

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.

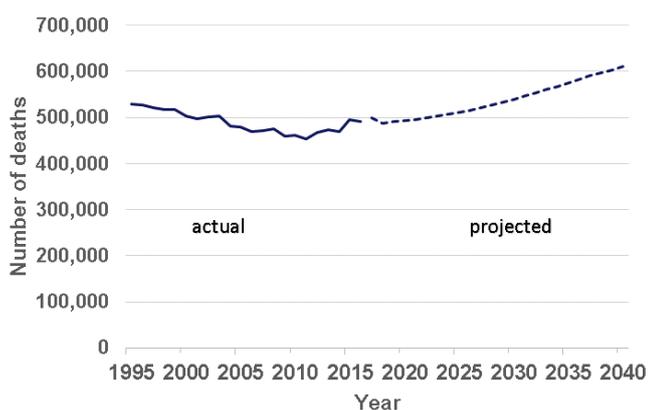
Due to the complexity of assessing unwarranted variation in health care services for palliative and end of life care it is recommended that providers and commissioners use the indicators shown in this Atlas alongside the End of life care profiles¹⁴ and local data, to create a picture of need, provision 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

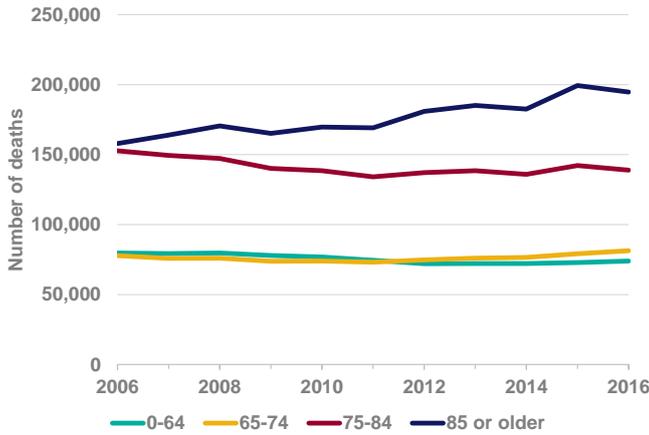
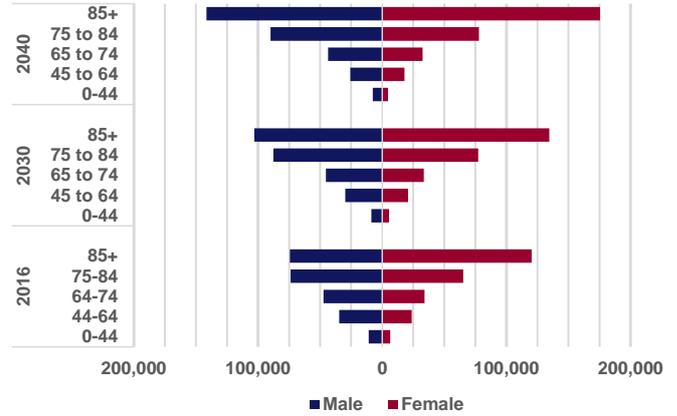


