by the International Health Conference, New York, 19 June - 22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of WHO, no. 2, p. 100) and entered into force on 7 April 1948. The definition has not been amended since 1948.

Source: [World Health Organization](#) [Accessed August 2018]

Healthy life-expectancy

See also ***Life-expectancy***

Average number of years that a person can expect to live in “full health” by taking into account years lived in less than full health due to disease and/or injury.

Source: World Health Organization (WHO) Health statistics and health information systems. [Health Status Statistics: Mortality](#) [Accessed August 2018]

Hospice

Hospice care aims to affirm life and death. It means working with and within local communities to tailor palliative care around the needs of each adult and child with a terminal or life-shortening condition, whatever that may be, and extends to supporting their carers, friends and family before and after bereavement.

Hospice care is provided by multi-disciplinary teams of staff and volunteers who offer expert support that places equal emphasis on someone’s clinical, physical, emotional, social and spiritual needs with the understanding that everyone will be different.

Source: Hospice UK [Our definition of hospice care](#) [Accessed August 2018]

Inequalities in health

Inequalities in health are objectively measured differences in health status, healthcare access and health outcomes.

Integrated care

Clinical integration, where care by professionals and providers to patients is integrated into a single or coherent process within and/or across professions such as through use of shared guidelines and protocols.

Source: Kodner DL, Spreeuwenberg C (2002) Integrated care: meaning, logic, applications and implications – a discussion paper. *International Journal of Integrated Care* 2: 1-6.

International classification of diseases (ICD)

ICD is the foundation for the identification of health trends and statistics globally, and the international standard for reporting diseases and health conditions. It is the diagnostic classification standard for all clinical and research purposes. ICD defines the universe of diseases, disorders, injuries and other related health conditions, listed in a comprehensive, hierarchical fashion that allows for:

- easy storage, retrieval and analysis of health information for evidenced-based decision-making
- sharing and comparing health information between hospitals, regions, settings and countries
- data comparisons in the same location across different time periods

Uses include monitoring of the incidence and prevalence of diseases, observing reimbursements and resource allocation trends, and keeping track of safety and quality guidelines. They also include the counting of deaths as well as diseases, injuries, symptoms, reasons for encounter, factors that influence health status, and external causes of disease.

Source: World Health Organization [Classifications](#) [Accessed August 2018]

Interquartile range (IQR)

The interquartile range (IQR) is a measure of variability, based on dividing a data set into quartiles. Quartiles divide a rank-ordered data set into 4 equal parts (numbers of observations). The values that divide each part are called the first, second and third quartiles, denoted by Q1, Q2 and Q3, respectively:

- Q1 is the 'middle' value in the first half of the rank-ordered data set
- Q2 is the median value in the set
- Q3 is the 'middle' value in the second half of the rank-ordered data set

The interquartile range is equal to Q3 minus Q1.

Source Adapted from: Stat Trek [Statistics and Probability Dictionary](#) [Accessed August 2018]

Life-expectancy

See also **Healthy life-expectancy**

Life-expectancy at a specific age is the average number of additional years a person of that age could expect to live if current mortality levels observed for ages above that age were to continue for the rest of that person's life.

Source: Population Division, DESA, United Nations [World Population Ageing 1950–2050, Annex 1](#) [Accessed August 2018]

Liver disease

The liver is the second largest organ in the body. It works hard, performing hundreds of complex functions, including:

- fighting infections and illness
- removing toxins (poisons), such as alcohol, from the body
- controlling cholesterol levels
- helping blood to clot (thicken)
- releasing bile, a liquid that breaks down fats and aids digestion

Liver disease doesn't usually cause any obvious signs or symptoms until it's fairly advanced and the liver is damaged.

Source: NHS Choices [Liver disease](#) [Accessed August 2018]

Mean (average)

The mean is the sum of values, e.g. total size of summed populations, divided by the number of values, eg number of populations in the sample.

Median

A value or quantity lying at the midpoint of a frequency distribution of observed values or quantities, such that there is an equal probability of falling above or below it.

Mental capacity

A person must be assumed to have mental capacity unless it is established that they lack capacity. An assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made, and not their ability to make decisions in general. Under the Mental capacity act 2005 (England and Wales), anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity:

- does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent)
- if so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

A person is unable to make a decision for themselves if they are unable to understand the information relevant to the decision, retain that information, use or weigh that information as part of the process of making the decision or to communicate the decision (whether by talking, sign language or any other means).

Source: [One chance to get it right](#) (2014) Leadership Alliance for the Care of Dying People [Accessed August 2018]

Palliative care

See also ***End of life care, Specialist palliative care***

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families
- enhances quality of life and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications

Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.

Source: [One chance to get it right](#) (2014) Leadership Alliance for the Care of Dying People [Accessed August 2018]

Prevalence

Prevalence refers to the total number of individuals in a population who have a disease or health condition at a specific period of time, usually expressed as a percentage of the population.

Public health

...the art and science of preventing disease, prolonging life and promoting health through the organized efforts of society.

Source: [Acheson](#) (1988) WHO [Accessed August 2018]

Quality

Quality is the degree to which a service meets pre-set standards of goodness.

Source: Donabedian A, personal communication.

Quality of life¹

... individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment.

Source: World Health Organization (WHO) Programme on Mental Health. WHOQOL: [Measuring Quality of Life](#). The World Health Organization Quality of Life Instruments (The WHOQOL-100 and the WHOQOL-BREF) [Accessed August 2018]

¹ Examples of other quality of life definitions can be found at: www.scotland.gov.uk/Publications/2006/01/13110743/11

Quality Outcomes Framework (QOF)

The Quality and Outcomes Framework (QOF) is the annual reward and incentive programme detailing GP practice achievement results.

