

A Picture of End-of-Life Care in England

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Document control

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1. Foreword

Demand for palliative and end-of-life care (PEOLC) in the UK is increasing rapidly. As a result of our growing and ageing population, in twenty years' time it is estimated that there will be 100,000 more people dying each year in the UK. As more people live for longer with multiple and complex conditions, the number of people with a need for palliative care has been projected to increase by up to 42% by 2040.

PEOLC is a core component of health and care and their services are in high demand. However, we knew prior to the pandemic that there were serious issues, meaning people did not always have choice, care was not always being personalised and gaps in services meant variability in people's experience and inequity in provision. The pandemic has further highlighted and exacerbated many of the existing gaps in high quality PEOLC and has resulted in death and dying climbing the policy agenda in the UK. Therefore, it is even more important that we try to ensure people approaching the end of their lives receive the best possible care and support.

Macmillan Cancer Support's vision for PEOLC flows from the organisational mission to help people with cancer live life as fully as they can. The approach to end-of-life is broader because the systems and providers that Macmillan works with provide end-of-life care for people with all manner of life-limiting conditions. Aside from Macmillan's learning and development offer and advocacy work in influencing for better quality and more equitable access to PEOLC, there are currently two main funding options where Macmillan is investing. The first is social investment where Macmillan has partnered with Social Finance to invest in transformational adult end-of-life care (cancer and non-cancer). The £36m Macmillan fund provides up-front funding for service transformation and is repayable only if mutually agreed outcomes are met. The second funding option is the Transformational Leadership programme where Macmillan is investing into system posts to transform palliative and end-of-life care. This programme aims to create leadership roles and will support both the influencing agenda and the development of business cases for the Social Investment programme.

One challenge with delivering equitable PEOLC services in the UK is the limited evidence and data around why there is so much inequity and variability in people's experience and access to the services they need. To support this evidence base and inform where investment is most needed, Macmillan commissioned the Strategy Unit to run in depth analyses exploring variation and the key factors underpinning end-of-life experience, creating a picture of end-of-life care in England.

Whilst the work outlined in this report relates to England, we are working with partners across the UK to scope out the potential for further analysis in each of the devolved nations.

We hope this report will also provide a useful resource for other organisations and system partners to improve services and patient experience.

Adrienne Betteley, Macmillan Cancer Support Strategic Advisor for End-of-Life Care

2. Executive summary

The quality of care at the end-of-life has been a consistent focus of health policy over the past decade, and many improvements have been delivered. It is still true however, that many people die in hospital when they would prefer to die at home. And many people experience multiple emergency department visits and unplanned hospital admissions in the period leading up to death. More often than not, these indicate a breakdown or failure in the care they were receiving.

Macmillan wanted to understand this picture in more detail. Specifically, who is more likely to experience poor outcomes associated with shortcomings in end-of-life care? Are there particular areas in England where those at end-of-life face significant challenges and how might the supply of services in an area be influencing these?

To answer these questions our report investigates which subgroups of deceased adults are more likely to experience poor outcomes and quantifies the magnitude of that risk. It highlights some contextual supply factors, such as the availability of community nursing and care home beds, that appear to be related to these outcomes. It then considers whether there are specific areas in England where palliative care services appear to be facing particularly difficult circumstances and what the nature of these might be.

The aim of this analysis is to equip decision-makers with insight as to who is most in need of improved support at end-of-life; the type of resource that may best help meet their needs; and specific areas within England that may benefit the most from increased support. The intention is that, by identifying these groups and factors, systems will be better able to focus their efforts in securing further improvements in quality end-of-life care for all.

2.1 Key messages

This report presents an opportunity for change and improvement by describing which subgroups may be at a disadvantage in accessing high-quality palliative care, and the magnitude of the disadvantage they face. Our analysis shows that the following subgroups are consistently more at risk of poor outcomes:

- The younger a person is when they die, the greater the risk of poor outcomes. For example, in the youngest age group (those dying aged 18-44) the likelihood of dying in hospital is considerably larger (57% higher). They are also more likely to have multiple emergency admissions (81% more likely) and multiple A&E attendances (36% more likely).
- Although those with a cancer cause of death are far less likely to die in hospital, they are at substantially greater risk for other outcomes. In particular, multiple emergency admissions (40% more likely) and multiple A&E attendances (31% more likely).

-
- A sizeable number - nearly a third - of people are living alone before they die. Those who live alone are far more likely to routinely experience poor outcomes. This is particularly noticeable in place of death. Those who live alone before death are 52% more likely to die in hospital than those who live with others.
 - Another subgroup with consistently poor outcomes is men. For example, compared to women, men are 20% more likely to die in hospital, 15% more likely to have multiple A&E attendances, 14% more likely to have multiple emergency admissions and 9% more likely to visit hospitals out-of-hours.
 - Those from rural areas seem to be routinely at lower risk of poor outcomes when compared to those in urban areas. However, rather than indicating a benefit, this may instead represent barriers in accessing hospital care for those at end-of-life who live in rural areas.
 - There is a greater risk of some poor outcomes for those who identify as either Asian/Asian British or Black/Black British when compared to those identifying as White. This is particularly notable when considering the likelihood of dying in hospital. Those who identify as Asian/Asian British are 58% more likely to die in hospital than those who identify as White. Whilst for those who are Black/Black British the likelihood is 18% higher.
 - Impacts from deprivation show clear gradients where, as deprivation increases, so too does the risk of poor outcomes. However, when compared to effects in other subgroups, deprivation is smaller in scale.
 - Certain areas of England seem to suffer from increased risk of poor outcomes. There may well be local knowledge and intelligence as to the reasons behind this. The intention here is that analysis by geography can help provide clarity regarding the challenges specific areas may face.

In addition, we consider the impact of the available supply of services. Generalist services such as primary care, district nurses, and care homes have a critical role to play in providing end-of-life care. Yet, little seems to be known about the degree to which increasing supply of these services may be able to improve palliative care. Our analysis shows that:

- A relatively modest increase in the amount of community care a person receives at end-of-life can substantially reduce the likelihood of dying in hospital. An additional 10 community contacts in the last 90 days of life may reduce the risk of dying in hospital by 18%.
- Although smaller in scale, increased community contacts also significantly reduce the risk of multiple A&E attendances, out-of-hours visits to hospital, and additional unplanned time in or at hospital.

-
- The availability of care home beds in an area shows that relatively modest increases in the number of beds can provide small but significant reductions to the risk of many poor outcomes.
 - Increased recording on primary care palliative care registers has a more mixed effect on the likelihood of poor end-of-life outcomes. It does not seem to affect the risk of dying in hospital or multiple A&E attendances. It does however reduce the risk of multiple emergency admissions and additional time in or at hospital.

3. A summary of the analytical approach

Our analysis seeks to measure differences in the likelihood of people experiencing poor outcomes at end-of-life. The principle of equity requires that those with similar levels of need should have an equivalent chance of avoiding poor outcomes, irrespective of their personal characteristics. In our decedent population - those people who died in a particular period – are all decedents at the same risk of experiencing poor outcomes? And if they aren't, which factors influence that risk, and what is the strength of that influence? Understanding these differences and disparities is crucial to understanding the current provision of end-of-life care. Allowing the identification of at-risk populations is a first step towards implementing targeted interventions, addressing specific risk factors, and improving outcomes for those at end-of-life.

To do this we use regression analysis. Regression analysis is a statistical method used to examine the relationship between an outcome (dependent variable) and some other factors of interest (independent variables). Many of these factors of interest are related and so it can be difficult to see which are exerting the strongest effect on an outcome. Regression helps us to tease out the impact of a factor, independently and of itself, on the outcome. Regression analysis is widely used in various fields, including economics, finance, social sciences, medical research, and many other areas. It helps researchers and analysts to understand the relationship between variables, make predictions, and identify the strength and significance of these relationships.

To support this analysis, we assembled a dataset of 400,000 adults who died in England in the financial year 2021/22. Any adults classified as a 'sudden death' were excluded. They were excluded as they are far less likely to require palliative care and the poor outcomes we consider here would not have the same meaning and implications for those who die suddenly. Sudden death is considered to be one where a decedent was highly functional until one month before death¹.

At the start of 2021/22, the UK continued its emergence from the COVID-19 pandemic. By July 2021 most legal limits on social contact had been removed in England with the final closed sectors of the economy also reopened (e.g., nightclubs)². Therefore, this analysis covers a period for deaths where life had returned to normal, although some lingering repercussions from the pandemic may still have been felt – particularly for those accessing healthcare.

¹ <https://agsjournals.onlinelibrary.wiley.com/doi/full/10.1046/j.1532-5415.2002.50268.x>

² <https://www.instituteforgovernment.org.uk/sites/default/files/2022-12/timeline-coronavirus-lockdown-december-2021.pdf>

4. Poor care outcomes

It can be a challenge from available data to provide clear analytical indicators to assess if a person had a 'good death'. There is a lack of data about the full range of services received by decedents, the quality of those services, and the extent of any unmet need. But we do have some data, we have data for a person at death, including their place of death. We also have data for hospital care. This allows us to link deceased individuals to their hospital activity, such as A&E attendances, emergency admissions, and outpatient appointments, in their time before death.

Using available data, the following outcome measures were developed. To ensure outcome measures were relevant, workshops were held with stakeholders, clinicians, and others working in palliative care.

The outcomes used are:

Place of death

- Did the person die in a hospital setting?

Urgent care

- Did the person have 3 or more emergency admissions in the **year** prior to death?
- Did the person have 2 or more A&E attendances in the **90 days** prior to death?
- Did the person have an out-of-hours emergency admission in the **90 days** prior to death?

Hospital care days

- The number of days **90 days prior** to death where there was **unplanned** hospital care. Including days with any; A&E attendance, emergency admission or stay in a hospital bed following an emergency admission.
- The number of days **90 days prior** to death where there was **planned** hospital care. Including days with any; outpatient appointment (which took place face-to-face, not remotely), planned admission or stay in a hospital bed following a planned admission.

4.1 Rationale for the chosen outcome measures

Place of death

Although most people say they would like to die at home, this may not be the preferred choice for all. Assumptions that all deaths at home are 'good' and all deaths at hospital are 'bad' can be an oversimplification. It does not take account of situations where a person's preferred place of death is at hospital. Neither does it consider if those who died at home could access well-coordinated quality care and the treatment they needed.

Yet, while there is a growing sense that death in hospitals may be flawed as an outcome measure, it remains true that most people would rather die at home than in hospital. And at present there is no source of data on people's preferences which could currently be considered accurate and robust enough for analytical use. Therefore, in the absence of an alternative, but being mindful of its limitations, we continue to use deaths in hospitals as a proxy for poor end-of-life care.

Urgent care

Reliance on urgent care for those approaching end-of-life may indicate poor care planning and integration of services. The three measures used here all provide a different perspective on how potentially inappropriate urgent care could present and through which we can view how each poor urgent care outcome may affect particular groups of decedents.

Hospital care days

For those who are dying time is an increasingly precious and scarce resource. Time spent in or at hospital can place a burden on those at end-of-life. It can involve them spending time travelling to or from hospital, waiting to be treated, or taking them away from familiar and comforting environments when staying overnight. However, hospital care is often in-line with need and people will benefit from visits and stays in hospital which have a positive impact on their welfare. Appreciating this difference, we have developed two outcomes for hospital care days.

Unplanned hospital care days are those in the last 90 days of life when a person has some form of unplanned care. This can include attending hospital A&E departments or spending a night in a hospital bed after an emergency admission.

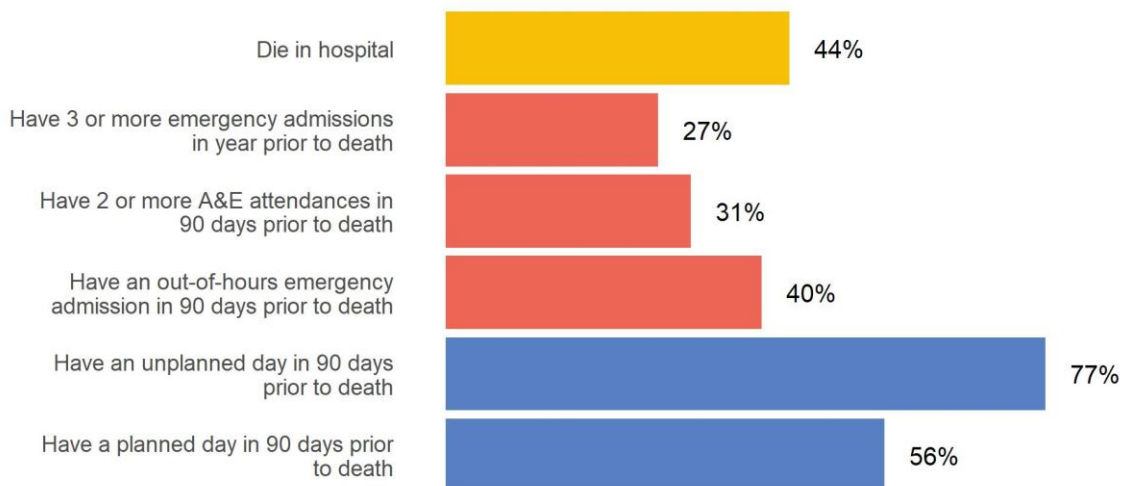
Planned hospital care days are counted similarly but where a person has some form of care which is planned. This might be attending hospital outpatient appointments, receiving planned inpatient treatment, or spending a night in a hospital bed after an elective admission.

Whilst unplanned care may reasonably be considered to imply a level of unmet need, planned care can be more ambiguous. Cancer patients for example can benefit from chemotherapy – and these are usually delivered as planned care – yet chemotherapy delivered in the period leading up to death may not carry any benefit to patients^{3,4}. This ambiguity should be borne in mind when interpreting results for this outcome. Planned hospital care days will neither be exclusively good or exclusively bad. Instead, this outcome provides an opportunity for understanding where differences lie, allowing those working in end-of-life care to further consider why such differences exist and what they might mean for patients.

4.2 Outcome measures in context

There were over 400,000 decedents included in our regression models. To provide a sense of scale Figure 1 shows the proportion of decedents who experienced each outcome. It shows that close to half died in hospital (44%). Upwards of a quarter experienced a poor urgent care outcome. Three-quarters (77%) had at least one day of unplanned hospital care in the 90 days before they died, and half (56%) had at least one day of planned hospital care.

Figure 1 – Proportion of decedents in regression models who experience each outcome



³ Earle CC, Landrum MB, Souza JM et al. Aggressiveness of cancer care near the end-of-life: is it a quality-of-care issue? *J Clin Oncol* 2008;26:3860–6.