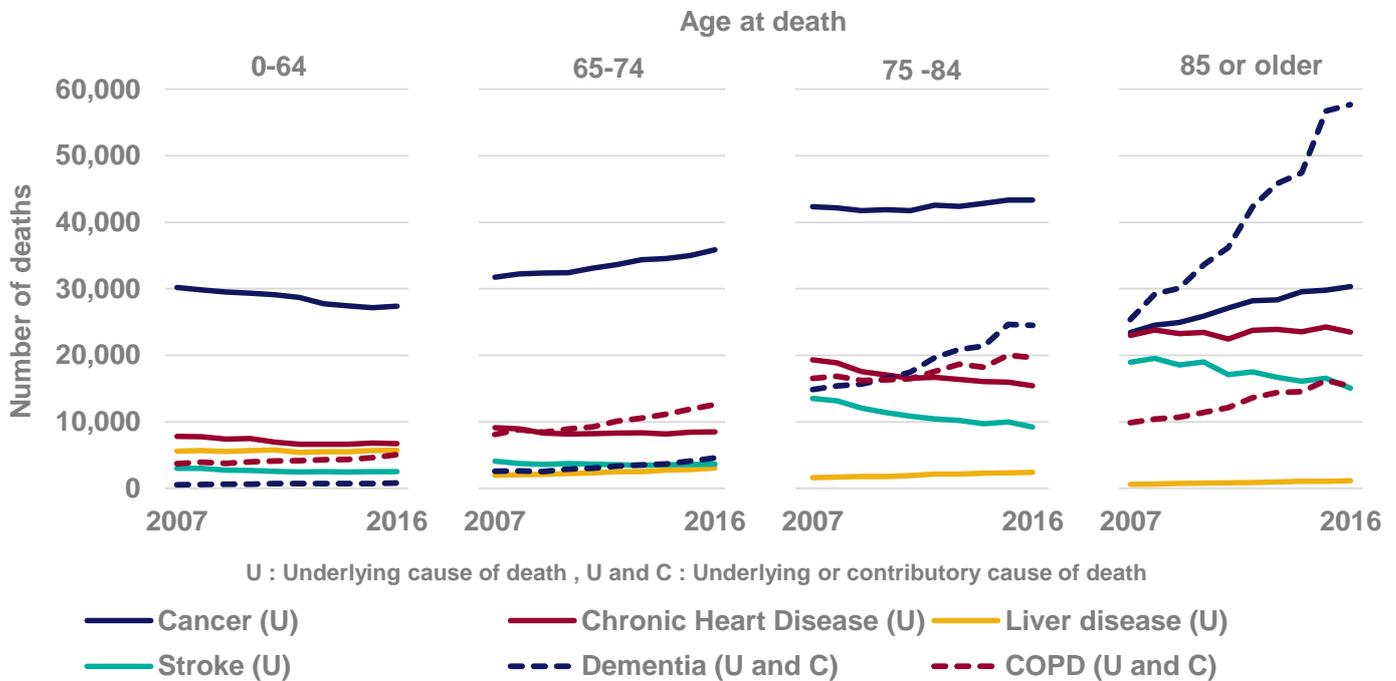
Figure 3: Current and projected number of deaths by age and sex, England 2016, 2030 and 2040^{15 16}