It rewards practices for the provision of quality care and helps standardise improvement in the delivery of primary medical services.

It is a voluntary process for all surgeries in England and was introduced as part of the GP contract in 2004. The indicators for the QOF change annually, with new measures and indicators been retired. For 2015/16, the QOF awards practices achievement points for:

- managing some of the most common chronic diseases, e.g. asthma, diabetes
- managing major public health concerns, eg smoking, obesity
- implementing preventative measures, eg regular blood pressure checks

Source: NHS Digital [Quality and Outcome Framework \(QOF\)](#) [Accessed August 2018]

Quintile

See **Introduction to the data** section.

Nursing care

In terms of care home funding, tasks identified by a nursing needs assessment as those that need to be carried out or supervised by a qualified nurse – injections, dressings etc. Will be paid for by the NHS. In a hospital setting often used to describe all tasks a patient requires that are not carried out by a doctor, so could include washing or toileting, as well as nursing procedures.

Source: [Elderly Accommodation Counsel](#) [Accessed August 2018]

Range

See also **Interquartile range**

The range is the difference between the highest and lowest value in the sample. The range provides a crude measure of the spread of the data.

Shared decision-making

In a shared decision, a health care provider communicates to the patient personalized information about the options, outcomes, probabilities, and scientific uncertainties of available treatment options, and the patient communicates his or her values and the relative importance he or she places on benefits and harms.

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press

Social Care

Social Care concerns itself with helping people live their lives comfortably, particularly those people who require a certain degree of extra practical and physical help.

Specialist palliative care

See also **Palliative care** and **End of life care**

Specialist palliative care is the active, total care of patients with progressive, advanced disease and [of] their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training.

(Tebbit, *National Council for Palliative Care*, 1999)

Source: [One chance to get it right](#) (2014) Leadership Alliance for the Care of Dying People [Accessed August 2018]

Standard deviation

See also **Variance**

The standard deviation is a measure of spread, and is the square root of the variance.

Standards

A minimum level of acceptable performance or results or excellent levels of performance or the range of acceptable performance or results.

Source: Kohn LT, Corrigan JM, Donaldson MS (eds) Committee on Quality of Health Care in America, Institute of Medicine. *To Err is Human. Building a Safer Health System*. National Academy Press, Washington: 2000.

Stroke

A stroke is a serious life-threatening medical condition that occurs when the blood supply to part of the brain is cut off.

Strokes are a medical emergency and urgent treatment is essential.

Source: NHS Choices [Stroke](#) [Accessed August 2018]

Structure

Structure comprises the inter-relation of healthcare facilities through which health services are provided. Healthcare is a localised activity, provided by the organisations that form the general healthcare structure, including hospitals, GP practices, clinics, ambulatory care, rehabilitation centres, home care and long-term nursing care.

Unpaid carer, see Carer

Unwarranted variation

Variation in the utilization of health care services that cannot be explained by variation in patient illness or patient preferences.

Source: Wennberg JE (2010) *Tracking Medicine. A Researcher's Quest to Understand Health Care*. Oxford University Press

Value

... value is expressed as what we gain relative to what we give up – the benefit relative to the cost.

Source: Institute of Medicine of the National Academies. *Learning Healthcare System Concepts v. 2008. The Roundtable on Evidence-Based Medicine*, Institute of Medicine. Annual Report

Value for money

Value for money is achieved “by focusing on the productivity of staff and on prevention rather than cure, as well as by carefully allocating resources to people in greatest need and by adopting the most effective approaches.”

Source: The Cabinet Office (2008) [Excellence and fairness: Achieving world class public services](#), page 12 [Archived] [Accessed August 2018]

Variation

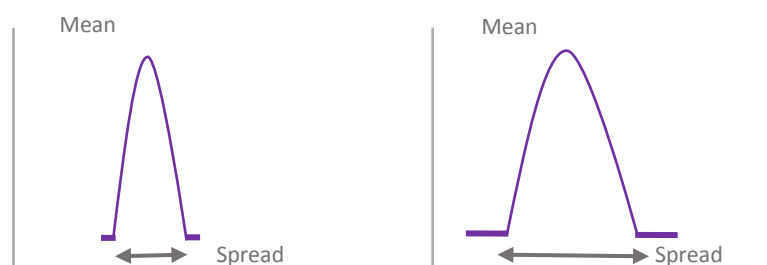
Everything we observe or measure varies. Some of this is random variation. Some variation in healthcare is desirable, even essential, since each patient and population is different and should be cared for uniquely. New and better treatments and improvements in care processes result in variation during the early phases of their introduction.

Source Adapted from: Neuhauser D, Provost L, Bergman B. The meaning of variation to healthcare managers, clinical and health-services researchers, and individual patients. *BMJ Qual Saf* 2011; 20 (Suppl 1): i36-i40. doi: 10.1136/bmjqs.2010.046334

Variance

See also **Range**

The variance is another measure of spread, which describes how far the values in the sample lie away from the mean value. It is the average of the squared differences from the mean and is a better measure of spread than the range.



This figure illustrates how 2 populations may have the same mean value, but different degrees of variation or spread: the graph on the right shows greater variation than that on the left.