⁴ <https://jamanetwork.com/journals/jamaoncology/fullarticle/2398177>

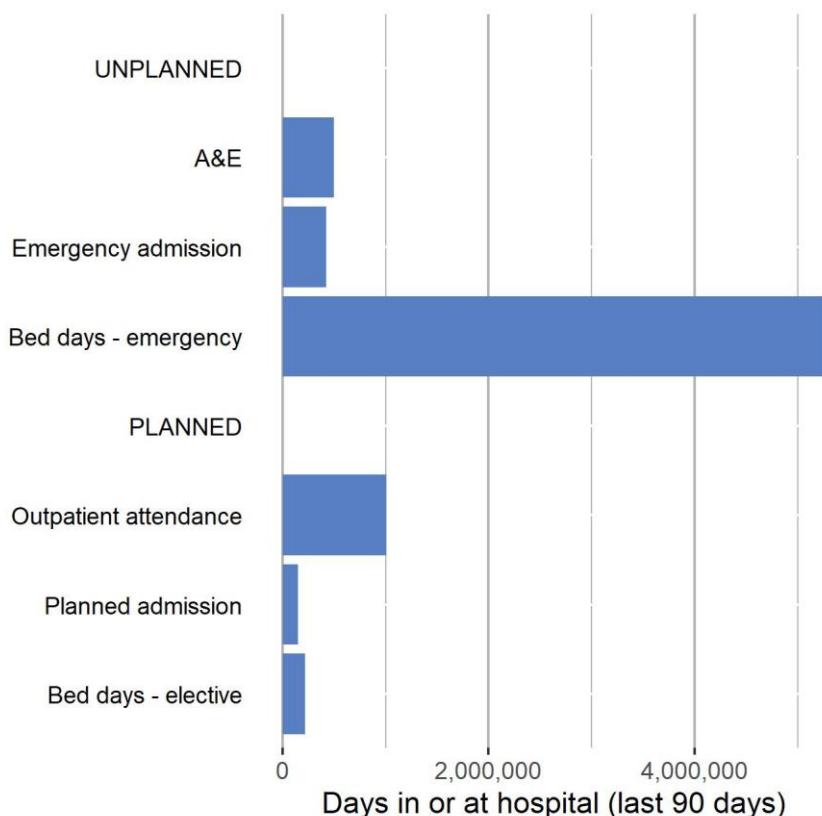
In addition, Figure 2 shows the number of days (in the last 90) contributing to unplanned and planned hospital care days by type and volume. It is clear to see that bed stays after an emergency admission dominate in unplanned days – there are over 5million of these days for our decedents. By comparison, emergency admission or A&E attendance days are relatively small.

In planned care, the main type is an outpatient attendance. Overall, the scale of planned care is much less than unplanned care. Meaning that, in the last 90 days of life there are far more unplanned care hospital days than there are planned ones.

For both outcome measures more than one type of activity can take place on the same day, but days are counted only once. For example, if a person attends A&E, is admitted to a hospital bed that same day and then stays overnight, this is counted as one unplanned hospital care day even though more than one type of activity takes place.

On average, mean unplanned hospital care days was 13.6 and mean planned hospital care days was 3.0.

Figure 2 - Activity types and volumes contributing to unplanned and planned hospital care days



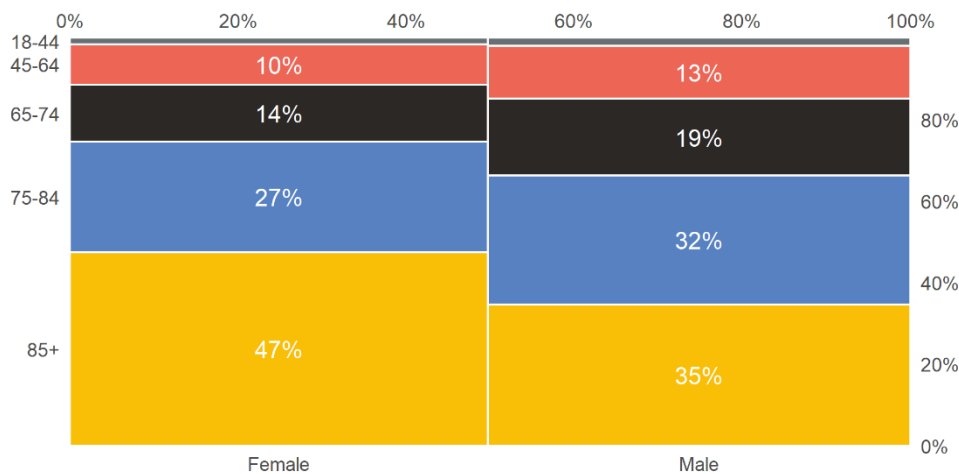
5. The decedent population

Before we consider the results of our analysis, we set out below, a description of our decedent population. We do this to aid understanding of the decedent population and are not implying here any relationships between the person factors presented in the charts.

5.1 Gender and age group

Although splits across gender are equal (females and males are both 50% of decedents) age profiles by gender do differ. Female decedents are older, nearly half (47%) were aged 85 or over when they died. For males, only a third (35%) are in this oldest age group.

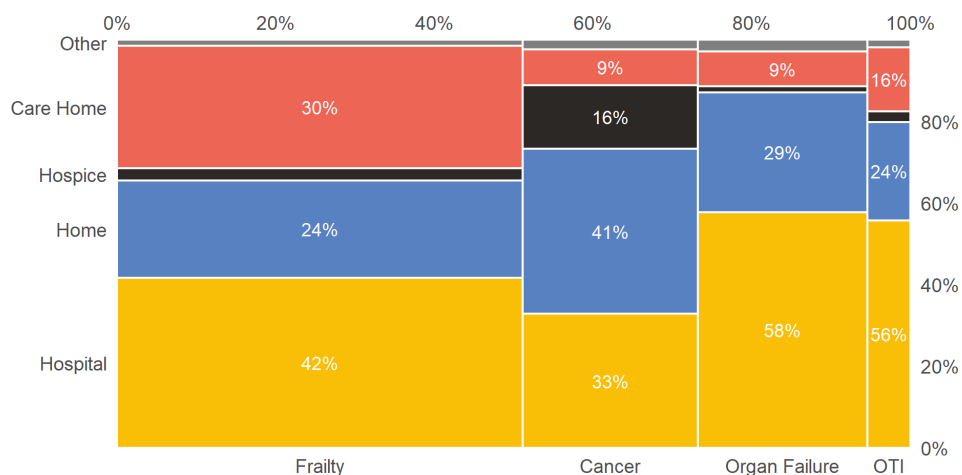
Figure 3 - Proportion of adult decedent population by gender and age group at death



5.2 Cause and place of death

Place of death differs significantly by cause. Frailty is the single largest underlying cause of death, accounting for close to half of all deaths (51%). Frailty has the largest proportion of deaths in a care home setting. Cancer is the cause of death for around a fifth of decedents (22%). Many with a cancer cause of death die at home (41%) and 1 in 6 (16%) die in a hospice setting. This is considerably higher than for other causes of death.

Figure 4 - Proportion of adult decedents by place of death and cause of death

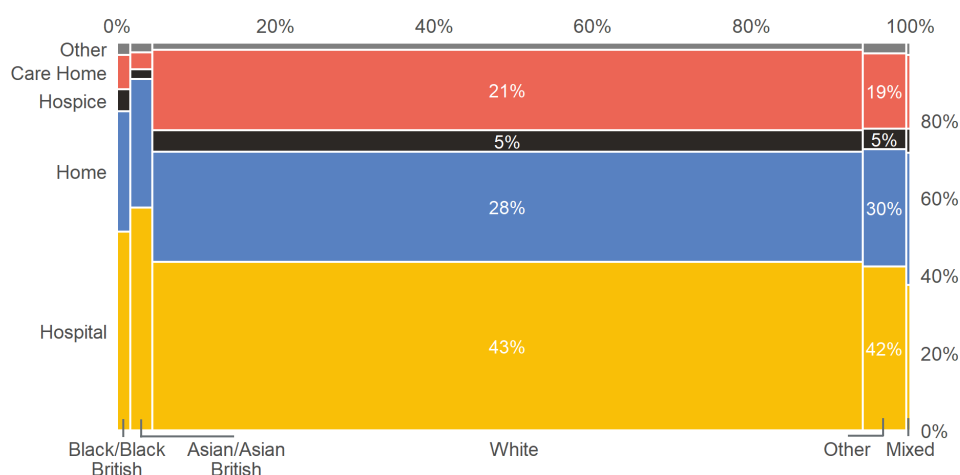


OTI = Other terminal illness

5.3 Ethnicity and place of death

Whilst hospital is the most common place of death for all ethnicities, it is highest for those from Asian/Asian British (57%) or Black/Black British backgrounds (51%). Correspondingly, these ethnicities have far smaller proportions of deaths in care homes. Asian/Asian British decedents have a smaller proportion of deaths at a hospice – with only 2.5% dying at this type of location.

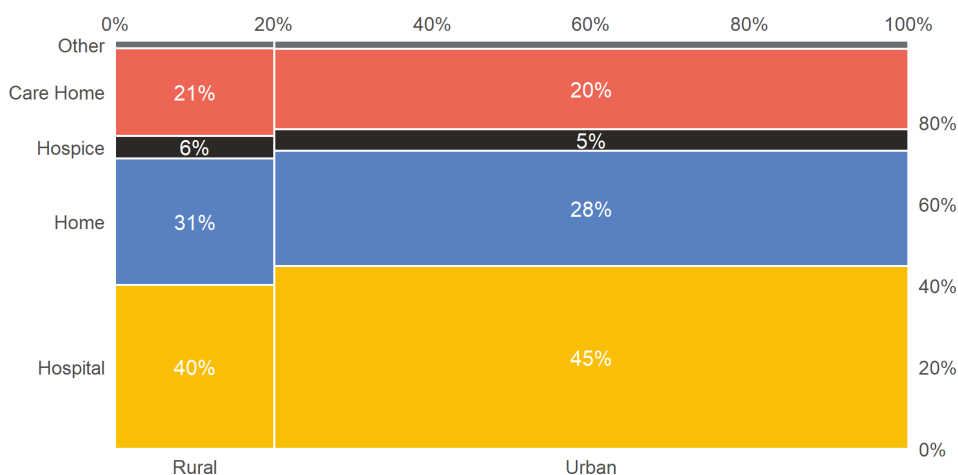
Figure 5 - Proportion of adult decedents by place of death and ethnicity



5.4 Urban-rural dwellers and place of death

A fifth of decedents live in rural areas (21%). Compared to urban dwellers, rural decedents have fewer deaths in hospital and more deaths at home.

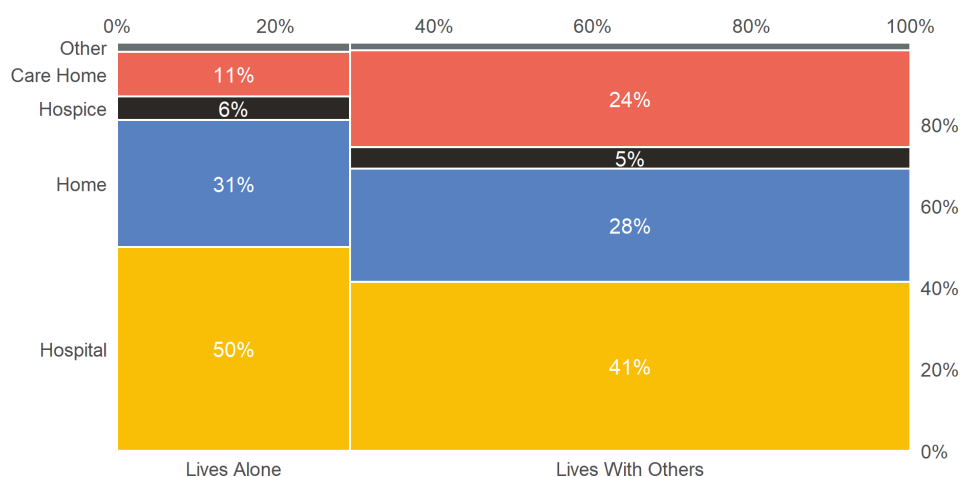
Figure 6 - Proportion of adult decedents by place of death and urban-rural dwellers



5.5 Place of death and living alone

Close to one in three decedents (29%) are identified as living alone⁵. For those identified as living alone, there is a greater proportion who die in hospital (50%) compared to those who live with others (41%). There is also a greater proportion of deaths at home for those living alone (31% versus 28%).

Figure 7 - Proportion of adult decedents by place of death and living alone at death



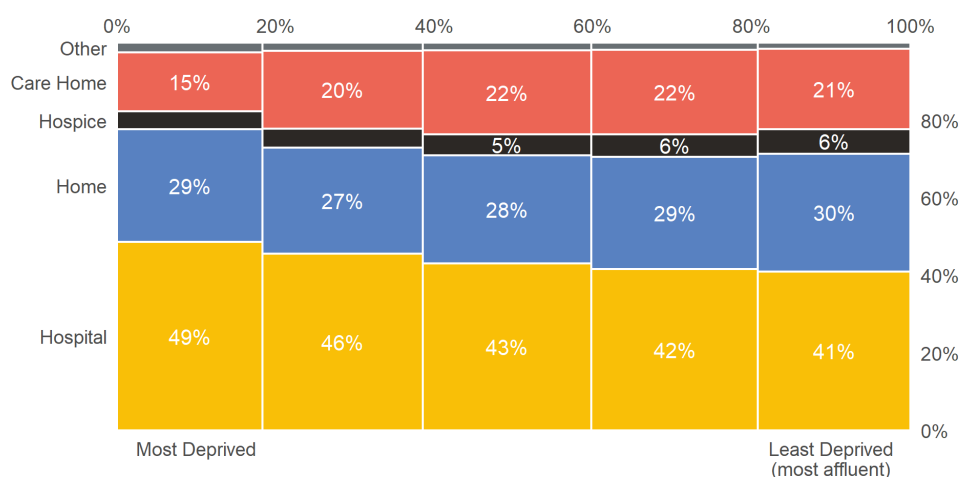
⁵ Classifying a person as 'living alone' should mean they do not live in a care home (which is classed as 'living with others'). However, 11% of those living alone are found to have died at a care home. This seeming inconsistency is due to what we intend when we say someone is 'living alone'. We take our data at a point in time (via yearly submissions from National Health Application and Infrastructure data) and the intention in our analysis is to see if those who have lived alone for a significant amount of time before death have differences in outcomes to those who spend more time living with others. It does not necessarily mean that they will have lived alone for the entirety of that time. They may well move into care homes relatively close to death and go on to die at that location.

5.6 Deprivation and place of death

As deprivation decreases then so too does the proportion of deaths taking place in hospital. Meaning, the more affluent a decedent's circumstances then the less likely they are to die in hospital. Correspondingly, the most affluent have more deaths in care homes. 21% of the most affluent die in a care home compared to 15% for the most deprived.