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

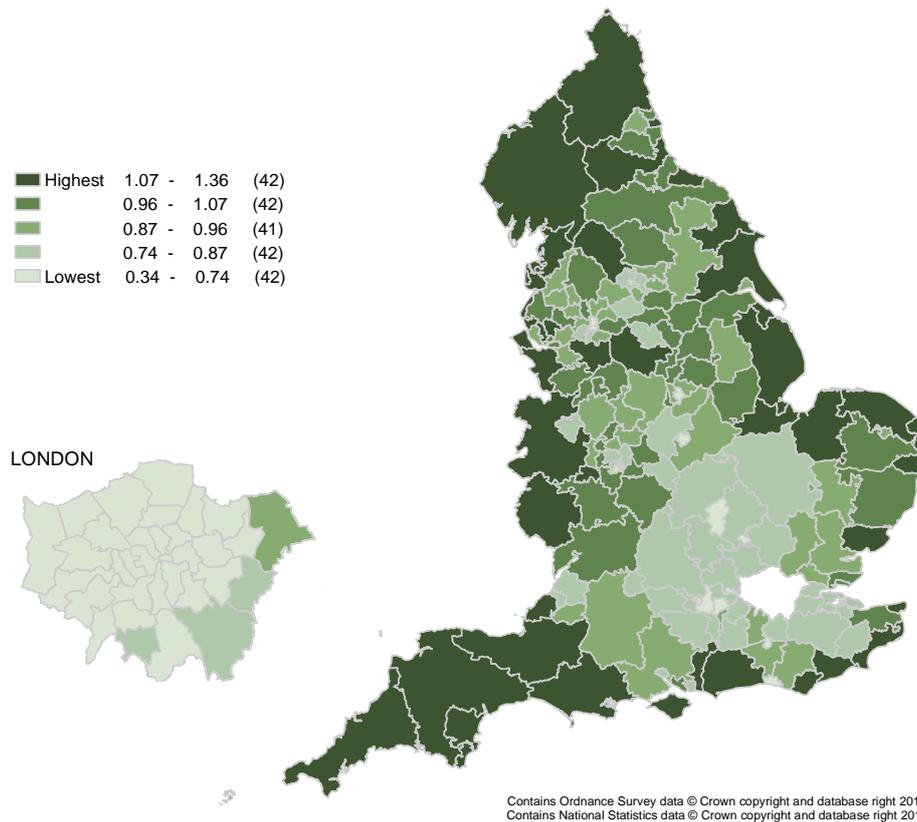


The variation in death rates across England

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

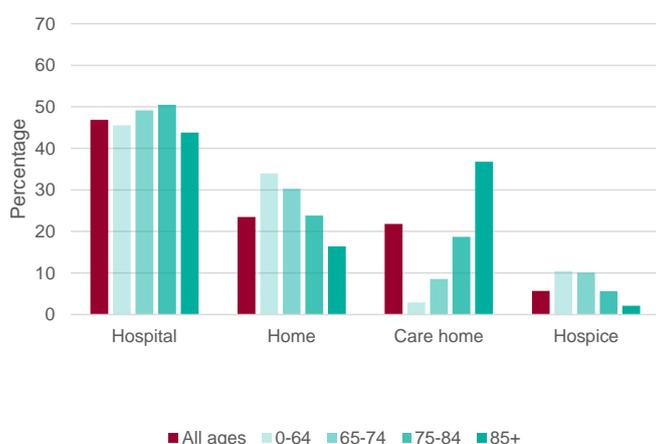
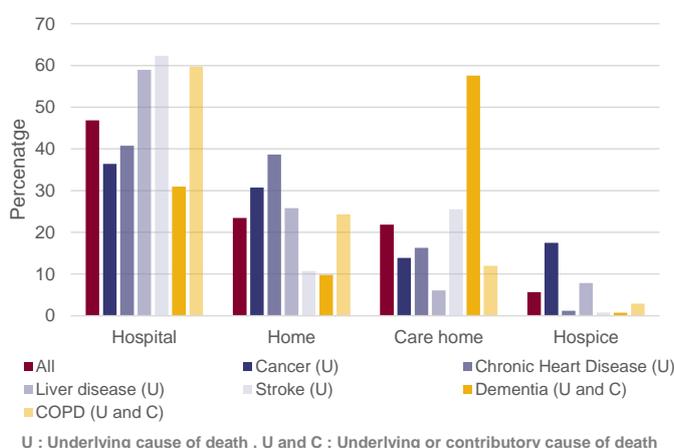


Figure 7: Distribution of deaths by place of death and cause of death, England 2016¹⁵



U : Underlying cause of death , U and C : Underlying or contributory cause of death