Appendix 1

Number of deaths and crude death rate by CCG (2016)

This appendix provides national and local data at CCG level on the number of deaths (excluding neonatal), population size (persons all ages), and crude death rate (%). This data is for 2016 calendar year.

Area name	Deaths (excluding neonatal)	Population	Crude death rate (%)
England	488,936	55,268,067	0.88
NHS Airedale, Wharfedale and Craven CCG	1,768	159,964	1.11
NHS Ashford CCG	1,070	126,151	0.85
NHS Aylesbury Vale CCG	1,598	211,449	0.76
NHS Barking and Dagenham CCG	1,180	206,460	0.57
NHS Barnet CCG	2,424	386,083	0.63
NHS Barnsley CCG	2,315	241,218	0.96
NHS Basildon and Brentwood CCG	2,343	259,764	0.90
NHS Bassetlaw CCG	1,197	114,847	1.04
NHS Bath and North East Somerset CCG	1,718	187,751	0.92
NHS Bedfordshire CCG	3,489	447,688	0.78
NHS Bexley CCG	2,002	244,760	0.82
NHS Birmingham Crosscity CCG	5,916	748,251	0.79
NHS Birmingham South and Central CCG	1,474	203,977	0.72
NHS Blackburn with Darwen CCG	1,345	147,049	0.91
NHS Blackpool CCG	1,856	139,195	1.33
NHS Bolton CCG	2,588	283,115	0.91
NHS Bracknell and Ascot CCG	881	137,659	0.64
NHS Bradford City CCG	509	84,904	0.60
NHS Bradford Districts CCG	2,879	339,658	0.85
NHS Brent CCG	1,693	328,254	0.52
NHS Brighton and Hove CCG	2,129	289,229	0.74
NHS Bristol CCG	3,362	454,213	0.74
NHS Bromley CCG	2,645	326,889	0.81
NHS Bury CCG	1,806	188,669	0.96
NHS Calderdale CCG	1,946	209,770	0.93
NHS Cambridgeshire and Peterborough CCG	7,120	884,561	0.80
NHS Camden CCG	1,093	246,181	0.44
NHS Cannock Chase CCG	1,311	135,099	0.97
NHS Canterbury and Coastal CCG	2,131	210,501	1.01
NHS Castle Point and Rochford CCG	1,876	175,401	1.07
NHS Central London (Westminster) CCG	815	178,358	0.46
NHS Central Manchester CCG	1,034	193,324	0.53

Area name	Deaths (excluding neonatal)	Population	Crude death rate (%)
NHS Chiltern CCG	2,469	325,923	0.76
NHS Chorley and South Ribble CCG	1,605	174,297	0.92
NHS City and Hackney CCG	1,118	282,927	0.40
NHS Corby CCG	568	68,187	0.83
NHS Coventry and Rugby CCG	3,667	456,726	0.80
NHS Crawley CCG	756	111,375	0.68
NHS Croydon CCG	2,415	382,304	0.63
NHS Cumbria CCG	5,686	503,967	1.13
NHS Darlington CCG	1,072	105,646	1.01
NHS Dartford, Gravesham and Swanley CCG	2,197	260,643	0.84
NHS Doncaster CCG	3,197	306,397	1.04
NHS Dorset CCG	8,950	771,884	1.16
NHS Dudley CCG	3,105	317,634	0.98
NHS Durham Dales, Easington and Sedgefield CCG	3,193	274,594	1.16
NHS Ealing CCG	1,940	343,196	0.57
NHS East and North Hertfordshire CCG	4,539	565,680	0.80
NHS East Lancashire CCG	3,637	375,813	0.97
NHS East Leicestershire and Rutland CCG	3,056	328,550	0.93
NHS East Riding of Yorkshire CCG	3,608	315,861	1.14
NHS East Staffordshire CCG	1,156	126,351	0.91
NHS East Surrey CCG	1,598	183,664	0.87
NHS Eastbourne, Hailsham and Seaford CCG	2,507	189,460	1.32
NHS Eastern Cheshire CCG	2,153	196,869	1.09
NHS Enfield CCG	2,006	331,395	0.61
NHS Erewash CCG	949	96,729	0.98
NHS Fareham and Gosport CCG	2,071	200,786	1.03
NHS Fylde & Wyre CCG	2,300	168,982	1.36
NHS Gloucestershire CCG	6,427	623,129	1.03
NHS Great Yarmouth and Waveney CCG	2,626	215,678	1.22
NHS Greater Huddersfield CCG	2,132	245,042	0.87
NHS Greater Preston CCG	1,796	203,519	0.88
NHS Greenwich CCG	1,595	279,766	0.57
NHS Halton CCG	1,249	126,903	0.98
NHS Hambleton, Richmondshire and Whitby CCG	1,527	153,165	1.00
NHS Hammersmith and Fulham CCG	854	179,654	0.48
NHS Hardwick CCG	1,184	111,402	1.06
NHS Haringey CCG	1,158	278,451	0.42
NHS Harrogate and Rural District CCG	1,622	156,312	1.04
NHS Harrow CCG	1,447	248,752	0.58