Here, and throughout this analysis⁶, deprivation is based on the Income Deprivation Affecting Older People (IDAOP)⁷ and not the Index of Multiple Deprivation (IMD).

Figure 8 - Proportion of adult decedents by place of death and deprivation quintile



⁶ IDAOP and IMD were both tested as a suitable deprivation variable for inclusion in regression models. IDAOP was found to be better explanatory variable and is therefore the only measure of deprivation used in this analysis

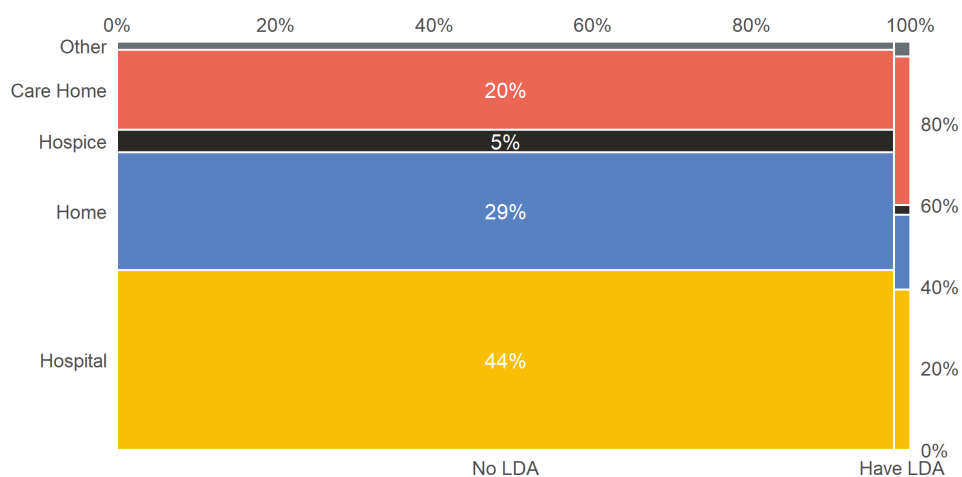
⁷ The Income Deprivation Affecting Older People Index (IDAOPI) measures the proportion of all those aged 60 and over who experience income deprivation.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/833974/File_3_-_IoD2019_Supplementary_Indices_-_IDACI_and_IDAOPI.xlsx

5.7 Learning disability, autism, or both and place of death

A small proportion (2%) of decedents are classified as having a learning disability, autism, or both⁸. This group is more likely to die in a care home (36% compared to 20% for those who aren't classified as having a learning disability, autism, or both). Reflecting that, for those with a learning disability, autism, or both, a type of supported or group home may often be their usual place of residence.

Figure 9 - Proportion of adult decedents by place of death and identified learning disability, autism, or both



LDA = Learning disability, autism, or both

⁸ This is comparable but slightly lower than the estimate of prevalence in the general population which is estimated to be 2.7%. Difference in prevalence may be accounted for by either the exclusion of sudden deaths and/or data quality in the recording of learning disabilities and autism

6. Regression results

In our regression models we consider what factors might influence the likelihood of poor outcomes. When we include these factors as model variables then we can examine their independent effect on the outcomes. From available data we selected the following model variables which we group into four broad themes; those which relate to equity; those which relate to differing levels of clinical need; the supply of services available to those at end-of-life; and, those relating to geography.

Model variables relating to equity

- Gender
- Rural-urban dweller
- Deprivation
- Ethnicity
- Learning disability, autism, or both
- Living alone
- Dies at weekend⁹

Model variables relating to clinical need

- Age
- Underlying cause of death

Model variables relating to supply of services

- Number of community contacts a person receives in the period before death
- Number of care home beds in a person's local area
- Level of palliative register recording in a person's local area

Model variable relating to geography

- Integrated Care Board

For most outcome measures (died in hospital, 3 or more emergency admissions in year prior to death, 2 or more A&E attendances 90 days prior to death, and out-of-hours emergency admission 90 days prior to death) our regression models are based on a binary outcome - either a person experienced the outcome, or they didn't. The likelihood is given as an odds ratio and a value of

⁹ Suitable for use only in the died in hospital outcome regression model

1.20 for a particular group would mean decedents in that group are 20% more likely to experience the outcome compared to the reference group.

For unplanned and planned hospital care days 90 days prior to death this is not the case. Here, instead of a yes/no outcome, we are counting the number of days in contact. This means values can range from 0 upwards to 90. For this type of regression, we construct our models in another way and results are interpreted slightly differently. Rather than an odds ratio instead we have an incidence rate ratio (IRR). This can be explained as the risk of having one additional unit – in our case a unit is a single day in contact with hospital services. For example, an IRR of 1.05 would mean decedents in that group are 5% more likely than the reference group to have a single additional hospital care day in their last 90 days.

To aid with interpretation we illustrate these examples more fully in the following section.

A full technical description of our models, their outputs, and data sources are included in the appendices.

6.1 Interpreting the charts

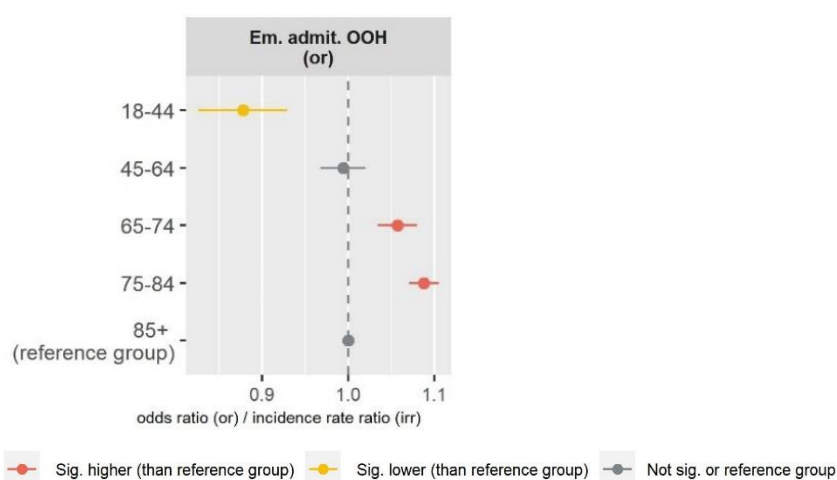
As an example, Figure 10 shows odds ratios for an out-of-hours emergency admission in the 90 days before death by age group. The impact is from age group alone, as our regression model has controlled for all other variables. The reference group¹⁰ is those aged 85 and over and is shown as a grey dot. The reference group will always have an odds ratio value of 1 (grey dashed line) and other age groups are all comparisons to the reference group.

Odds ratios higher than 1 are to the right side of the dashed line and mean the likelihood of the outcome is greater than for the reference group (red). When they are lower than 1 then they are to the left side and mean the likelihood is less (yellow).

It may not be possible to say if an odds ratio is higher or lower. Horizontal lines through dots indicate confidence intervals or the range in which we feel reasonably certain the true value lies¹¹. When confidence intervals cross the grey dashed line then we cannot be sure if they really are higher or lower. We classify this as 'not significantly different' (grey)¹².

In this example, those aged 75-84 have an odds ratio estimate of 1.09. A value greater than 1 puts them to the right side of the line and, since the confidence interval does not cross the line, we are reasonably certain they are higher than the reference group. An odds ratio of 1.09 in effect means you are 9% more likely to have an out-of-hours emergency admission if you are 75-84 compared to those who are 85 and over. If you were 18-44 then the odds ratio is 0.88 (below 1 and to the left side of the line), meaning you are 12% less likely to have an out-of-hours admission than those who are 85 and over¹³.

Figure 10 – Example of regression chart



¹⁰ Logistic regression requires a reference group to compare to. Each are selected using appropriate strategies

¹¹ At the 95% level

¹² Width of confidence intervals is affected by sample size and variability within the data

¹³ Odds ratio/IRR/confidence interval values are not labelled within charts, however values can be found in Appendix B

Charts use the following descriptions for each outcome:

Table 1 – Outcome measures with their short description

- Die in hospital - ***Die in hospital***
- Have 3 or more emergency admissions in year prior to death - ***3+ Em. Admits.***
- Have 2 or more A&E attendances in 90 days prior to death - ***2+ A&E atts.***
- Have an out-of-hours emergency admission in 90 days prior to death - ***Em. admit. OOH***
- Have an unplanned day in 90 days prior to death - ***Unplanned day***
- Have a planned day in 90 days prior to death - ***Planned day***

6.2 Equity

In this section we describe the risk of poor outcomes from a perspective of equity. Which groups are more likely to suffer poor outcomes? What is the scale of that difference and what specific problems or barriers faced at end-of-life might account for these differences?

Generally, the risk of poor outcomes is greater when:

- From Asian/Asian British backgrounds or Black/Black British backgrounds;
- Living alone;
- Living in more deprived circumstances;
- Male; and,
- Living in urban areas.

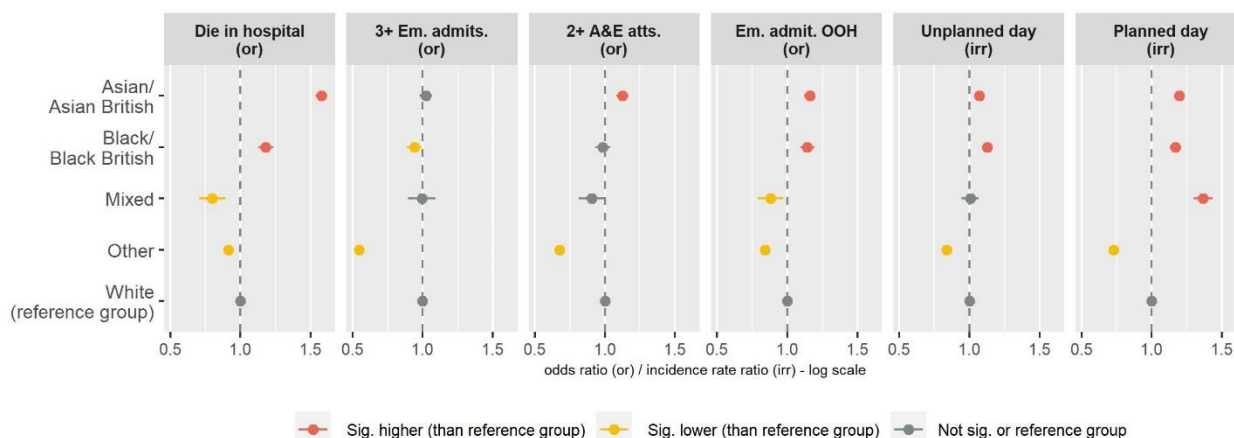
6.2.1 Ethnicity

Those who are Asian/Asian British or Black/Black British compared to White decedents are often at greater risk of poor outcomes.

This is particularly stark for deaths in hospital. Those from Asian/Asian British backgrounds are 58% more likely to die in hospital than White decedents. For those who are Black/Black British the risk is 18% higher. This variance in the likelihood of hospital as a place of death is borne out by other studies which suggest that for certain ethnic groups, there can be barriers to non-hospital places of death. These barriers may include issues such as language, religious or cultural needs, or the perception of hospices¹⁴.

The ethnic groups presented here will not be homogeneous. For example, Asian/Asian British is a contraction of several distinct ethnic backgrounds. Differences within groups may be present but are not visible to us here.

Figure 11 - Effect of ethnicity group on outcomes



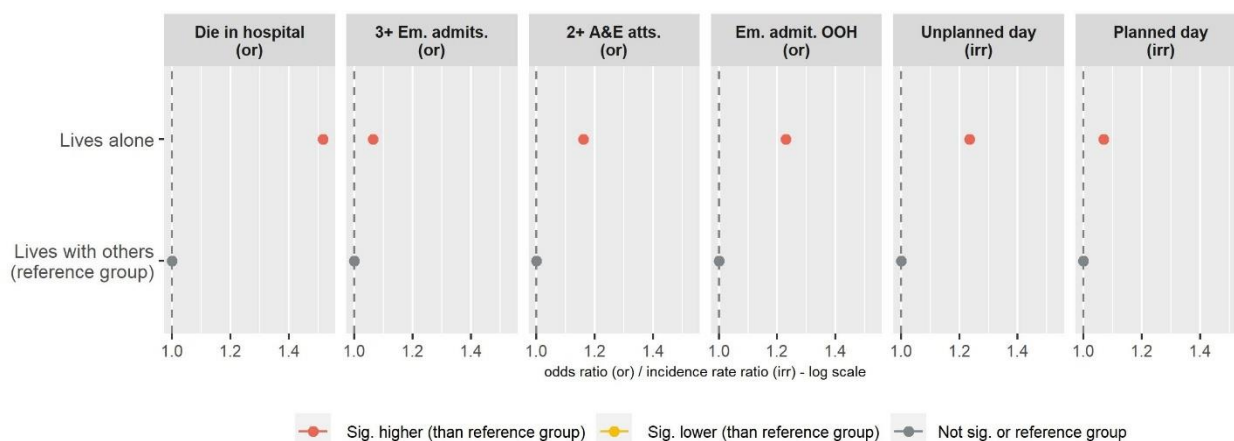
¹⁴ https://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_BAME_FINAL_2.pdf

6.2.2 Living alone

Those who live alone are consistently more likely to experience poor outcomes. You are 52% more likely to die in hospital if you live alone. Also, to have greater risks of all poor urgent care outcomes – particularly out-of-hours admissions (23%) – and are 24% more likely to have one more unplanned hospital care day.

In general, we see increased healthcare use for those who live alone¹⁵ (aged 65 and over). So, it seems that, even at end-of-life, those who live alone struggle in accessing the support necessary to avoid poor outcomes. Potentially, the absence of informal carers at home - and the lack of support and assistance in navigating services which they can provide – means those who live alone are more likely to rely on hospital services to meet their needs. Perhaps ensuring those who live alone are identified on local systems is a key first step, before considering how their specific needs might be met.