Inequalities

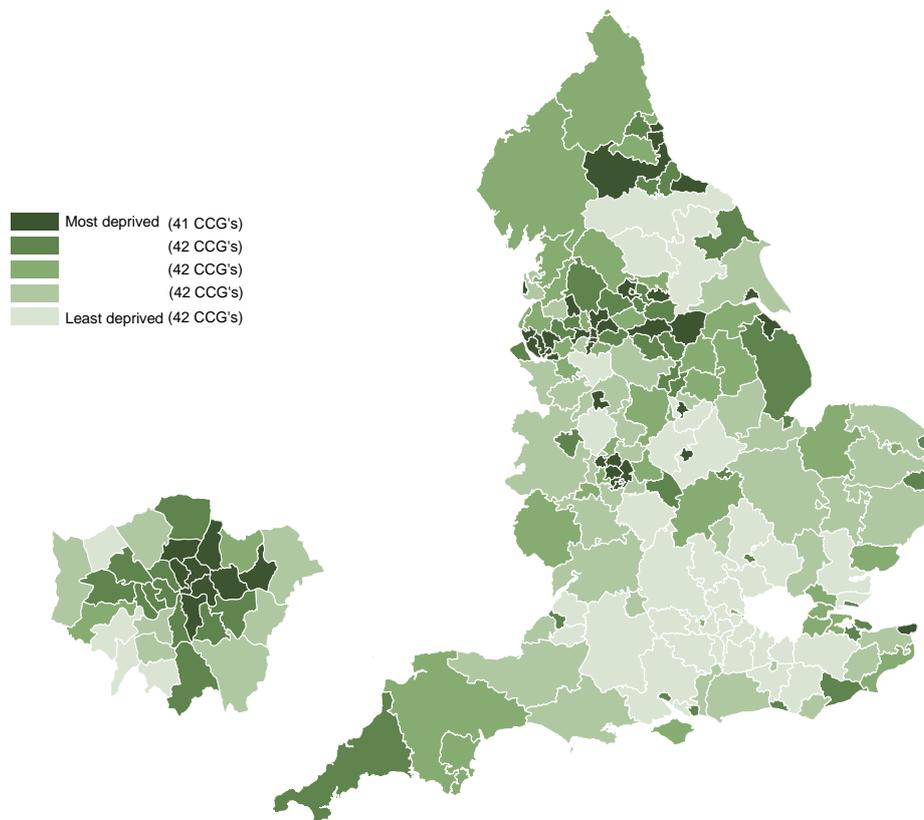
Palliative and end of life care is provided across many service delivery settings, and commissioning these services requires shared responsibilities. Commissioners and providers are required to consider equity of access when planning and delivering their palliative and end of life care services (Equality 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.