Area name	Deaths (excluding neonatal)	Population	Crude death rate (%)
NHS Hartlepool and Stockton-On-Tees CCG	2,906	288,498	1.01
NHS Hastings and Rother CCG	2,307	185,787	1.24
NHS Havering CCG	2,379	252,783	0.94
NHS Herefordshire CCG	2,096	189,309	1.11
NHS Herts Valleys CCG	4,606	591,808	0.78
NHS Heywood, Middleton and Rochdale CCG	2,043	216,165	0.95
NHS High Weald Lewes Havens CCG	1,623	172,550	0.94
NHS Hillingdon CCG	1,829	302,471	0.60
NHS Horsham and Mid Sussex CCG	2,042	233,525	0.87
NHS Hounslow CCG	1,503	271,139	0.55
NHS Hull CCG	2,481	260,240	0.95
NHS Ipswich and East Suffolk CCG	3,941	400,979	0.98
NHS Isle of Wight CCG	1,757	139,798	1.26
NHS Islington CCG	999	232,865	0.43
NHS Kernow CCG	6,291	555,995	1.13
NHS Kingston CCG	1,053	176,107	0.60
NHS Knowsley CCG	1,598	147,915	1.08
NHS Lambeth CCG	1,430	327,910	0.44
NHS Lancashire North CCG	1,753	162,786	1.08
NHS Leeds North CCG	1,829	201,180	0.91
NHS Leeds South and East CCG	2,216	253,675	0.87
NHS Leeds West CCG	2,521	326,888	0.77
NHS Leicester City CCG	2,505	348,343	0.72
NHS Lewisham CCG	1,457	301,867	0.48
NHS Lincolnshire East CCG	3,009	233,394	1.29
NHS Lincolnshire West CCG	2,266	236,941	0.96
NHS Liverpool CCG	4,449	484,578	0.92
NHS Luton CCG	1,498	216,791	0.69
NHS Mansfield and Ashfield CCG	2,056	197,941	1.04
NHS Medway CCG	2,133	278,542	0.77
NHS Merton CCG	1,196	205,029	0.58
NHS Mid Essex CCG	3,532	388,438	0.91
NHS Milton Keynes CCG	1,793	270,509	0.66
NHS Nene CCG	5,480	648,647	0.84
NHS Newark & Sherwood CCG	1,227	119,724	1.02
NHS Newbury and District CCG	876	107,124	0.82
NHS Newham CCG	1,255	340,978	0.37
NHS North & West Reading CCG	752	100,349	0.75
NHS North Derbyshire CCG	3,081	273,187	1.13

Area name	Deaths (excluding neonatal)	Population	Crude death rate (%)
NHS North Durham CCG	2,458	247,549	0.99
NHS North East Essex CCG	3,779	329,233	1.15
NHS North East Hampshire and Farnham CCG	1,613	210,545	0.77
NHS North East Lincolnshire CCG	1,755	159,144	1.10
NHS North Hampshire CCG	1,723	221,875	0.78
NHS North Kirklees CCG	1,684	192,005	0.88
NHS North Lincolnshire CCG	1,760	170,786	1.03
NHS North Manchester CCG	1,264	184,617	0.68
NHS North Norfolk CCG	2,197	171,890	1.28
NHS North Somerset CCG	2,429	211,681	1.15
NHS North Staffordshire CCG	2,324	218,322	1.06
NHS North Tyneside CCG	2,126	203,307	1.05
NHS North West Surrey CCG	2,981	344,601	0.87
NHS Northern, Eastern and Western Devon CCG	9,641	898,025	1.07
NHS Northumberland CCG	3,647	316,002	1.15
NHS Norwich CCG	1,843	200,358	0.92
NHS Nottingham City CCG	2,332	325,282	0.72
NHS Nottingham North and East CCG	1,387	150,323	0.92
NHS Nottingham West CCG	1,076	112,671	0.95
NHS Oldham CCG	2,110	232,724	0.91
NHS Oxfordshire CCG	5,323	668,746	0.80
NHS Portsmouth CCG	1,740	214,832	0.81
NHS Redbridge CCG	1,730	299,249	0.58
NHS Redditch and Bromsgrove CCG	1,756	181,740	0.97
NHS Richmond CCG	1,175	195,846	0.60
NHS Rotherham CCG	2,741	261,930	1.05
NHS Rushcliffe CCG	1,042	115,204	0.90
NHS Salford CCG	2,180	248,726	0.88
NHS Sandwell and West Birmingham CCG	3,814	495,053	0.77
NHS Scarborough and Ryedale CCG	1,342	111,353	1.21
NHS Sheffield CCG	4,888	575,424	0.85
NHS Shropshire CCG	3,477	313,373	1.11
NHS Slough CCG	845	147,181	0.57
NHS Solihull CCG	2,027	211,763	0.96
NHS Somerset CCG	6,032	549,447	1.10
NHS South Cheshire CCG	1,799	179,826	1.00
NHS South Devon and Torbay CCG	3,625	279,891	1.30
NHS South East Staffs and Seisdon Peninsular CCG	2,128	225,183	0.95
NHS South Eastern Hampshire CCG	2,276	212,282	1.07