Figure 12 - Effect of living alone or with others on outcomes



¹⁵ <https://www.health.org.uk/news-and-comment/news/older-people-living-alone-are-50-more-likely-to-visit-ae-than-those-who-live-with>

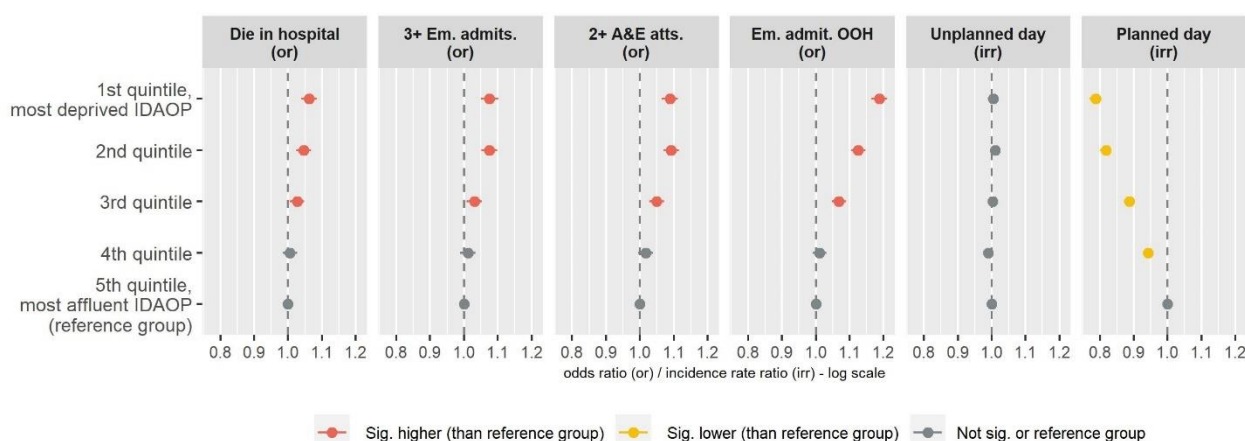
6.2.3 Deprivation

When considering deprivation there are clear gradients for most outcomes. Those in the most deprived circumstances are, compared to the most affluent, more likely to die in hospital (6%) and have a greater risk of all poor urgent care outcomes – particularly out-of-hours admissions (19%).

In planned hospital care days, the gradient of the slope reverses and the most deprived are much less likely to experience these – a 27% reduction in risk of an additional planned hospital care day compared to the most affluent. This may well indicate a particular lack of access to planned care for those in more deprived circumstances.

Interestingly, with unplanned hospital care days there is no significant difference by deprivation¹⁶. We know that the key component of this indicator is bed stays in hospital after an emergency admission (section 4.2). This may suggest a positive situation for those at end-of-life, whereby the length of time it takes to leave hospital after an emergency admission in the last 90 days of life is not related to a person’s financial circumstances and ability to pay for care outside of hospitals.

Figure 13 - Effect of quintiles of income deprivation affecting older adults on outcomes

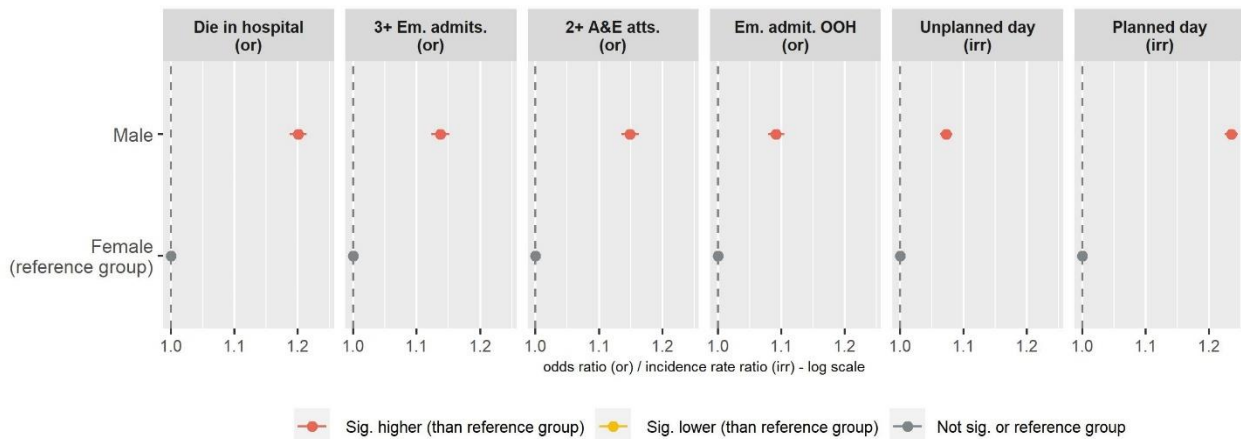


¹⁶ Please note that it is not possible to link unplanned hospital care days to urgent care outcomes. These are very distinct measures involving different decedents and methodologies. For example, a person may have a very long unplanned stay in hospital (counted in days) but not be included in any of the urgent care outcomes as they do not meet the threshold for these (counted as binary yes/no)

6.2.4 Gender

Compared to females, males fare substantially worse across all outcomes. Males are 20% more likely to die in hospital, have a substantially greater risk of all poor urgent care outcomes, and are 23% more likely to have one more planned hospital care day in their last 90 days.

Figure 14 - Effect of gender on outcomes

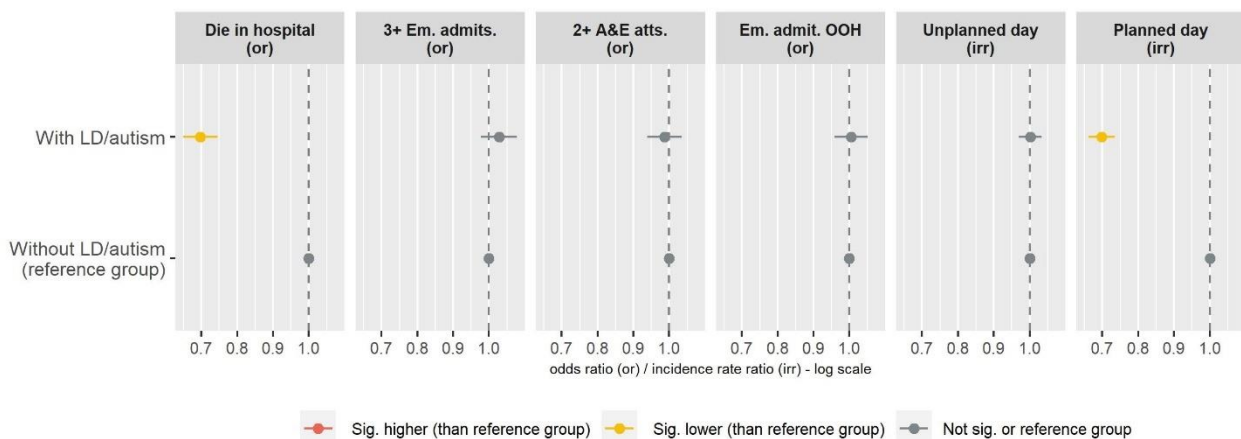


6.2.5 Learning disabilities, autism, or both

Those with a learning disability, autism, or both account for a small number of decedents (1 in 50). For many outcomes they have no significant difference to other decedents. They are however 30% less likely to die in hospital. Reflecting the higher use of care homes as a place of death for this group (section 5.7).

They are also 30% less likely to use an extra planned hospital care day. As described previously it is unclear whether lesser use of planned care hospital days should be considered as a benefit, since it may rather indicate barriers in accessing planned care.

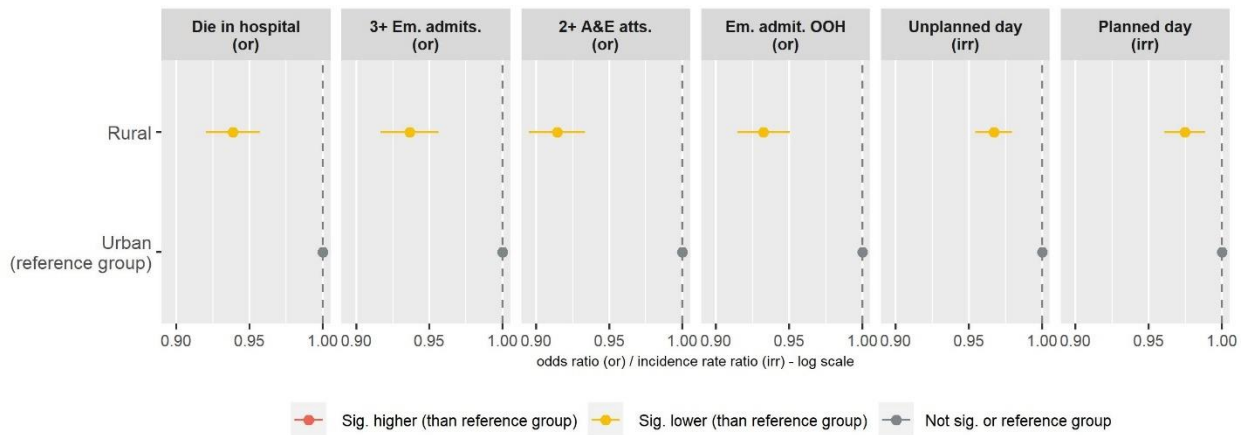
Figure 15 - Effect of a learning disability, autism, or both on outcomes



6.2.6 Urban-rural dwellers

Those living in rural areas have substantial reductions in the likelihood of all outcomes. At first glance this may appear as an advantage to rural dwellers, but interpreting these results can be challenging. It is not clear whether lower risks for those in rural areas are associated with genuinely better outcomes, or if they reflect the barriers rural dwellers often face when accessing healthcare¹⁷.

Figure 16 - Effect of living in urban or rural areas on outcomes



¹⁷ <https://www.rsnonline.org.uk/major-inquiry-highlights-the-rban-rural-divide-in-accessing-health-and-care#:~:text=The%20discrepancy%20is%20down%20to,social%20care%20in%20rural%20areas>

6.3 Clinical need

To account for different levels of need between decedents we classify people, based on their underlying cause of death, into four different cause groups – cancer, frailty, organ failure, and other terminal illness – and use this as a model variable.

However, consider two women with terminal breast cancer. One is in their 40s with no other conditions, and the other is in their 80s with many additional health problems. Treatment plans are likely to vary between these two individuals. Therefore, we also use age group as a model variable.

Generally, the risk of poor outcomes is greater when:

- Younger; and,
- The cancer group has a higher risk of poor outcomes in urgent care.

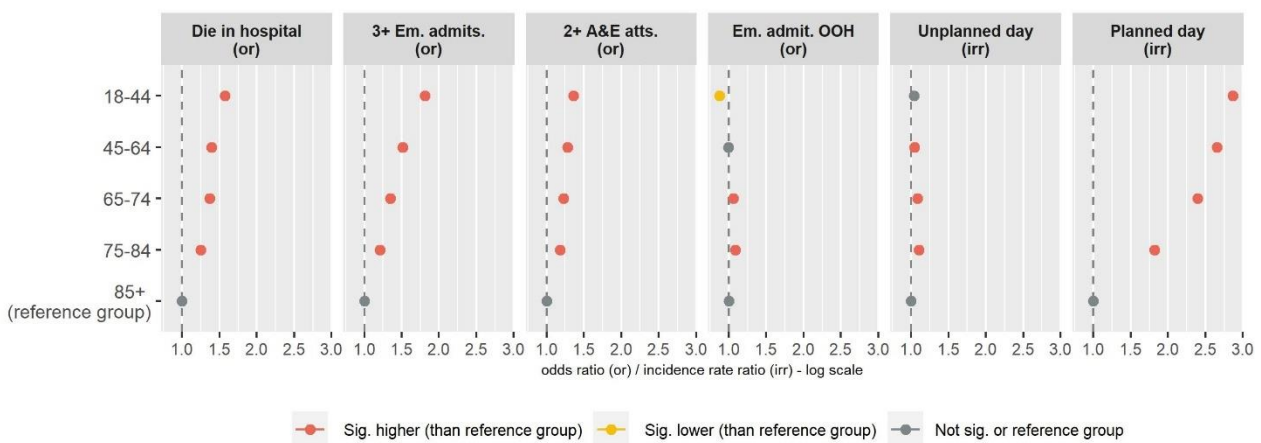
6.3.1 Age at death

There are many clear gradients with age and the scale of impact here is particularly large. Younger people make up a decreasing share of the decedent population (section 5.1) but are more likely to die in hospital (57%) and have poorer urgent care outcomes for emergency admissions and A&E attendances (81% and 36%). However, they are less likely to experience out-of-hours admissions (12%).

Possibly, given their more marginal presence in the decedent population, younger age may be a barrier to accessing good quality palliative care. Perhaps for those dying earlier in life then conversations regarding end-of-life plans may be more difficult for them, their families, and carers - leading to an increased risk of poor outcomes for younger decedents.

There is a notable increase in the likelihood of planned hospital days. Those aged 18-44 are nearly 3 times as likely to have an additional planned hospital care day than those aged 85 and over. However, as mentioned earlier, planned days can point to benefits for those at end-of-life.

Figure 17 - Effect of age group on outcomes



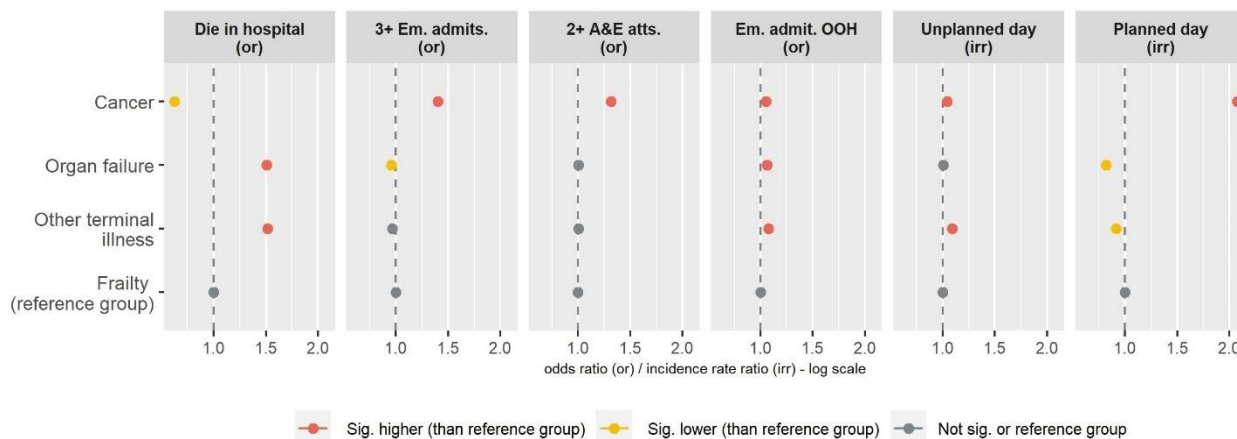
6.3.2 Cause of death

Cancer decedents are 38% less likely than frailty patients to die in hospital – as we would perhaps expect given the place of death and cause of death proportions seen earlier (section 5.2). But cancer patients are much more likely to experience poor outcomes when it comes to urgent care. Even in their last 90 days, a period relatively close to death, cancer decedents are more likely to have 2 or more A&E attendances (31%) and an out-of-hours admission (5%).

Planned hospital care days are also much more likely for cancer decedents. They are over twice as likely to have a single extra planned hospital care day in their last 90 days than the frailty group. This particularly substantial increase is likely to reflect more frequent hospital attendance for chemotherapy treatment and that this group also uses more elective bed days (a planned overnight stay) than other cause of death groups¹⁸.