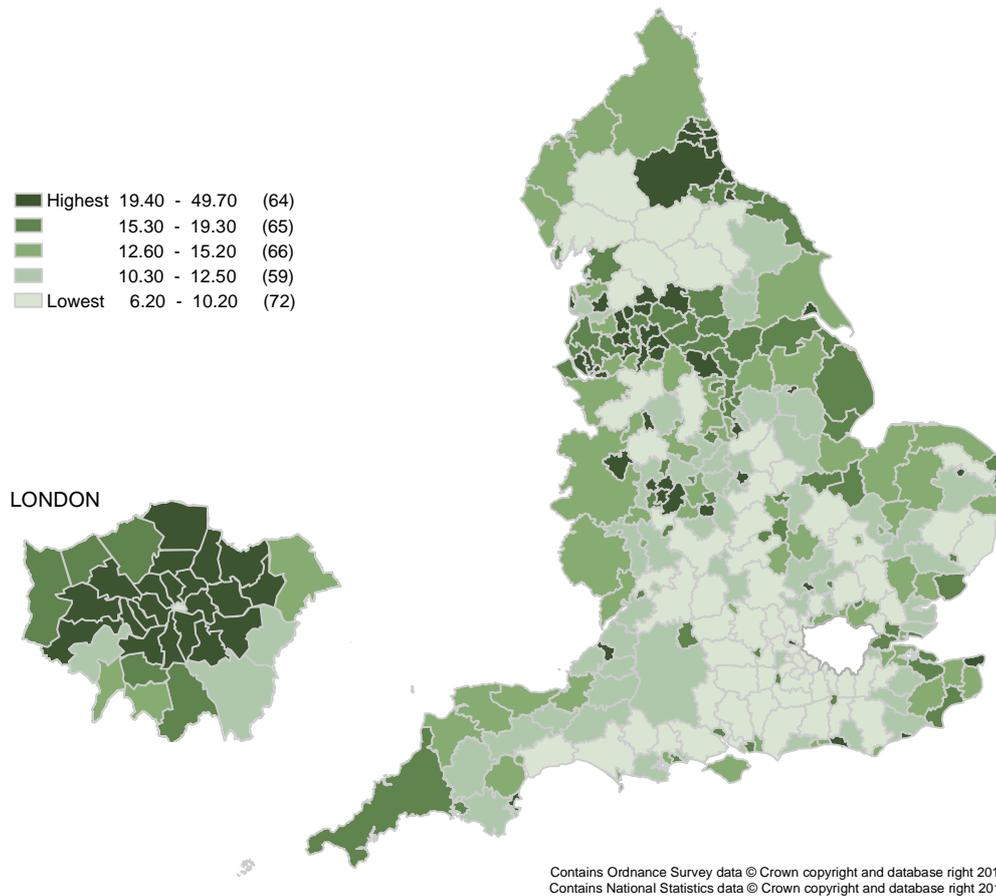
Figure 8: Index of multiple deprivation 2015 average LSOA score CCG quintiles²⁸



Contains Ordnance Survey data © Crown copyright and database right 2016.
Contains National Statistics data © Crown copyright and database right 2016.

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.