Area name	Deaths (excluding neonatal)	Population	Crude death rate (%)
NHS South Gloucestershire CCG	2,214	277,623	0.80
NHS South Kent Coast CCG	2,327	207,551	1.12
NHS South Lincolnshire CCG	1,585	147,848	1.07
NHS South Manchester CCG	1,233	163,322	0.75
NHS South Norfolk CCG	2,553	246,360	1.04
NHS South Reading CCG	698	112,030	0.62
NHS South Sefton CCG	1,721	158,878	1.08
NHS South Tees CCG	3,006	275,802	1.09
NHS South Tyneside CCG	1,700	149,418	1.14
NHS South Warwickshire CCG	2,533	262,687	0.96
NHS South West Lincolnshire CCG	1,199	125,230	0.96
NHS South Worcestershire CCG	2,983	301,411	0.99
NHS Southampton CCG	1,910	254,275	0.75
NHS Southend CCG	1,923	179,799	1.07
NHS Southern Derbyshire CCG	4,848	527,445	0.92
NHS Southport and Formby CCG	1,559	115,383	1.35
NHS Southwark CCG	1,345	313,223	0.43
NHS St Helens CCG	1,964	178,455	1.10
NHS Stafford and Surrounds CCG	1,462	153,953	0.95
NHS Stockport CCG	2,682	290,557	0.92
NHS Stoke On Trent CCG	2,586	261,440	0.99
NHS Sunderland CCG	2,936	277,962	1.06
NHS Surrey Downs CCG	2,613	288,199	0.91
NHS Surrey Heath CCG	848	96,685	0.88
NHS Sutton CCG	1,520	202,220	0.75
NHS Swale CCG	1,002	114,823	0.87
NHS Swindon CCG	1,725	223,646	0.77
NHS Tameside and Glossop CCG	2,505	256,424	0.98
NHS Telford and Wrekin CCG	1,449	172,976	0.84
NHS Thanet CCG	1,793	140,652	1.27
NHS Thurrock CCG	1,246	167,025	0.75
NHS Tower Hamlets CCG	1,042	304,854	0.34
NHS Trafford CCG	1,975	234,673	0.84
NHS Vale of York CCG	3,288	357,930	0.92
NHS Vale Royal CCG	972	103,702	0.94
NHS Wakefield CCG	3,289	336,834	0.98
NHS Walsall CCG	2,646	278,715	0.95
NHS Waltham Forest CCG	1,411	275,843	0.51
NHS Wandsworth CCG	1,496	316,096	0.47

Area name	Deaths (excluding neonatal)	Population	Crude death rate (%)
NHS Warrington CCG	1,907	208,809	0.91
NHS Warwickshire North CCG	1,910	190,248	1.00
NHS West Cheshire CCG	2,541	231,978	1.10
NHS West Essex CCG	2,717	302,504	0.90
NHS West Hampshire CCG	5,302	558,297	0.95
NHS West Kent CCG	4,177	481,572	0.87
NHS West Lancashire CCG	1,206	113,401	1.06
NHS West Leicestershire CCG	3,375	393,013	0.86
NHS West London (K&C & QPP) CCG	1,108	225,982	0.49
NHS West Norfolk CCG	2,117	175,098	1.21
NHS West Suffolk CCG	2,156	227,781	0.95
NHS Wigan Borough CCG	3,187	323,060	0.99
NHS Wiltshire CCG	4,605	488,409	0.94
NHS Windsor, Ascot and Maidenhead CCG	1,123	142,861	0.79
NHS Wirral CCG	3,703	321,238	1.15
NHS Wokingham CCG	1,190	161,878	0.74
NHS Wolverhampton CCG	2,570	256,621	1.00
NHS Wyre Forest CCG	1,099	99,902	1.10
NHS Newcastle and Gateshead CCG	4,721	498,070	0.95
NHS Coastal West Sussex CCG	6,226	498,865	1.25
NHS Guildford and Waverley CCG	1,724	207,782	0.83

Appendix 2

Projected deaths for 2030 at lower tier local authority level

This appendix provides national and local authority data on the number of deaths (2014), projected deaths (2030), and crude death rate (%). The data for individual local authorities in the projected deaths column has been rounded so does not therefore add up to the England value.

Area name	Actual deaths	Projected deaths	Crude death rate (%)	
	2014	2030	2014	2030
England	468,875	513,768	0.86	0.85
Adur	694	735	1.10	1.02
Allerdale	1,100	1,163	1.14	1.21
Amber Valley	1,254	1,445	1.01	1.08
Arun	2,049	2,229	1.33	1.25
Ashfield	1,221	1,375	1.00	1.01
Ashford	1,087	1,224	0.88	0.84
Aylesbury Vale	1,369	1,764	0.74	0.80
Babergh	903	1,139	1.02	1.20
Barking and Dagenham	1,266	1,157	0.64	0.45
Barnet	2,349	2,749	0.63	0.60
Barnsley	2,305	2,563	0.97	0.98
Barrow-in-Furness	755	729	1.12	1.15
Basildon	1,522	1,617	0.84	0.79
Basingstoke and Deane	1,282	1,579	0.74	0.81
Bassetlaw	1,181	1,347	1.03	1.13
Bath and North East Somerset	1,560	1,663	0.86	0.84
Bedford	1,314	1,565	0.80	0.80
Bexley	1,896	1,953	0.79	0.69
Birmingham	8,516	7,861	0.77	0.64
Blaby	785	922	0.82	0.87
Blackburn with Darwen	1,234	1,183	0.84	0.82
Blackpool	1,782	1,615	1.27	1.16
Bolsover	874	896	1.13	1.08
Bolton	2,469	2,617	0.88	0.88
Boston	686	758	1.03	1.02
Bournemouth	1,915	1,933	1.00	0.86
Bracknell Forest	668	873	0.57	0.65
Bradford	4,416	4,413	0.84	0.78
Braintree	1,331	1,691	0.89	1.01
Breckland	1,461	1,730	1.09	1.16
Brent	1,612	1,891	0.50	0.51
Brentwood	776	798	1.03	0.92
Brighton and Hove	1,976	1,970	0.70	0.63