Organ failure and those with other terminal illnesses are more likely to die in hospital than those with frailty. Although disease trajectory and death can be less predictable for organ failure than for cancer, improvements in accessing hospice pathways for organ failure decedents - as is currently the case with cancer - could provide greater opportunities for those dying from organ failure to use hospice settings as a place of death.

Figure 18 - Effect of cause of death group on outcomes



¹⁸ <https://www.strategyunitwm.nhs.uk/publications/health-service-use-last-two-years-life>

6.3.3 Weekend deaths

Those dying at the weekend were 3% less likely to die in hospital. This reduction in the likelihood of dying in hospital may at first glance appear to be good but it could also indicate problems in accessing hospitals at weekends.

More generally, we see reductions in emergency admissions at weekends and it may well be that this too affects those at end-of-life. It appears to happen because at weekends the direct admission route to hospital via GPs is closed and thresholds for emergency admission via A&E, when adjusted for casemix, also increase¹⁹. These differences in patient acuity and routes to hospital admission at weekends indicate a potential different set of end-of-life needs to meet.

¹⁹ <https://emj.bmj.com/content/34/12/773>

6.4 Supply of services

Ensuring the supply of high-quality services to meet the needs of those at end-of-life is fundamental in ensuring good palliative care. Whilst we consider three key services in this analysis, we recognise there are other important services not included. For example, we are not able to include information on services provided by hospices, social care, or volunteer organisations. This is due to a lack of available data in these areas.

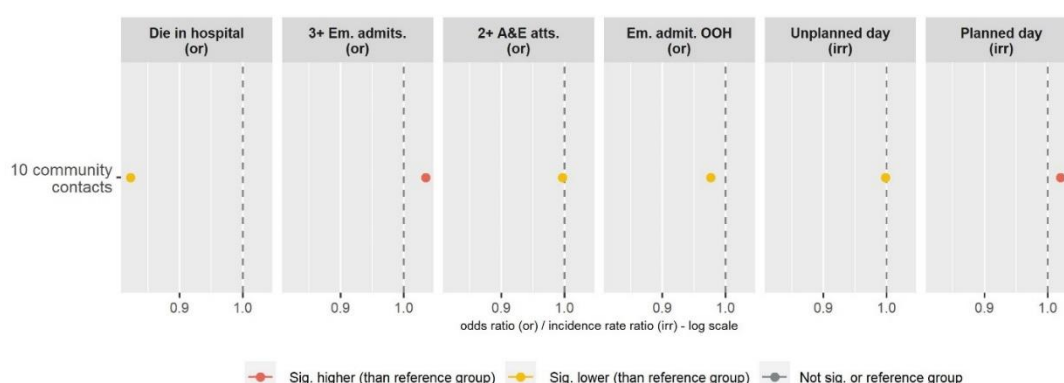
6.4.1 Community services

In this section we look at the number of community contacts a person receives in the period before they die and how this relates to outcomes. It shows that impact from community services at end-of-life is felt across all outcomes, but the direction and scale of its impact differs. It is particularly substantial for place of death. Here an extra 10 community contacts in the last 90 days reduces the likelihood of a person dying in hospital by 18%. However, to some extent, increased involvement from community services reducing deaths in hospital will be causal. This is because community nurses do not visit patients in hospital and so, since death in hospital will mean a hospital stay immediately prior to death, community contacts may naturally be less than when a person dies at home. Although the exact extent of any causal effect cannot be quantified here it should be noted that, since terminal lengths of stay are generally short, it is assumed effects are limited.

Community contacts also have a significant but small effect on the likelihood of 2 or more A&E attendances (10 contacts reduce risk by 0.4%) and out-of-hours admissions (10 contacts reduce risk by 2%). Community contacts also reduce the likelihood of an additional unplanned care day (10 contacts reduce risk by 0.2%) - potentially by preventing A&E attendances or emergency admissions in the first place, but also perhaps through facilitating earlier discharge for people at end-of-life.

For 3 or more emergency admissions²⁰ and planned hospital care days, it appears more involvement from community services may increase likelihood. However, rather than community contacts 'causing' this, it is more likely to reflect how some decedents are more complex and require both intensive community involvement and hospital support.

Figure 19 - Effect of increasing community contacts on outcomes



²⁰ 3 or more emergency admissions in the last year of life uses community contacts based in the last year of life. Other outcomes use community contacts in the last 90 days

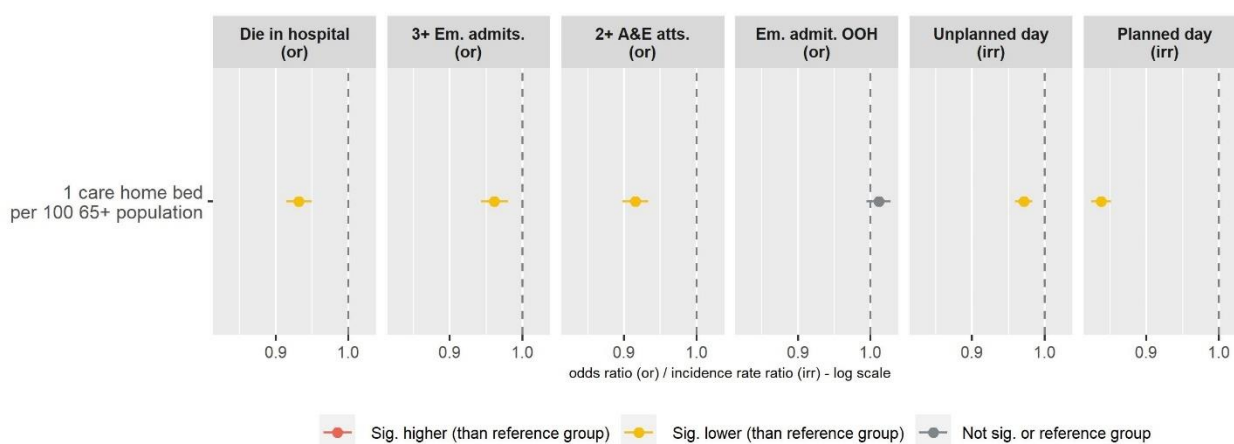
6.4.2 Care home beds

The amount of care home beds in an area has a significant effect, reducing risk for nearly all outcomes. It is most keenly felt in planned hospital care days, reducing the risk of an extra day by 16%.

The effect from care home beds is measured as the number of care home beds per 100 people in the general, not just decedent, population who are aged 65 and over. If, for example, in an area there are 1,000 care homes beds and 25,000 people aged 65 and over live in that area, this means there are 4 beds available per 100 people aged 65 and over. If the number of beds was the same but there were 50,000 people aged 65 and over, then supply is less - at 2 beds per 100 people aged 65 and over.

There are 11 million people over 65 in England so an extra 11 thousand care home beds would be needed to see the changes in risk described in the charts. This is just under a 3% increase on the current number of beds (428,837²¹).

Figure 20 - Effect of increasing care home bed numbers on outcomes



²¹ <https://www.cqc.org.uk/about-us/transparency/using-cqc-data>

6.4.3 Palliative care registers

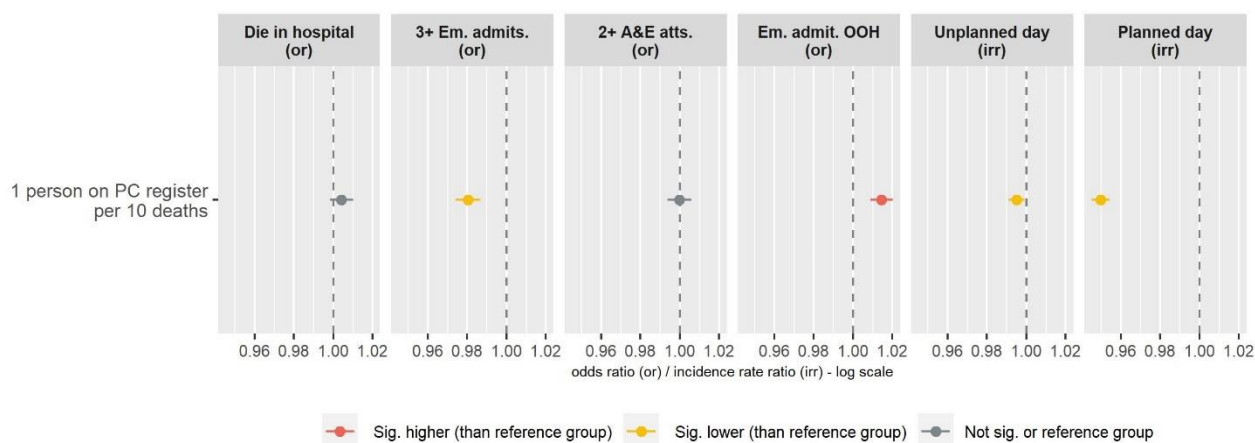
We use the number of people on palliative care registers²² in an area to help understand how the quality of primary care services can impact outcomes. The palliative care register approach has the potential to improve care for people with progressive life-threatening illnesses from the time of diagnosis. So, the lower the rate of recording, the more likely we might be to expect poor outcomes.

However, the level of palliative care recording has a somewhat mixed effect on outcomes. It does not, as might be expected, seem to have any significant effect on the risk of dying in hospital and it slightly increases the risk of having an out-of-hours admission (1.4%). Higher levels however do reduce the risk of 3 or more emergency admissions, and unplanned and planned hospital care days.

Reasons for this might be that including people on registers should only be an initial step. Improvements in outcomes would only be delivered when this was followed up with advance care planning and the proactive management of those on registers.

It should also be noted that, numbers on registers as a proportion of deaths do vary widely by place. In some areas of England proportions on registers are a third of deaths, whilst in other areas all decedents appear to be recorded on palliative care registers.

Figure 21 - Effect of increasing rates of palliative care register recording on outcomes



²² <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/general-practice-data-hub/quality-outcomes-framework-qof>

6.5 Geographical variation

Independent of the other model variables there remains wide variation across the 40 included Integrated Care Boards (ICBs) across England²³. ICBs are relatively new NHS organisations and palliative care services form a specific part of their legal responsibility in commissioning health services that meet their population needs²⁴. Therefore, our intent here is to assist ICBs²⁵ by facilitating understanding of where there may be issues and the nature of those issues. Only with clear insights can ICBs start to address challenges in the current provision of end-of-life care.

Figure 22 – Effect of ICB on outcomes



²³ There are 42 ICBs in England but two (Dorset and Bristol, North Somerset and South Gloucester) were excluded from this analysis due to poor levels of recording for community contacts

²⁴ <https://www.england.nhs.uk/wp-content/uploads/2022/07/Palliative-and-End-of-Life-Care-Statutory-Guidance-for-Integrated-Care-Boards-ICBs-September-2022.pdf>

²⁵ A table with ICB outcome measure values and count of significantly higher outcomes are included in appendix A

6.6 Model fit and what does this tell us?

Having seen the likelihood of outcomes for each group we now consider how completely our regression models explain differences in outcomes.

Variables used in regression models have been tested for their incremental effects, significance, and contribution to model fit. However, although the models developed for this analysis are deemed to be the most appropriate within available data, there remains some uncertainty over how well they explain variance in likelihoods.

We used the C-statistic as a test of 'goodness of fit' for our models. This gives the probability that a randomly selected person who experienced an outcome had a higher risk score than a person who did not experience the outcome. Effectively, it indicates how well a model fits the data.

C-statistic values range from 0 to 1. The closer to 1 the value is then the better the model fits. A value of 0.7 or above would indicate a good model whilst a value of 0.5 would indicate a model is no better than random chance. The C-statistic values for all but one of our models are slightly below the threshold to be considered 'good'²⁶. This indicates a level of uncertainty in the results but is useful in highlighting possible gaps in our understanding and data sources. It is likely for example, that being able to include variables such as the supply of hospice services, social care, and other services in an area would improve model fit. This in turn would provide further detail into how all services involved in palliative care play a part in reducing the likelihood of poor outcomes.

Table 2 – C-statistic values for models using binary regression

	C-statistic value
Die in hospital	0.69
2+ Em. admits.	0.68
2+ A&E atts.	0.67
Em. admit. OOH	0.70

²⁶ Please note that models for unplanned and planned days with hospital care are not suitable for a C-statistic value and are therefore not included in Table 2

7. Appendices

7.1 Appendix A: ICB results summary and count

	Die in hospital (or)	3+ Em. admits (or)	2+ A&E atts. (or)	Em. Admit. OOH (or)	Unplanned day (irr)	Planned day (irr)	Number of significantly higher outcomes
Cheshire & Merseyside	1.27	0.96	0.99	1	1.08	1.12	3
Coventry & Warwickshire	1.19	1	1.08	1.38	1.01	0.82	3
NE & N Cumbria	1.17	1.00	1	0.81	0.97	1.02	1
Northamptonshire	1.16	1.20	1.23	1.44	1.11	0.81	5
Hertfordshire & W Essex	1.16	1.10	1.22	0.97	1.06	1.01	4
NE London	1.15	1.00	1.01	0.81	1.04	0.78	1
Birmingham & and Solihull	1.13	1.11	0.90	1.00	1.09	1.04	3
SW London	1.12	1.11	1.16	1.20	1.16	1.40	6
Staffordshire & Stoke-on-Trent	1.12	1.20	1.06	0.32	1.05	1.10	5
Humber & N Yorkshire	1.10	0.90	0.89	1.03	0.96	1	1
South Yorkshire	1.08	1.05	1.01	0.83	1	0.94	1
Bedfordshire, Luton & Milton Keynes	1.08	1.17	1.07	1.44	1.09	0.83	5
Nottingham & Nottinghamshire	1.07	1.10	0.79	0.96	1.03	1.34	3
SE London	1.06	1.15	1.00	1.20	1.15	1.07	5
NW London	1.06	1.28	1.19	1.09	1.07	0.95	4
Mid & S Essex	1.03	1.09	1.15	1.54	1.01	0.80	3
W Yorkshire	1.03	0.84	0.94	0.61	0.97	0.67	0
Norfolk & Waveney	1.02	0.82	0.88	1.15	0.98	1.12	2
N Central London	1.02	1.00	1.16	1.18	1.04	1.37	3
Black Country	1.01	0.96	1.14	0.52	0.96	1.13	2
Lancashire & S Cumbria	1.01	0.85	0.98	1.23	1.03	1.01	1
Greater Manchester	1	1.07	1.07	1.30	1.00	0.91	3
Derby & Derbyshire	0.99	1.26	0.84	1.12	0.98	1.03	2
Lincolnshire	0.98	0.76	1.09	1.19	0.93	0.80	2
Somerset	0.98	1.13	0.62	0.66	1.04	0.68	1
Surrey Heartlands	0.95	1.24	1.32	0.71	1.06	2.57	4
Buckinghamshire, Oxfordshire & W Berkshire	0.92	1.16	1.10	0.62	0.94	2.29	3
Sussex	0.91	0.95	0.82	1.10	0.96	0.84	1
Cambridge & Peterborough	0.89	1.09	0.97	1.29	1.06	0.76	3
Gloucestershire	0.88	0.87	0.66	0.92	0.87	1.18	1
Cornwall & Isles of Scilly	0.88	0.75	0.54	0.91	0.82	1.10	1
Frimley	0.86	0.99	1.42	0.58	1.03	3.00	2
Herefordshire & Worcestershire	0.84	0.92	0.85	0.96	0.89	0.90	0
Kent & Medway	0.83	0.96	1.05	0.82	0.94	0.86	1
Hampshire & Isle of Wight	0.83	1.17	0.89	1.07	0.97	0.88	2
Suffolk & NE Essex	0.82	1.08	0.88	0.91	0.93	3.34	2
Shropshire, Telford & Wrekin	0.80	0.87	0.73	1.04	0.86	0.87	0
Leicester, Leicestershire & Rutland	0.79	1.07	0.74	0.91	1.05	0.77	1
Bath, NE Somerset, Swindon & Wiltshire	0.78	0.93	0.57	0.94	0.94	0.92	0
Devon	0.77	0.85	0.49	0.55	0.82	1.06	1