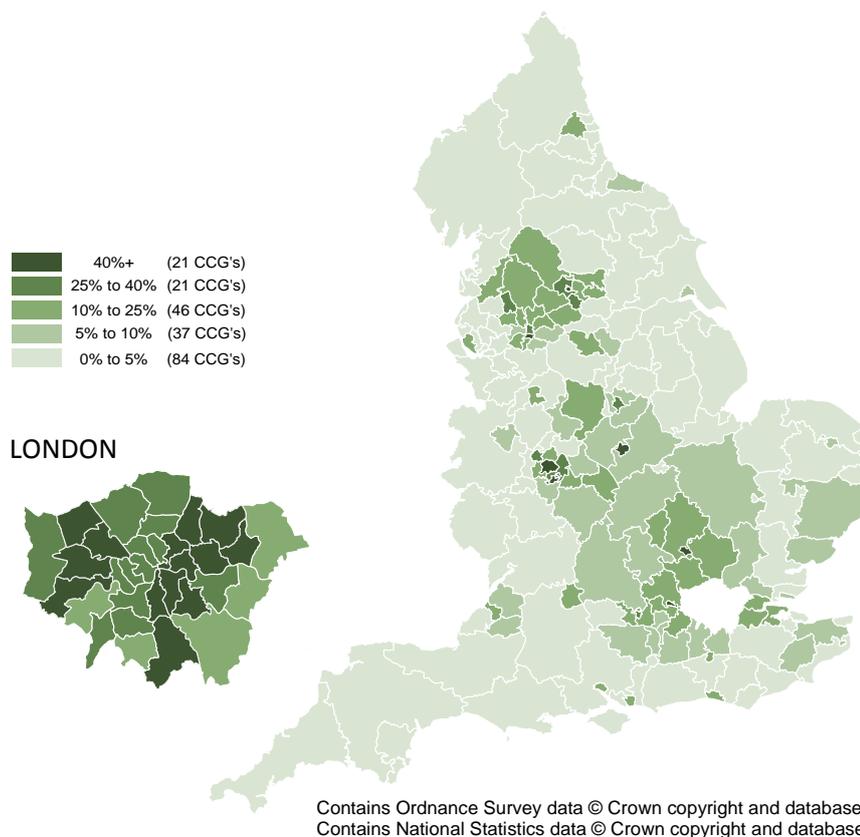
Figure 9: Pensioner poverty in England, 2015²⁸



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.

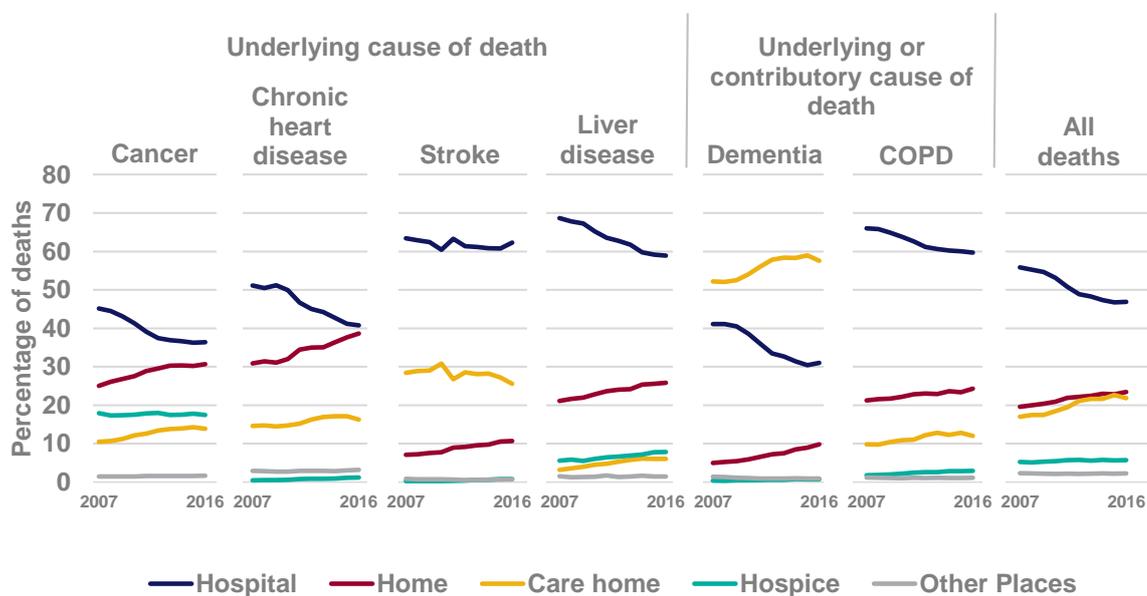
The role of hospitals in end of life

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.