Area name	Actual deaths	Projected deaths	Crude death rate (%)	
	2014	2030	2014	2030
Bristol, City of	3,222	3,139	0.73	0.61
Broadland	1,353	1,586	1.07	1.16
Bromley	2,630	2,638	0.82	0.69
Bromsgrove	1,040	1,214	1.09	1.17
Broxbourne	671	813	0.70	0.75
Broxtowe	1,063	1,123	0.95	0.91
Burnley	911	898	1.04	1.03
Bury	1,748	1,889	0.93	0.94
Calderdale	1,868	2,064	0.90	0.92
Cambridge	827	906	0.64	0.64
Camden	1,060	1,321	0.45	0.45
Cannock Chase	882	1,011	0.89	0.98
Canterbury	1,562	1,669	0.99	0.93
Carlisle	1,071	1,162	0.99	1.05
Castle Point	976	1,155	1.10	1.21
Central Bedfordshire	1,902	2,449	0.71	0.74
Charnwood	1,397	1,616	0.80	0.79
Chelmsford	1,343	1,619	0.78	0.85
Cheltenham	1,064	1,101	0.91	0.86
Cherwell	1,268	1,413	0.88	0.89
Cheshire East	3,586	4,306	0.96	1.08
Cheshire West and Chester	3,227	3,563	0.97	1.03
Chesterfield	1,107	1,148	1.06	1.06
Chichester	1,356	1,503	1.17	1.17
Chiltern	764	877	0.81	0.88
Chorley	1,044	1,269	0.94	1.00
Christchurch	674	664	1.38	1.18
City of London	28	61	0.35	0.60
Colchester	1,527	1,668	0.85	0.79
Copeland	742	807	1.06	1.20
Corby	537	640	0.82	0.78
Cornwall	5,869	6,572	1.08	1.07
Cotswold	883	987	1.04	1.06
County Durham	5,348	5,762	1.03	1.04
Coventry	2,673	2,626	0.79	0.64
Craven	607	697	1.09	1.21
Crawley	697	755	0.63	0.59
Croydon	2,408	2,660	0.64	0.60
Dacorum	1,099	1,294	0.73	0.75
Darlington	1,087	1,130	1.03	1.05
Dartford	823	975	0.81	0.79
Daventry	674	888	0.85	1.03

Area name	Actual deaths	Projected deaths	Crude death rate (%)	
	2014	2030	2014	2030
Derby	2,159	2,178	0.86	0.78
Derbyshire Dales	776	896	1.09	1.21
Doncaster	3,014	3,071	0.99	0.99
Dover	1,231	1,379	1.09	1.12
Dudley	3,088	3,152	0.98	0.95
Ealing	1,889	2,100	0.55	0.55
East Cambridgeshire	697	812	0.80	0.80
East Devon	1,813	1,943	1.33	1.27
East Dorset	1,032	1,148	1.17	1.19
East Hampshire	1,090	1,416	0.93	1.11
East Hertfordshire	1,011	1,261	0.71	0.76
East Lindsey	1,779	1,982	1.29	1.35
East Northamptonshire	818	1,040	0.92	1.06
East Riding of Yorkshire	3,591	4,233	1.07	1.19
East Staffordshire	1,070	1,217	0.93	0.97
Eastbourne	1,265	1,344	1.25	1.17
Eastleigh	984	1,176	0.76	0.79
Eden	485	635	0.92	1.20
Elmbridge	1,037	1,171	0.78	0.80
Enfield	2,004	2,201	0.62	0.56
Epping Forest	1,375	1,328	1.07	0.88
Epsom and Ewell	599	645	0.76	0.69
Erewash	1,114	1,215	0.98	0.98
Exeter	1,030	998	0.83	0.72
Fareham	1,171	1,346	1.02	1.07
Fenland	1,077	1,169	1.10	1.07
Forest Heath	522	589	0.83	0.79
Forest of Dean	869	1,026	1.04	1.14
Fylde	1,019	1,108	1.32	1.35
Gateshead	2,112	2,090	1.05	1.01
Gedling	1,121	1,191	0.97	0.93
Gloucester	1,062	1,157	0.85	0.81
Gosport	778	920	0.92	1.04
Gravesham	894	956	0.85	0.78
Great Yarmouth	1,177	1,219	1.20	1.17
Greenwich	1,591	1,679	0.59	0.51
Guildford	1,005	1,125	0.70	0.69
Hackney	1,045	1,188	0.40	0.37
Halton	1,184	1,330	0.94	1.02
Hambleton	863	1,008	0.96	1.08
Hammersmith and Fulham	846	966	0.47	0.50
Harborough	795	975	0.90	0.98