7.2 Appendix B: Model variables and results

Binary logistic regression model for outcome of dying in hospital:

Category	Group	Odds ratio estimate	95% CI	P value	
Categorical	Age group	18-44	1.57	[1.52,1.63]	0.00
		45-64	1.40	[1.37,1.42]	0.00
		65-74	1.37	[1.34,1.39]	0.00
		75-84	1.25	[1.23,1.27]	0.00
		85+ (reference group)	1.00	-	-
	Gender	Male	1.20	[1.19,1.21]	0.00
		Female (reference group)	1.00	-	-
	Rural-urban	Rural	0.94	[0.92,0.96]	0.00
		Urban (reference group)	1.00	-	-
	Deprivation quintile (IDAOP)	1st	1.06	[1.04,1.09]	0.00
		2nd	1.05	[1.02,1.07]	0.00
		3rd	1.03	[1.01,1.05]	0.01
		4th	1.01	[0.98,1.03]	0.59
		5th (reference group)	1.00	-	-
	Cause	Cancer	0.62	[0.6,0.65]	0.00
		Organ Failure	1.51	[1.49,1.53]	0.00
		Other Terminal Illness	1.52	[1.48,1.55]	0.00
		Frailty (reference group)	1.00	-	-
	Ethnicity	Asian/Asian British	1.58	[1.54,1.62]	0.00
		Black/Black British	1.18	[1.13,1.23]	0.00
Mixed		0.80	[0.7,0.89]	0.00	
Other		0.91	[0.88,0.94]	0.00	
LDA	White (reference group)	1.00	-	-	
	With LDA identified	0.70	[0.65,0.75]	0.00	
Lives alone	No LDA identified (reference group)	1.00	-	-	
	Lives alone	1.52	[1.5,1.53]	0.00	
Died at weekend	Lives with others (reference group)	1.00	-	-	
	Weekend	0.97	[0.96,0.99]	0.00	
Died at weekend	Weekday (reference group)	1.00	-	-	
	Lancashire & S Cumbria	1.01	[0.96,1.06]	0.62	
ICB	South Yorkshire	1.08	[1.03,1.13]	0.00	
	Herefordshire & Worcestershire	0.84	[0.78,0.9]	0.00	
	Mid & S Essex	1.03	[0.98,1.08]	0.25	
	Bedfordshire, Luton & Milton Keynes	1.08	[1.02,1.14]	0.02	
	Birmingham & Solihull	1.13	[1.07,1.18]	0.00	
	NE & N Cumbria	1.17	[1.13,1.21]	0.00	
	Derby & Derbyshire	0.99	[0.93,1.04]	0.65	
	Suffolk & NE Essex	0.82	[0.76,0.87]	0.00	
	Devon	0.77	[0.71,0.82]	0.00	
	Lincolnshire	0.98	[0.93,1.04]	0.60	
	Leicester, Leicestershire & Rutland	0.79	[0.73,0.85]	0.00	
	SE London	1.06	[1,1.12]	0.04	
	Kent & Medway	0.83	[0.79,0.88]	0.00	
	Hertfordshire & W Essex	1.16	[1.11,1.21]	0.00	
	NE London	1.15	[1.09,1.21]	0.00	
	N Central London	1.02	[0.96,1.08]	0.54	
	Norfolk & Waveney	1.02	[0.97,1.07]	0.42	
	Staffordshire & Stoke-on-Trent	1.12	[1.07,1.17]	0.00	
	Frimley	0.86	[0.79,0.93]	0.00	
	Sussex	0.91	[0.87,0.96]	0.00	
	Shropshire, Telford & Wrekin	0.80	[0.73,0.88]	0.00	
	Humber & N Yorkshire	1.10	[1.05,1.15]	0.00	
	Bath, NE Somerset, Swindon & Wiltshire	0.78	[0.72,0.84]	0.00	
	Northamptonshire	1.16	[1.1,1.23]	0.00	
	Gloucestershire	0.88	[0.82,0.95]	0.00	
	Hampshire & Isle of Wight	0.83	[0.78,0.87]	0.00	
	NW London	1.06	[0.99,1.12]	0.08	
	Somerset	0.98	[0.92,1.05]	0.61	
	Nottingham & Nottinghamshire	1.07	[1.01,1.12]	0.02	
	Cornwall & Isles of Scilly	0.88	[0.81,0.94]	0.00	
	Buckinghamshire, Oxfordshire & W Berkshire	0.92	[0.87,0.97]	0.00	
	Black Country	1.01	[0.96,1.07]	0.61	
Cambridge & Peterborough	0.89	[0.83,0.96]	0.00		
SW London	1.12	[1.07,1.18]	0.00		
W Yorkshire	1.03	[0.99,1.07]	0.18		
Coventry & Warwickshire	1.19	[1.13,1.25]	0.00		
Surrey Heartlands	0.95	[0.88,1.01]	0.09		
Cheshire & Merseyside	1.27	[1.23,1.31]	0.00		
Greater Manchester (reference group)	1.00	-	-		
Continuous	Community contacts in last 90 days (per 10 contacts)	0.82	[0.82,0.83]	0.00	
	Care homes beds (per 100 aged 65+)	0.93	[0.91,0.95]	0.00	
	Number on palliative care register (per 10 deaths)	1.00	[1,1.01]	0.17	

For this outcome deaths 'elsewhere' are excluded. This allows comparison between hospital and locations of home, hospice, care home.

Binary logistic regression model results for outcome of 3 or more emergency admissions in the year before death:

Category	Group	Odds ratio estimate	95% CI	P value
Age group	18-44	1.81	[1.76,1.86]	0.00
	45-64	1.51	[1.48,1.54]	0.00
	65-74	1.35	[1.32,1.37]	0.00
	75-84	1.21	[1.19,1.23]	0.00
	85+ (reference group)	1.00	-	-
Gender	Male	1.14	[1.12,1.15]	0.00
	Female (reference group)	1.00	-	-
Rural-urban	Rural	0.94	[0.92,0.96]	0.00
	Urban (reference group)	1.00	-	-
Deprivation quintile (IDAOP)	1st	1.08	[1.05,1.1]	0.00
	2nd	1.08	[1.05,1.1]	0.00
	3rd	1.03	[1.01,1.05]	0.01
	4th	1.01	[0.99,1.03]	0.31
	5th (reference group)	1.00	-	-
Cause	Cancer	1.40	[1.38,1.42]	0.00
	Organ Failure	0.96	[0.94,0.98]	0.00
	Other Terminal Illness	0.97	[0.93,1]	0.06
	Frailty (reference group)	1.00	-	-
Ethnicity	Asian/Asian British	1.02	[0.98,1.07]	0.32
	Black/Black British	0.94	[0.88,1]	0.03
	Mixed	0.99	[0.9,1.09]	0.89
	Other	0.55	[0.51,0.58]	0.00
	White (reference group)	1.00	-	-
LDA	With LDA identified	1.03	[0.98,1.08]	0.28
	No LDA identified (reference group)	1.00	-	-
Lives alone	Lives alone	1.06	[1.05,1.08]	0.00
	Lives with others (reference group)	1.00	-	-
Categorical	Lancashire & S Cumbria	0.85	[0.78,0.91]	0.00
	South Yorkshire	1.05	[0.99,1.12]	0.11
	Herefordshire & Worcestershire	0.92	[0.84,1]	0.03
	Mid & S Essex	1.09	[1.02,1.16]	0.01
	Bedfordshire, Luton & Milton Keynes	1.17	[1.09,1.25]	0.00
	Birmingham & Solihull	1.11	[1.04,1.18]	0.00
	NE & N Cumbria	1.00	[0.94,1.06]	0.95
	Derby & Derbyshire	1.26	[1.19,1.33]	0.00
	Suffolk & NE Essex	1.08	[1.01,1.15]	0.03
	Devon	0.85	[0.78,0.92]	0.00
	Lincolnshire	0.76	[0.68,0.84]	0.00
	Leicester, Leicestershire & Rutland	1.07	[0.99,1.15]	0.10
	SE London	1.15	[1.08,1.23]	0.00
	Kent & Medway	0.96	[0.89,1.02]	0.17
	Hertfordshire & W Essex	1.10	[1.03,1.17]	0.01
	NE London	1.00	[0.92,1.07]	0.91
	N Central London	1.00	[0.92,1.08]	0.93
	Norfolk & Waveney	0.82	[0.75,0.89]	0.00
	Staffordshire & Stoke-on-Trent	1.20	[1.13,1.27]	0.00
	Frimley	0.99	[0.9,1.08]	0.85
	Sussex	0.95	[0.89,1.02]	0.17
	Shropshire, Telford & Wrekin	0.87	[0.78,0.95]	0.00
	Greater Manchester	1.07	[1.01,1.13]	0.03
	Humber & N Yorkshire	0.90	[0.84,0.97]	0.00
	Bath, NE Somerset, Swindon & Wiltshire	0.93	[0.85,1]	0.05
	Northamptonshire	1.20	[1.12,1.28]	0.00
	Gloucestershire	0.87	[0.79,0.96]	0.00
	Hampshire & Isle of Wight	1.17	[1.11,1.24]	0.00
	NW London	1.28	[1.2,1.36]	0.00
	Somerset	1.13	[1.05,1.21]	0.00
	Nottingham & Nottinghamshire	1.10	[1.03,1.17]	0.01
	Cornwall & Isles of Scilly	0.75	[0.67,0.84]	0.00
	Buckinghamshire, Oxfordshire & W Berkshire	1.16	[1.1,1.23]	0.00
	Black Country	0.96	[0.89,1.03]	0.25
	Cambridge & Peterborough	1.09	[1.01,1.17]	0.03
	SW London	1.11	[1.04,1.19]	0.01
W Yorkshire	0.84	[0.77,0.9]	0.00	
Surrey Heartlands	1.24	[1.16,1.32]	0.00	
Cheshire & Merseyside	0.96	[0.9,1.02]	0.20	
Coventry & Warwickshire (reference group)	1.00	-	-	
Continuous	Community contacts in last year (per 10 contacts)	1.03	[1.03,1.04]	0.00
	Care homes beds (per 100 aged 65+)	0.96	[0.94,0.98]	0.00
	Number on palliative care register (per 10 deaths)	0.98	[0.97,0.99]	0.00

Binary logistic regression model results for outcome of 2 or more A&E attendances in the 90 days before death:

Category	Group	Odds ratio estimate	95% CI	P value
Age group	18-44	1.36	[1.31,1.41]	0.00
	45-64	1.28	[1.25,1.31]	0.00
	65-74	1.22	[1.2,1.25]	0.00
	75-84	1.18	[1.16,1.2]	0.00
	85+ (reference group)	1.00	-	-
Gender	Male	1.15	[1.14,1.16]	0.00
	Female (reference group)	1.00	-	-
Rural-urban	Rural	0.91	[0.9,0.93]	0.00
	Urban (reference group)	1.00	-	-
Deprivation quintile (IDAOP)	1st	1.09	[1.06,1.11]	0.00
	2nd	1.09	[1.07,1.12]	0.00
	3rd	1.05	[1.03,1.07]	0.00
	4th	1.02	[1,1.04]	0.12
	5th (reference group)	1.00	-	-
Cause	Cancer	1.31	[1.29,1.34]	0.00
	Organ Failure	1.00	[0.98,1.02]	0.75
	Other Terminal Illness	1.00	[0.97,1.04]	0.79
	Frailty (reference group)	1.00	-	-
Ethnicity	Asian/Asian British	1.13	[1.08,1.17]	0.00
	Black/Black British	0.98	[0.93,1.04]	0.51
	Mixed	0.91	[0.81,1]	0.04
	Other	0.68	[0.64,0.71]	0.00
	White (reference group)	1.00	-	-
LDA	With LDA identified	0.99	[0.94,1.03]	0.59
	No LDA identified (reference group)	1.00	-	-
Lives alone	Lives alone	1.16	[1.15,1.18]	0.00
	Lives with others (reference group)	1.00	-	-
Categorical	Lancashire & S Cumbria	0.98	[0.93,1.02]	0.31
	South Yorkshire	1.01	[0.97,1.06]	0.59
	Herefordshire & Worcestershire	0.85	[0.79,0.91]	0.00
	Mid & S Essex	1.15	[1.09,1.2]	0.00
	Bedfordshire, Luton & Milton Keynes	1.07	[1.01,1.13]	0.03
	Birmingham & Solihull	0.90	[0.85,0.95]	0.00
	Derby & Derbyshire	0.84	[0.79,0.89]	0.00
	Suffolk & NE Essex	0.88	[0.83,0.94]	0.00
	Devon	0.49	[0.43,0.55]	0.00
	Lincolnshire	1.09	[1.03,1.15]	0.00
	Leicester, Leicestershire & Rutland	0.74	[0.68,0.8]	0.00
	SE London	1.00	[0.94,1.06]	0.94
	Kent & Medway	1.05	[1,1.09]	0.05
	Hertfordshire & W Essex	1.22	[1.17,1.27]	0.00
	NE London	1.01	[0.95,1.07]	0.68
	N Central London	1.16	[1.1,1.22]	0.00
	Norfolk & Waveney	0.88	[0.83,0.93]	0.00
	Staffordshire & Stoke-on-Trent	1.06	[1,1.11]	0.04
	Frimley	1.42	[1.36,1.49]	0.00
	Sussex	0.82	[0.77,0.86]	0.00
	Shropshire, Telford & Wrekin	0.73	[0.65,0.81]	0.00
	Greater Manchester	1.07	[1.03,1.11]	0.00
	Humber & N Yorkshire	0.89	[0.84,0.93]	0.00
	Bath, NE Somerset, Swindon & Wiltshire	0.57	[0.5,0.64]	0.00
	Northamptonshire	1.23	[1.16,1.29]	0.00
	Gloucestershire	0.66	[0.59,0.73]	0.00
	Hampshire & Isle of Wight	0.89	[0.84,0.94]	0.00
	NW London	1.19	[1.12,1.25]	0.00
	Somerset	0.62	[0.55,0.69]	0.00
	Nottingham & Nottinghamshire	0.79	[0.73,0.84]	0.00
	Cornwall & Isles of Scilly	0.54	[0.46,0.62]	0.00
	Buckinghamshire, Oxfordshire & W Berkshire	1.10	[1.05,1.15]	0.00
	Black Country	1.14	[1.08,1.19]	0.00
Cambridge & Peterborough	0.97	[0.91,1.03]	0.35	
SW London	1.16	[1.11,1.22]	0.00	
W Yorkshire	0.94	[0.9,0.99]	0.01	
Coventry & Warwickshire	1.08	[1.03,1.14]	0.01	
Surrey Heartlands	1.32	[1.26,1.39]	0.00	
Cheshire & Merseyside	0.99	[0.95,1.02]	0.46	
NE & N Cumbria (reference group)	1.00	-	-	
Continuous	Community contacts in last 90 days (per 10 contacts)	1.00	[0.99,1]	0.00
	Care homes beds (per 100 aged 65+)	0.92	[0.9,0.93]	0.00
	Number on palliative care register (per 10 deaths)	1.00	[0.99,1.01]	0.95