References

- ¹ Office for National Statistics (ONS) [Death registrations summary tables - England and Wales \(2016\)](#) [Accessed August 2018]
- ² Ennis L, Kinley J, Hockley J and others (2015) [The cost of providing end of life care for nursing care home residents: A retrospective cohort study](#) Volume 28 Issue 1-2, page 16-23 [Accessed August 2018]
- ³ Barnarto A (2007) End of Life Care: Can we rationalise costs. *Critical Quarterly* 49 (3): 84-92
- ⁴ Department of Health and Social Care (2015) [Choice in end of life care](#) [Accessed August 2018]
- ⁵ 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]
- ⁶ National Institute of Health and Care Excellence (NICE) (2015) [Care of dying adults in the last days of life \[NG31\]](#) [Accessed August 2018]
- ⁷ National Institute of Health and Care Excellence (NICE) (2017) [Care of dying adults in the last days of life \[QS144\]](#) [Accessed August 2018]
- ⁸ 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) [Accessed August 2018]
- ⁹ 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]
- ¹⁰ Public Health England (PHE) (2018) [Statistical commentary: End of Life Care Profiles, February 2018 update](#) [Accessed August 2018]
- ¹¹ Wennberg JE, Cooper M and others (1996) [The Dartmouth Atlas of Health Care](#) [Accessed August 2018]
- ¹² Wennberg J (2010) [Tracking Medicine: A Researcher's Quest to Understand Health Care](#) Oxford University Press [Accessed August 2018]
- ¹³ Care Quality Commission (CQC) (2016) [A different ending: End of life care review](#) [Accessed August 2018]
- ¹⁴ Public Health England (PHE) [End of Life Care Profiles](#) [Accessed August 2018]
- ¹⁵ Office for National Statistics (ONS) Public Health England Annual Births and Mortality Extracts
- ¹⁶ Office for National Statistics (ONS) [Subnational population projections for England: 2016-based](#) [Accessed August 2018]
- ¹⁷ Ekind SN, Bone AE, 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]
- ¹⁸ Dying Matters [Find your 1%: supporting GPs in delivering quality end of life care](#) [Accessed August 2018]
- ¹⁹ Office for National Statistics (ONS) [Clinical Commissioning Group Mid-Year Population Estimates \(National Statistics\)](#) [Accessed August 2018]
- ²⁰ Steinhilber K, Christakis NA and others (2000) [Factors considered important at the end of life by patients, family, physicians, and other care providers](#) *JAMA*, 284(19), p.2476 [Accessed August 2018]
- ²¹ Mistry B, Bainbridge D, Bryant D and others [What matters most of end-of-life care? Perspectives from community-based palliative care providers and administrators](#) [Accessed August 2018]
- ²² Higginson I (2003) [Priorities and preferences for end of life care in England, Wales and Scotland](#) [Accessed August 2018]
- ²³ Waghorn M, Young H, Davies A (2011) [Opinions of patients with cancer on the relative importance of place of death in the context of a 'good death'](#) *BMJ Supportive Palliative Care* 1:310-314 [Accessed August 2018]
- ²⁴ Abel J, Pring A, Rich A and others (2013) [The impact of advance care planning of place of death, a hospice retrospective cohort study](#) *BMJ Supportive & Palliative Care* 2013;3:168-173 [Accessed August 2018]
- ²⁵ Dixon J, King D, Knapp M (2016) [Advance care planning in England: Is there an association with place of death? Secondary analysis of data from the National Survey of Bereaved People](#) *BMJ Supportive & Palliative Care* doi: 10.1136/bmjspcare-2015-00097 [Accessed August 2018]
- ²⁶ Office for National Statistics (ONS) (2016) [National Survey of Bereaved People \(VOICES\): England, 2015](#) [Accessed August 2018]
- ²⁷ Public Health England (PHE) National End of Life Care Intelligence Network (2012) [Deprivation and Death: Variation in place and cause of death](#) [Accessed August 2018]
- ²⁸ Ministry of Housing, Communities & Local Government (2015) [English indices of deprivation 2015](#) [Accessed August 2018]
- ²⁹ Nazroo JY *American Journal of Public Health* (2003) [The Structuring of Ethnic Inequalities in Health: Economic Position, Racial Discrimination, and Racism](#) [Accessed August 2018]
- ³⁰ Smith GD (2000) [Learning to live with complexity: ethnicity, socioeconomic position, and health in Britain and the United States](#) *American Journal of Public Health* [Accessed August 2018]
- ³¹ Wohland P, Rees P, Nazroo J, and others (2015) [Inequalities in healthy life expectancy between ethnic groups in England and Wales in 2001](#) *Ethnicity & Health Journal*. Doi: 10.1080/13557858.2014.921892 [Accessed August 2018]
- ³² Kaufman JS, Dolman L, Rushani D and others (2015) [The contribution of genomic research to explaining racial disparities in cardiovascular disease: a systematic review](#) *American Journal of Epidemiology* 181 (7): 464-472 [Accessed August 2018]
- ³³ Public Health England (PHE), King's College London, Marie Curie Cancer Care (2013) [Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK](#) Demographic profile and the current state of palliative and end of life care provision [Accessed August 2018]
- ³⁴ Zeh P, Harbinder SK, Cannaby AM and others (2014) [Cultural barriers impeding ethnic minority groups from accessing effective diabetes care services: a systematic review of observational studies](#) *Diversity and Equality in Health and Care* 2014; 11 (1): 9-33 [Accessed August 2018]
- ³⁵ Taylor SP, Nicolle C, Maguire M (2013) [Cross-cultural communication barriers in health care](#) *Nursing Standard* 2013; 27 (31): 35-43 [Accessed August 2018]
- ³⁶ *Health Service Journal* [Race inequality of NHS staff is putting patients at risk](#) (2015) 125 (6437): 20-21 [Accessed August 2018]
- ³⁷ Social Care Institute for Excellence (SCIE) (2018) [Growing innovative models of health, care and support for adults](#) [Accessed August 2018]
- ³⁸ National Council for Hospice and Specialist Palliative Care Services (2001) [Wider horizons: Care of the Dying in a Multicultural Society](#) [Accessed August 2018]
- ³⁹ Atkinson M, Clark M, Clay D, and others (2001) Systematic review of ethnicity and health service access for London. Final report. Centre for Health Services Studies (CHESS) and Centre for Research in Ethnic Relations (CRER) at the University of Warwick, Mary Seacole Research Centre (MSRC) at De Montfort University
- ⁴⁰ Johnson M (2001) *Palliative Care, Cancer and Minority Ethnic Communities: A Literature Review*. Leicester: Mary Seacole Research Institute, De Montfort University