Area name	Actual deaths	Projected deaths	Crude death rate (%)	
	2014	2030	2014	2030
Haringey	1,173	1,293	0.44	0.41
Harlow	734	707	0.87	0.73
Harrogate	1,601	1,821	1.02	1.13
Harrow	1,453	1,585	0.59	0.56
Hart	636	830	0.68	0.84
Hartlepool	972	998	1.05	1.05
Hastings	949	998	1.04	1.01
Havant	1,255	1,407	1.03	1.07
Havering	2,193	2,302	0.89	0.78
Herefordshire, County of	1,920	2,155	1.03	1.06
Hertsmere	912	1,004	0.89	0.85
High Peak	814	943	0.89	0.99
Hillingdon	1,864	2,006	0.64	0.55
Hinckley and Bosworth	913	1,122	0.85	0.94
Horsham	1,228	1,491	0.92	1.00
Hounslow	1,372	1,627	0.52	0.51
Huntingdonshire	1,251	1,704	0.72	0.87
Hyndburn	812	829	1.01	1.05
Ipswich	1,123	1,137	0.83	0.78
Isle of Wight	1,690	1,836	1.21	1.23
Isles of Scilly	20	24	0.88	1.14
Islington	1,003	1,147	0.45	0.42
Kensington and Chelsea	785	961	0.50	0.59
Kettering	828	990	0.85	0.90
King's Lynn and West Norfolk	1,621	1,784	1.08	1.10
Kingston upon Hull, City of	2,476	2,236	0.96	0.84
Kingston upon Thames	972	1,160	0.57	0.55
Kirklees	3,685	4,084	0.85	0.86
Knowsley	1,492	1,436	1.02	0.96
Lambeth	1,378	1,494	0.43	0.41
Lancaster	1,481	1,487	1.05	0.98
Leeds	6,317	6,424	0.82	0.76
Leicester	2,458	2,457	0.73	0.64
Lewes	1,003	1,173	1.00	1.01
Lewisham	1,536	1,584	0.53	0.45
Lichfield	1,026	1,314	1.00	1.22
Lincoln	806	876	0.84	0.85
Liverpool	4,200	4,107	0.89	0.80
Luton	1,429	1,527	0.68	0.61
Maidstone	1,431	1,750	0.88	0.92
Maldon	614	801	0.98	1.18
Malvern Hills	951	1,158	1.25	1.39

Area name	Actual deaths	Projected deaths	Crude death rate (%)	
	2014	2030	2014	2030
Manchester	3,579	3,305	0.69	0.56
Mansfield	1,047	1,107	0.99	0.99
Medway	2,227	2,417	0.81	0.76
Melton	445	558	0.87	1.00
Mendip	1,093	1,271	0.99	1.05
Merton	1,213	1,250	0.60	0.53
Mid Devon	709	830	0.90	0.96
Mid Suffolk	875	1,176	0.88	1.08
Mid Sussex	1,318	1,532	0.91	0.93
Middlesbrough	1,484	1,343	1.07	0.92
Milton Keynes	1,687	2,178	0.65	0.71
Mole Valley	857	932	0.99	0.99
New Forest	2,037	2,266	1.14	1.15
Newark and Sherwood	1,191	1,364	1.01	1.05
Newcastle upon Tyne	2,533	2,351	0.87	0.74
Newcastle-under-Lyme	1,185	1,312	0.94	0.98
Newham	1,264	1,510	0.39	0.37
North Devon	1,108	1,150	1.18	1.16
North Dorset	660	797	0.94	1.04
North East Derbyshire	1,054	1,182	1.06	1.14
North East Lincolnshire	1,570	1,693	0.98	1.04
North Hertfordshire	1,232	1,427	0.94	0.93
North Kesteven	993	1,273	0.89	1.03
North Lincolnshire	1,654	1,860	0.98	1.05
North Norfolk	1,367	1,514	1.33	1.34
North Somerset	2,181	2,592	1.05	1.08
North Tyneside	2,171	2,135	1.07	0.98
North Warwickshire	615	750	0.98	1.16
North West Leicestershire	857	1,000	0.89	0.95
Northampton	1,688	1,913	0.77	0.75
Northumberland	3,416	3,859	1.08	1.20
Norwich	1,043	964	0.76	0.63
Nottingham	2,299	2,149	0.73	0.62
Nuneaton and Bedworth	1,153	1,317	0.91	0.98
Oadby and Wigston	563	630	1.01	1.06
Oldham	2,216	2,090	0.97	0.86
Oxford	910	961	0.58	0.55
Pendle	873	838	0.97	0.92
Peterborough	1,486	1,557	0.78	0.71
Plymouth	2,266	2,423	0.87	0.87
Poole	1,604	1,696	1.07	1.02

Area name	Actual deaths	Projected deaths	Crude death rate (%)	
	2014	2030	2014	2030
Portsmouth	1,715	1,655	0.82	0.72
Preston	1,205	1,163	0.86	0.81
Purbeck	469	513	1.03	1.06
Reading	1,021	1,122	0.63	0.64
Redbridge	1,657	1,822	0.57	0.50
Redcar and Cleveland	1,429	1,477	1.06	1.10
Redditch	622	746	0.74	0.87
Reigate and Banstead	1,342	1,490	0.94	0.87
Ribble Valley	607	698	1.04	1.15
Richmond upon Thames	1,110	1,342	0.57	0.58
Richmondshire	446	530	0.85	1.03
Rochdale	1,992	1,970	0.94	0.89
Rochford	746	871	0.88	0.95
Rossendale	650	708	0.94	0.96
Rother	1,329	1,410	1.44	1.36
Rotherham	2,597	2,725	1.00	1.00
Rugby	884	1,024	0.86	0.89
Runnymede	616	739	0.73	0.75
Rushcliffe	963	1,194	0.85	0.94
Rushmoor	629	809	0.66	0.81
Rutland	340	448	0.89	1.12
Ryedale	512	659	0.97	1.18
Salford	2,146	2,147	0.89	0.77
Sandwell	2,814	2,727	0.89	0.76
Scarborough	1,323	1,391	1.22	1.28
Sedgemoor	1,184	1,354	0.99	0.99
Sefton	3,192	3,206	1.17	1.15
Selby	728	928	0.85	0.98
Sevenoaks	1,002	1,172	0.85	0.87
Sheffield	4,768	4,808	0.85	0.77
Shepway	1,228	1,334	1.12	1.10
Shropshire	3,040	3,755	0.98	1.14
Slough	755	830	0.52	0.51
Solihull	1,947	2,039	0.93	0.89
South Bucks	641	776	0.94	0.99
South Cambridgeshire	1,150	1,370	0.75	0.76
South Derbyshire	818	1,018	0.83	0.90
South Gloucestershire	2,029	2,463	0.75	0.79
South Hams	874	1,011	1.04	1.13
South Holland	1,060	1,117	1.17	1.10
South Kesteven	1,281	1,611	0.93	1.04
South Lakeland	1,174	1,331	1.14	1.29

Area name	Actual deaths	Projected deaths	Crude death rate (%)	
	2014	2030	2014	2030
South Norfolk	1,248	1,455	0.97	0.95
South Northamptonshire	681	914	0.77	0.93
South Oxfordshire	1,178	1,408	0.86	0.95
South Ribble	939	1,101	0.86	0.99
South Somerset	1,654	1,920	1.01	1.08
South Staffordshire	1,084	1,385	0.98	1.20
South Tyneside	1,629	1,626	1.10	1.06
Southampton	1,761	1,747	0.72	0.64
Southend-on-Sea	1,771	1,864	1.00	0.92
Southwark	1,357	1,426	0.45	0.39
Spelthorne	863	950	0.88	0.85
St Albans	1,046	1,134	0.72	0.68
St Edmundsbury	955	1,225	0.85	1.03
St. Helens	1,837	1,947	1.04	1.05
Stafford	1,326	1,455	1.00	1.04
Staffordshire Moorlands	1,024	1,196	1.05	1.20
Stevenage	749	797	0.87	0.82
Stockport	2,683	2,798	0.94	0.90
Stockton-on-Tees	1,780	1,856	0.92	0.89
Stoke-on-Trent	2,368	2,341	0.94	0.89
Stratford-on-Avon	1,302	1,527	1.08	1.18
Stroud	1,183	1,382	1.03	1.08
Suffolk Coastal	1,354	1,644	1.09	1.26
Sunderland	2,927	2,951	1.06	1.04
Surrey Heath	736	937	0.84	1.00
Sutton	1,569	1,573	0.79	0.67
Swale	1,268	1,496	0.90	0.91
Swindon	1,616	1,939	0.75	0.80
Tameside	2,120	2,333	0.96	1.00
Tamworth	632	753	0.82	0.95
Tandridge	806	954	0.94	0.97
Taunton Deane	1,209	1,417	1.07	1.13
Teignbridge	1,478	1,609	1.16	1.13
Telford and Wrekin	1,296	1,634	0.76	0.91
Tendring	1,953	2,106	1.40	1.35
Test Valley	1,008	1,338	0.84	1.02
Tewkesbury	824	980	0.96	0.97
Thanet	1,652	1,736	1.19	1.08
Three Rivers	753	881	0.83	0.85
Thurrock	1,155	1,270	0.71	0.66
Tonbridge and Malling	887	1,125	0.71	0.78

Area name	Actual deaths	Projected deaths	Crude death rate (%)	
	2014	2030	2014	2030
Torbay	1,742	1,804	1.31	1.26
Torridge	786	869	1.20	1.17
Tower Hamlets	1,062	1,261	0.37	0.33
Trafford	1,913	1,977	0.82	0.76
Tunbridge Wells	949	1,096	0.82	0.86
Uttlesford	697	870	0.83	0.84
Vale of White Horse	1,032	1,259	0.83	0.90
Wakefield	3,157	3,428	0.95	0.97
Walsall	2,630	2,563	0.96	0.86
Waltham Forest	1,473	1,507	0.55	0.48
Wandsworth	1,442	1,600	0.46	0.45
Warrington	1,884	2,166	0.91	0.96
Warwick	1,111	1,211	0.80	0.80
Watford	716	808	0.75	0.70
Waveney	1,420	1,484	1.22	1.22
Waverley	1,147	1,276	0.93	0.95
Wealden	1,623	1,910	1.05	1.06
Wellingborough	648	711	0.85	0.86
Welwyn Hatfield	973	1,008	0.84	0.73
West Berkshire	1,147	1,390	0.74	0.85
West Devon	575	743	1.06	1.23
West Dorset	1,218	1,422	1.21	1.31
West Lancashire	1,074	1,290	0.96	1.12
West Lindsey	850	1,093	0.93	1.08
West Oxfordshire	1,011	1,236	0.93	1.02
West Somerset	425	496	1.24	1.41
Westminster	1,083	1,298	0.46	0.46
Weymouth and Portland	759	798	1.17	1.18
Wigan	2,955	3,424	0.92	1.01
Wiltshire	4,309	5,145	0.89	0.98
Winchester	1,088	1,213	0.91	0.91
Windsor and Maidenhead	1,204	1,388	0.82	0.85
Wirral	3,548	3,567	1.11	1.08
Woking	754	856	0.76	0.79
Wokingham	1,142	1,433	0.72	0.81
Wolverhampton	2,445	2,322	0.97	0.84
Worcester	809	861	0.80	0.79
Worthing	1,320	1,403	1.24	1.15
Wychavon	1,236	1,368	1.03	1.04
Wycombe	1,240	1,429	0.71	0.75
Wyre	1,387	1,471	1.28	1.29
Wyre Forest	1,016	1,224	1.03	1.19
York	1,771	1,859	0.87	0.81

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**Atlas of variation for palliative and
end of life care in England**

Reducing unwarranted variation to
improve health outcomes and value