- ⁴¹ Elkan R, Avis M, Cox K and others (2007) [The reported views and experiences of cancer service users from minority ethnic groups: a critical review of the literature](#) *European Journal of Cancer Care* 16: 109–21 [Accessed August 2018]
- ⁴² Evans N, Meñaca A, Andrew EV, and others (2012) [Systematic Review of the Primary Research on Minority Ethnic Groups and End-of-Life Care From the United Kingdom](#) *J Pain Symptom Manage* 43: 261–86 [Accessed August 2018]
- ⁴³ Office for National Statistics (ONS) 2011 Census, table KS201EW
- ⁴⁴ Public Health England (PHE) National End of Life Care Intelligence Network (2018) [Place of death by ethnic group for people who died from cancer](#) [Accessed September 2018]
- ⁴⁵ Harding R, Epiphaniou R, Chidgey-Clark J (2012) [Needs, Experiences and preferences of sexual minorities for end of life care and palliative care: a systematic review](#) *Journal of Palliative Medicine* 15:602-611 [Accessed August 2018]
- ⁴⁶ Almack K, Moss B and Smith T (2015) Research and policy about end of life care for LGBT people: identifying implications for social work services, in Fish J and Karban K, eds, *Social Work and Lesbian, Gay, Bisexual and Trans Health Inequalities: International Perspectives*. Bristol: Policy Press, p173-186
- ⁴⁷ The University of Sheffield and Crisis (2012) [Homelessness kills: An analysis of the mortality of homeless people in early twenty-first century England](#) [Accessed August 2018]
- ⁴⁸ Shulman C, Hudson BF, Low, J and others (2018) [End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care](#) [Accessed August 2018]
- ⁴⁹ Care Quality Commission (CQC) and Faculty for Homeless and Inclusion Health (2017) [A second class ending. Exploring the barriers and championing outstanding end of life care for people who are homeless](#) [Accessed August 2018]
- ⁵⁰ University of Bristol (2013) [Confidential Inquiry into premature deaths of people with learning disabilities \(CIPOLD\)](#) [Accessed August 2018]
- ⁵¹ 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](#) [Accessed August 2018]
- ⁵² Prisons and Probation Ombudsman for England and Wales (2013) [Learning from PPO Investigations End of Life Care](#) [Accessed 2018]
- ⁵³ NHS England (2015) [Transforming end of life care in acute hospitals. The route to success 'how to' guide](#) [Accessed August 2018]
- ⁵⁴ Gomes B, Higgingson IJ [Factors influencing death at home in terminally ill patients with cancer: systematic review](#) *Figure 4 Model of variations of place of death* 10.1136/bmj.38740.614954.55 [Accessed August 2018]
- ⁵⁵ Public Health England (PHE) National End of Life Care Intelligence Network (2011) [Predicting Death: Estimating the proportion of deaths that are 'unexpected'](#) [Accessed August 2018]
- ⁵⁶ Hanratty B, Lawson E, Grande G and others *Transitions at the end of life for older adults – patient, carer and professional perspectives: a mixed-methods study*. *Health Serv Deliv Res* 2014;2(17)
- ⁵⁷ National Audit Office (NAO), London: The Stationery Office (2008) [End of Life Care](#) [Accessed August 2018]
- ⁵⁸ Guy's and St Thomas' NHS Foundation Trust [The AMBER care bundle](#) [Accessed August 2018]
- ⁵⁹ [Recommended Summary Plan for Emergency Care and Treatment \(ReSPECT\)](#) [Accessed August 2018]
- ⁶⁰ 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]
- ⁶¹ Public Health England (PHE) (2017) [End of life care economic tool. Tool, guidance on how to use and report](#) [Accessed August 2018]
- ⁶² Public Health England (PHE) National End of Life Care Intelligence Network and Office for National Statistics (ONS) [Number and proportion of deaths by place of occurrence](#) [Accessed August 2018]
- ⁶³ Public Health England (PHE) [Dementia Profile](#) [Accessed August 2018]
- ⁶⁴ NHS England (2017) ['Where to look' packs](#) [Accessed August 2018]
- ⁶⁵ NHS England and NHS RightCare (2016) [Long Term Condition packs](#) [Accessed August 2018]
- ⁶⁶ End of Life Care Coalition (2017) [End of Life Care in Sustainability and Transformation Plans: an analysis](#) [Accessed August 2018]
- ⁶⁷ [Ambitions for Palliative and End of Life Care Case Studies](#) [Accessed August 2018]
- ⁶⁸ Ambitions for Palliative and End of Life Care Case Studies [Health Education Yorkshire and the Humber](#) funded training significantly increases practice based Advance Care Planning in settings across the district. More people supported to have their preference for end of life care discussed and recorded. [Accessed August 2018]
- ⁶⁹ Ambitions for Palliative and End of Life Care Case Studies [Coordinate My Care: joining up London's end of life care services – Coordinate My Care \(CMC\) is an integrated model of care, underpinned by IT, which is currently being rolled out across London](#) [Accessed August 2018]
- ⁷⁰ Ambitions for Palliative and End of Life Care Case Studies [University Hospital Southampton NHS Foundation Trust: A whole system approach to improving acute end of life care](#) [Accessed August 2018]
- ⁷¹ Ambitions for Palliative and End of Life Care Case Studies Leeds – [Improved recognition and shared decision making through the use of EPaCCS](#) [Accessed August 2018]
- ⁷² Royal College of Physicians (2016) [End of Life Care Audit – Dying in Hospital: National report for England 2016](#) [Accessed August 2018]