Binary logistic regression model results for outcome of an out-of-hours emergency admission in the 90 days before death:

Category	Group	Odds ratio estimate	95% CI	P value		
Categorical	Age group	18-44	0.88	[0.83,0.93]	0.00	
		45-64	0.99	[0.97,1.02]	0.65	
		65-74	1.06	[1.03,1.08]	0.00	
		75-84	1.09	[1.07,1.11]	0.00	
		85+ (reference group)	1.00	-	-	
	Gender	Male	1.09	[1.08,1.1]	0.00	
		Female (reference group)	1.00	-	-	
	Rural-urban	Rural	0.93	[0.91,0.95]	0.00	
		Urban (reference group)	1.00	-	-	
	Deprivation quintile (IDAOP)		1st	1.19	[1.17,1.21]	0.00
			2nd	1.13	[1.1,1.15]	0.00
			3rd	1.07	[1.05,1.09]	0.00
			4th	1.01	[0.99,1.03]	0.30
			5th (reference group)	1.00	-	-
	Cause		Cancer	1.05	[1.03,1.07]	0.00
			Organ Failure	1.06	[1.04,1.08]	0.00
			Other Terminal Illness	1.08	[1.05,1.11]	0.00
			Frailty (reference group)	1.00	-	-
	Ethnicity		Asian/Asian British	1.16	[1.12,1.2]	0.00
			Black/Black British	1.14	[1.09,1.19]	0.00
			Mixed	0.88	[0.79,0.97]	0.01
			Other	0.84	[0.81,0.87]	0.00
			White (reference group)	1.00	-	-
	LDA		With LDA identified	1.00	[0.96,1.05]	0.85
			No LDA identified (reference group)	1.00	-	-
	Lives alone		Lives alone	1.23	[1.21,1.24]	0.00
			Lives with others (reference group)	1.00	-	-
ICB		Lancashire & S Cumbria	1.23	[1.19,1.28]	0.00	
		South Yorkshire	0.83	[0.78,0.87]	0.00	
		Herefordshire & Worcestershire	0.96	[0.91,1.02]	0.21	
		Mid & S Essex	1.54	[1.48,1.59]	0.00	
		Bedfordshire, Luton & Milton Keynes	1.44	[1.38,1.5]	0.00	
		Birmingham & Solihull	1.00	[0.95,1.05]	0.97	
		NE & N Cumbria	0.81	[0.77,0.84]	0.00	
		Derby & Derbyshire	1.12	[1.07,1.17]	0.00	
		Suffolk & NE Essex	0.91	[0.86,0.96]	0.00	
		Devon	0.55	[0.49,0.6]	0.00	
		Lincolnshire	1.19	[1.14,1.25]	0.00	
		Leicester, Leicestershire & Rutland	0.91	[0.85,0.97]	0.00	
		SE London	1.20	[1.14,1.26]	0.00	
		Kent & Medway	0.82	[0.77,0.86]	0.00	
		Hertfordshire & W Essex	0.97	[0.92,1.02]	0.23	
		NE London	0.81	[0.75,0.87]	0.00	
		N Central London	1.18	[1.11,1.24]	0.00	
		Norfolk & Waveney	1.15	[1.1,1.2]	0.00	
		Staffordshire & Stoke-on-Trent	0.32	[0.26,0.38]	0.00	
		Frimley	0.58	[0.51,0.65]	0.00	
		Sussex	1.10	[1.06,1.15]	0.00	
		Shropshire, Telford & Wrekin	1.04	[0.97,1.11]	0.24	
		Greater Manchester	1.30	[1.26,1.34]	0.00	
		Humber & N Yorkshire	1.03	[0.99,1.07]	0.21	
		Bath, NE Somerset, Swindon & Wiltshire	0.94	[0.88,1]	0.04	
		Northamptonshire	1.44	[1.38,1.51]	0.00	
		Gloucestershire	0.92	[0.86,0.98]	0.01	
		Hampshire & Isle of Wight	1.07	[1.02,1.11]	0.01	
		NW London	1.09	[1.03,1.15]	0.01	
		Somerset	0.66	[0.6,0.73]	0.00	
		Nottingham & Nottinghamshire	0.96	[0.91,1.01]	0.10	
		Cornwall & Isles of Scilly	0.91	[0.84,0.98]	0.01	
		Buckinghamshire, Oxfordshire & W Berkshire	0.62	[0.57,0.67]	0.00	
	Black Country	0.52	[0.47,0.57]	0.00		
	Cambridge & Peterborough	1.29	[1.23,1.35]	0.00		
	SW London	1.20	[1.14,1.25]	0.00		
	W Yorkshire	0.61	[0.57,0.65]	0.00		
	Coventry & Warwickshire	1.38	[1.33,1.43]	0.00		
	Surrey Heartlands	0.71	[0.65,0.77]	0.00		
	Cheshire & Merseyside (reference group)	1.00	-	-		
Continuous		Community contacts in last 90 days (per 10 contacts)	0.98	[0.97,0.98]	0.00	
		Care homes beds (per 100 aged 65+)	1.01	[0.99,1.03]	0.20	
		Number on palliative care register (per 10 deaths)	1.01	[1.01,1.02]	0.00	

Negative binominal regression model results for outcome of unplanned hospital care day in the 90 days before death:

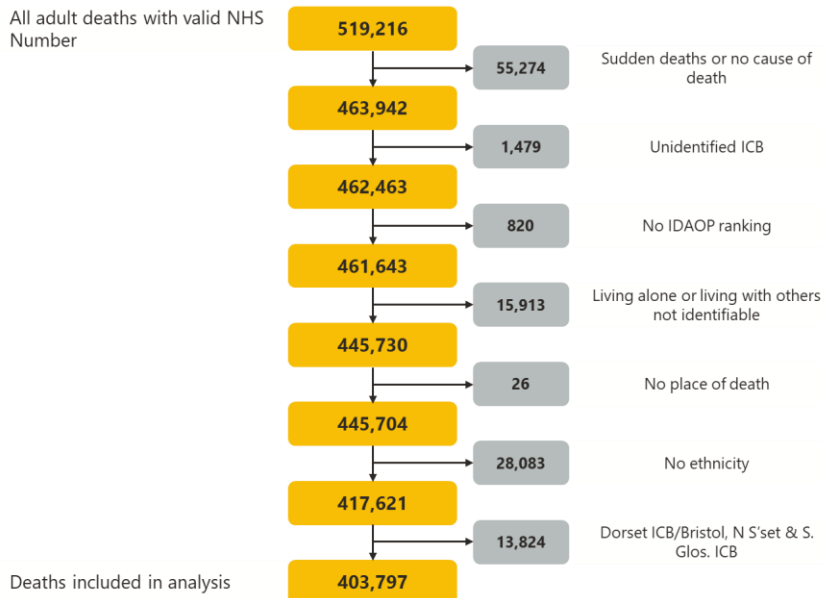
Category	Group	Odds ratio estimate	95% CI	P value	
Categorical	Age group	18-44	1.04	[1,1.07]	0.06
		45-64	1.05	[1.03,1.07]	0.00
		65-74	1.08	[1.07,1.1]	0.00
		75-84	1.10	[1.09,1.12]	0.00
		85+ (reference group)	1.00	-	-
	Gender	Male	1.07	[1.06,1.08]	0.00
		Female (reference group)	1.00	-	-
	Rural-urban	Rural	0.97	[0.95,0.98]	0.00
		Urban (reference group)	1.00	-	-
	Deprivation quintile (IDAOP)	1st	1.00	[0.99,1.02]	0.61
		2nd	1.01	[1,1.03]	0.17
		3rd	1.00	[0.99,1.02]	0.75
		4th	0.99	[0.98,1]	0.19
		5th (reference group)	1.00	-	-
	Cause	Cancer	1.04	[1.03,1.06]	0.00
		Organ Failure	1.01	[0.99,1.02]	0.41
		Other Terminal Illness	1.09	[1.07,1.11]	0.00
		Frailty (reference group)	1.00	-	-
	Ethnicity	Asian/Asian British	1.07	[1.04,1.1]	0.00
		Black/Black British	1.13	[1.09,1.16]	0.00
		Mixed	1.01	[0.95,1.07]	0.78
		Other	0.83	[0.81,0.85]	0.00
	LDA	White (reference group)	1.00	-	-
		With LDA identified	1.00	[0.97,1.03]	0.89
	Lives alone	No LDA identified (reference group)	1.00	-	-
Lives alone		1.24	[1.23,1.25]	0.00	
Lives alone	Lives with others (reference group)	1.00	-	-	
	Lancashire & S Cumbria	1.03	[1,1.07]	0.09	
ICB	Herefordshire & Worcestershire	0.89	[0.85,0.94]	0.00	
	Mid & S Essex	1.01	[0.97,1.05]	0.72	
	Bedfordshire, Luton & Milton Keynes	1.09	[1.04,1.13]	0.00	
	Birmingham & Solihull	1.09	[1.05,1.13]	0.00	
	NE & N Cumbria	0.97	[0.94,1]	0.07	
	Derby & Derbyshire	0.98	[0.94,1.02]	0.30	
	Suffolk & NE Essex	0.93	[0.89,0.97]	0.00	
	Devon	0.82	[0.78,0.86]	0.00	
	Lincolnshire	0.93	[0.88,0.97]	0.00	
	Leicester, Leicestershire & Rutland	1.05	[1,1.1]	0.04	
	SE London	1.15	[1.11,1.2]	0.00	
	Kent & Medway	0.94	[0.9,0.98]	0.00	
	Hertfordshire & W Essex	1.06	[1.02,1.1]	0.01	
	NE London	1.04	[0.99,1.08]	0.09	
	N Central London	1.04	[0.99,1.09]	0.10	
	Norfolk & Waveney	0.98	[0.94,1.02]	0.42	
	Staffordshire & Stoke-on-Trent	1.05	[1.01,1.09]	0.01	
	Frimley	1.03	[0.97,1.08]	0.35	
	Sussex	0.96	[0.93,1]	0.05	
	Shropshire, Telford & Wrekin	0.86	[0.81,0.91]	0.00	
	Greater Manchester	1.00	[0.97,1.04]	0.81	
	Humber & N Yorkshire	0.96	[0.93,1]	0.04	
	Bath, NE Somerset, Swindon & Wiltshire	0.94	[0.89,0.98]	0.01	
	Northamptonshire	1.11	[1.06,1.16]	0.00	
	Gloucestershire	0.87	[0.82,0.92]	0.00	
	Hampshire & Isle of Wight	0.97	[0.94,1.01]	0.13	
	NW London	1.07	[1.02,1.11]	0.01	
	Somerset	1.04	[1,1.09]	0.09	
	Nottingham & Nottinghamshire	1.03	[0.99,1.07]	0.18	
	Cornwall & Isles of Scilly	0.82	[0.78,0.87]	0.00	
	Buckinghamshire, Oxfordshire & W Berkshire	0.94	[0.9,0.98]	0.00	
	Black Country	0.96	[0.92,1]	0.04	
Cambridge & Peterborough	1.06	[1.01,1.1]	0.02		
SW London	1.16	[1.12,1.21]	0.00		
W Yorkshire	0.97	[0.94,1.01]	0.10		
Coventry & Warwickshire	1.01	[0.97,1.06]	0.50		
Surrey Heartlands	1.06	[1.02,1.11]	0.01		
Cheshire & Merseyside	1.08	[1.04,1.11]	0.00		
South Yorkshire (reference group)	1.00	-	-		
Continuous	Community contacts in last 90 days (per 10 contacts)	1.00	[1,1]	0.00	
	Care homes beds (per 100 aged 65+)	0.97	[0.96,0.98]	0.00	
	Number on palliative care register (per 10 deaths)	1.00	[0.99,1]	0.02	

Negative binominal regression model results for outcome of planned hospital care day in the 90 days before death:

Category	Group	Odds ratio estimate	95% CI	P value
Age group	18-44	2.87	[2.83,2.91]	0.00
	45-64	2.65	[2.63,2.67]	0.00
	65-74	2.39	[2.38,2.41]	0.00
	75-84	1.82	[1.8,1.83]	0.00
	85+ (reference group)	1.00	-	-
Gender	Male	1.23	[1.22,1.24]	0.00
	Female (reference group)	1.00	-	-
Rural-urban	Rural	0.97	[0.96,0.99]	0.00
	Urban (reference group)	1.00	-	-
Deprivation quintile (IDAOP)	1st	0.79	[0.77,0.81]	0.00
	2nd	0.82	[0.8,0.83]	0.00
	3rd	0.89	[0.87,0.9]	0.00
	4th	0.94	[0.93,0.96]	0.00
	5th (reference group)	1.00	-	-
Cause	Cancer	2.07	[2.06,2.09]	0.00
	Organ Failure	0.82	[0.8,0.84]	0.00
	Other Terminal Illness	0.92	[0.89,0.94]	0.00
	Frailty (reference group)	1.00	-	-
Ethnicity	Asian/Asian British	1.20	[1.16,1.23]	0.00
	Black/Black British	1.17	[1.13,1.21]	0.00
	Mixed	1.37	[1.3,1.43]	0.00
	Other	0.73	[0.7,0.75]	0.00
	White (reference group)	1.00	-	-
LDA	With LDA identified	0.70	[0.66,0.74]	0.00
	No LDA identified (reference group)	1.00	-	-
Lives alone	Lives alone	1.07	[1.06,1.08]	0.00
	Lives with others (reference group)	1.00	-	-
Categorical	Lancashire & S Cumbria	1.01	[0.97,1.05]	0.52
	South Yorkshire	0.94	[0.9,0.98]	0.00
	Herefordshire & Worcestershire	0.90	[0.86,0.95]	0.00
	Mid & S Essex	0.80	[0.75,0.84]	0.00
	Bedfordshire, Luton & Milton Keynes	0.83	[0.78,0.88]	0.00
	Birmingham & Solihull	1.04	[1,1.08]	0.07
	NE & N Cumbria	1.02	[0.99,1.06]	0.16
	Derby & Derbyshire	1.03	[0.99,1.08]	0.13
	Suffolk & NE Essex	3.34	[3.3,3.38]	0.00
	Devon	1.06	[1.02,1.1]	0.01
	Lincolnshire	0.80	[0.75,0.84]	0.00
	Leicester, Leicestershire & Rutland	0.77	[0.72,0.82]	0.00
	SE London	1.07	[1.02,1.12]	0.01
	Kent & Medway	0.86	[0.82,0.9]	0.00
	Hertfordshire & W Essex	1.01	[0.96,1.05]	0.81
	NE London	0.78	[0.73,0.83]	0.00
	N Central London	1.37	[1.32,1.43]	0.00
	Norfolk & Waveney	1.12	[1.08,1.16]	0.00
	Staffordshire & Stoke-on-Trent	1.10	[1.06,1.14]	0.00
	Frimley	3.00	[2.95,3.05]	0.00
	Sussex	0.84	[0.81,0.88]	0.00
	Shropshire, Telford & Wrekin	0.87	[0.81,0.93]	0.00
	Greater Manchester	0.91	[0.87,0.95]	0.00
	Bath, NE Somerset, Swindon & Wiltshire	0.92	[0.87,0.97]	0.00
	Northamptonshire	0.81	[0.76,0.87]	0.00
	Gloucestershire	1.18	[1.13,1.23]	0.00
	Hampshire & Isle of Wight	0.88	[0.84,0.92]	0.00
	NW London	0.95	[0.89,1]	0.04
	Somerset	0.68	[0.63,0.73]	0.00
	Nottingham & Nottinghamshire	1.34	[1.29,1.38]	0.00
	Cornwall & Isles of Scilly	1.10	[1.05,1.15]	0.00
	Buckinghamshire, Oxfordshire & W Berkshire	2.29	[2.25,2.33]	0.00
	Black Country	1.13	[1.09,1.18]	0.00
Cambridge & Peterborough	0.76	[0.71,0.81]	0.00	
SW London	1.40	[1.36,1.45]	0.00	
W Yorkshire	0.67	[0.63,0.71]	0.00	
Coventry & Warwickshire	0.82	[0.77,0.86]	0.00	
Surrey Heartlands	2.57	[2.52,2.62]	0.00	
Cheshire & Merseyside	1.12	[1.08,1.15]	0.00	
Humber & N Yorkshire (reference group)	1.00	-	-	
Continuous	Community contacts in last 90 days (per 10 con	1.02	[1.02,1.02]	0.00
	Care homes beds (per 100 aged 65+)	0.84	[0.82,0.85]	0.00
	Number on palliative care register (per 10 deat	0.95	[0.95,0.95]	0.00

7.3 Appendix C: Study population

Inclusion criteria



Demographic and clinical characteristics of study population

Group	Category	Number
Age group	18-44	7,213
	45-64	46,197
	65-74	66,268
	75-84	118,492
	85+	165,627
Cause	Cancer	89,158
	Frailty	206,403
	Other terminal illness	21,949
	Organ Failure	86,287
Ethnic group	Asian/Asian British	11,189
	Black/Black British	6,599
	Mixed	2,113
	Other	22,041
	White	361,855
Living alone	Lives Alone	118,503
	Lives With Others	285,294
IDAOP quintile	1st quintile (most deprived)	74,074
	2nd	81,446
	3rd	85,848
	4th	84,872
	5th quintile (least deprived)	77,557
Learning disability, autism, or both	Have learning disability, autism, or both	8,234
	No learning disability, autism, or both	395,563
Gender	Female	200,820
	Male	202,977
Rural-Urban	Rural	81,051
	Urban	322,746

Integrated Care Boards of study population

Group	Category	Number
ICB	Cheshire & Merseyside	21,628
	Coventry & Warwickshire	7,431
	NE & N Cumbria	26,934
	Northamptonshire	5,356
	Hertfordshire & W Essex	9,862
	NE London	8,453
	Birmingham & Solihull	9,368
	SW London	7,384
	Staffordshire & Stoke-on-Trent	9,146
	Humber & N Yorkshire	14,905
	South Yorkshire	11,819
	Bedfordshire, Luton & Milton Keynes	5,943
	Nottingham & Nottinghamshire	8,886
	SE London	8,492
	NW London	9,444
	Mid & S Essex	9,121
	W Yorkshire	17,741
	Norfolk & Waveney	9,784
	N Central London	6,437
	Black Country	9,534
	Lancashire & S Cumbria	15,306
	Greater Manchester	20,845
	Derby & Derbyshire	9,039
	Lincolnshire	7,101
	Somerset	5,300
	Surrey Heartlands	7,431
	Buckinghamshire, Oxfordshire & W Berks	11,689
	Sussex	14,526
	Cambridge & Peterborough	5,976
	Gloucestershire	5,150
	Cornwall & Isles of Scilly	5,247
	Frimley	4,421
	Herefordshire & Worcestershire	6,889
	Kent & Medway	14,165
	Hampshire & Isle of Wight	14,182
	Suffolk & NE Essex	8,678
	Shropshire, Telford & Wrekin	4,149
	Leicester, Leicestershire & Rutland	8,021
	Bath, NE Somerset, Swindon & Wiltshire	6,869
	Devon	11,145

7.4 Appendix D: Data sources and processing

7.4.1 Mortality data

This is an anonymised record-level data set containing information that is gathered and collated as part of the death registration process in England. The data set includes information such as the location and underlying cause of death, the age, gender, and area of residence for the decedent.

Decedents have been identified from this data set based on all those adults (aged 18+ at death), registered with an English GP practice, who died between 1st April 2021 and 31st March 2022.

People without a valid NHS number have been excluded (0.01%) and a small number of duplicate records have also been removed (0.007%).

7.4.1.1 Place of death

For the purposes of this report place of death is assigned to one of the five categories defined by the National End-of-Life Care Intelligence Network²⁷. They are:

- Home;
- Care home;
- Hospice;
- Hospital²⁸; and,
- Elsewhere.

²⁷ <https://www.gov.uk/government/publications/classification-of-place-of-death>

²⁸ Where palliative care beds are in community hospitals, deaths in these beds are still counted as 'hospital' as it is not possible to identify them separately

7.4.1.2 Cause of death

The underlying cause of death is assigned to a cause group based on research by Dr June Lunney and Dr Joanne Lynn²⁹. The full list of cause groups are organ failure, sudden death, cancer, other terminal illness, and frailty. Decedents have been categorised into one of these 5 groups with 0.1% of deaths unable to be assigned a cause group.

Deaths attributed to the underlying causes of frailty, cancer, organ failure and other terminal illness are included in this analysis. Deaths attributed to sudden death are excluded.

It can be difficult to assign deceased people to the frailty group based on cause of death alone. To define frailty, we therefore utilise work done by Whole Systems Partnership for the National End-of-Life Care Intelligence Network (NEoLCIN). This work additionally assigns decedents by age group on the following basis:

- aged 65-74 then 10% of deaths are frailty related;
- aged 75-84 then 30% of deaths are frailty related; and,
- aged 85+ then 80% of deaths are frailty related.

In recent years a new cause of death code has been utilised, namely for recording COVID-19³⁰. Where COVID-19 (identified or unidentified) is recorded as the underlying cause of death then decedents have been assigned to the category of organ failure³¹.

7.4.1.3 Demographic data

Person demographic information is largely taken from mortality data, and as such, information relating to a person's Integrated Care Board, Lower Super Output Area, etc is that which was recorded at the point of death.

Further demographic information was added to the mortality record on the following basis:

1. Ethnicity – the linked activity data sets of inpatient, outpatient and A&E were used to obtain most recently recorded valid ethnicity. 7% of records did not find a valid ethnicity code and a further 4% had a code of 'not stated' – a valid code and used where a respondent does not wish to give their ethnicity.
2. Lives alone - decedents were matched to National Health Application and Infrastructure Services person data to identify whether or not they were living alone. Any record indicating a

²⁹ JAMA. 2003 May 14;289(18):2387-92. & J Am Geriatr Soc. 2002 Jun;50(6):1108-12.

³⁰ <https://www.who.int/standards/classifications/classification-of-diseases/emergency-use-icd-codes-for-covid-19-disease-outbreak>

³¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7270480/pdf/main.pdf>

decedent was living alone was flagged in the data set. 4% of people were not found and it could not be identified if they were living alone or not.

3. Learning difficulties or autism - decedents were identified as having a learning disability or autism by searching in Mental Health Minimum Data Set (MHMDS), Improving Access to Psychological Therapies (IAPT), inpatient, outpatient and A&E data sets for the presence, at any time, of codes to indicate diagnosis or disability codes for learning disability or autism³².
4. Deprivation – the level of deprivation was assigned using decedents' Lower Super Output Area³³. It was calculated under two slightly different but similar bases; the index of multiple deprivation³⁴ and the index of income deprivation affecting older people³⁵. These are described more fully in appendix 1.
5. Rurality – the rural or urban classification³⁶ was also assigned using decedents' Lower Super Output Area.

7.4.2 Activity data

Activity data for decedents was obtained from the data sets for inpatients, A&E, outpatients, and community contacts. This activity data was obtained by identifying any activity that took place for decedents in the relevant period prior to death.

7.4.2.1 Inpatients

Data on admissions to hospital.

7.4.2.2 A&E

Attendances at A&E departments. Here, activity was also flagged as to whether it led to an admission taking place out of hours (OOH). This was done for A&E attendances with the disposal code indicating an admission and where the departure date was out of hours (defined as weekdays between 6.30pm and 8am, or Saturdays and Sundays). A&E attendances were used rather than admissions since time of day is not available on inpatient data. This was applied regardless of the type of A&E attendance and/or bank holidays.

³² Full description of method in appendix 1

³³

https://www.datadictionary.nhs.uk/nhs_business_definitions/lower_layer_super_output_area.html#:~:text=A%20Lower%20Layer%20Super%20Output,statistics%20in%20England%20and%20Wales.

³⁴ https://data.england.nhs.uk/ncdr/data_element/indices-of-multiple-deprivation-imd-decile/

³⁵ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/845345/File_7_-_All_IoD2019_Scores_Ranks_Deciles_and_Population_Denominators_3.csv/preview

³⁶ <https://data.gov.uk/dataset/b1165cea-2655-4cf7-bf22-dfbd3cdeb242/rural-urban-classification-2011-of-lower-layer-super-output-areas-in-england-and-wales>

7.4.2.3 Outpatients

Outpatient data was only included where the attendance status indicated that the appointment took place. Any appointments which were not attended or cancelled were excluded. All types of appointment were included, for example whether with a consultant or a nurse.

7.4.2.4 Community services

The Community Services Data Set (CSDS) is considered an experimental data set and therefore results should be interpreted with caution³⁷. Providers submit data but under their own local interpretation. For example, some providers submit just those contacts recorded with attendance outcome of 'attended'; some submit all attendance outcomes, and some do not record any attendance outcome at all. For this analysis we've used best practice^{38,39} and counted all contacts submitted in the data set regardless of whether they are recorded as attended, did not attend or with no attendance outcome recorded.

Given the issues described above we have removed from the data any community contacts occurring while a patient was staying in hospital (according to inpatient data). This removed approximately 10% of community activity in the 90 days prior to death.

7.4.2.5 Learning disability, autism, or both index

Decedents were flagged as having a learning disability or autism using previous methodology developed by The Strategy Unit. This previous work generates an index of people from 2017/18 onwards who are identified as having a learning difficulty or autism. In generating the index, we have drawn on the mental health services dataset (MHSDS), the improving access to psychological therapies dataset (IAPT) and secondary uses service (SUS) data for hospital inpatient spells and outpatient appointments. The MHSDS covers learning disability and autism services as well as specialist and community mental health teams for children and adults.

Dependant on datasets used, there are a range of fields that were screened for learning disability or autism classifications. These included diagnostic codes, reason for referral to service codes, treatment specialty codes, team type for contact codes and some other identifier flags that are added during central processing prior to our access to the data. The table below summarises the datasets and fields that were used.

³⁷ <https://digital.nhs.uk/data-and-information/publications/statistical/community-services-statistics-for-children-young-people-and-adults/january-2022/data-quality-statement>

³⁸ <https://digital.nhs.uk/data-and-information/find-data-and-publications/supplementary-information/2018-supplementary-information-files/referrals-to-end-of-life-eol-support-teams-and-services-analysis-from-the-community-services-data-set>

³⁹ <https://digital.nhs.uk/data-and-information/find-data-and-publications/supplementary-information/2018-supplementary-information-files/referrals-to-end-of-life-eol-support-teams-and-services-analysis-from-the-community-services-data-set>

Dataset	Tables or fields used	Possible to distinguish between learning disability or autism?
MHSDS	Derived flag - "LDA"	N
	Derived flag – "Assuring Transformation"	N
	Derived flag – "Transforming Care category"	Y
	Disability code	N (LD only)
	Primary or other reason for referral	Y
	Service or team types referred to	Y
	Inpatient ward or bed types	Y (partially for autism)
	Previous or current diagnosis (ICD-10 or SNOMED)	Y
	Mental Health Act category	N (LD only)
	Treatment function code (of assigned care professional)	N (LD only)
IAPT	Disability code	N (LD only)
	LTC diagnosis codes as above	Y
SUS	Inpatient or Outpatient diagnosis (ICD-10)	Y
	Inpatient or Outpatient treatment function codes	N
	A&E attendance codes (SNOMED)	Y

7.4.3 Service data

7.4.3.1 Palliative Care Register

Data on the number of people on general practice palliative care registers is published by NHS Digital on an annual basis as part of the Quality and Outcomes Framework (QOF). In this analysis the data source is Quality and Outcome Framework, 2021/22⁴⁰.

⁴⁰ <https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2021-22> as at January 2023

7.4.3.2 Care Homes

The Care Quality Commission (CQC) produce a list of locations with relevant site information⁴¹. The site information allows care homes to be identified and flags which services they offer residents. Locations will provide multiple services and not all services offered are necessarily relevant to this analysis. However, it is not possible to assign individual care homes beds to each service, so locations are deemed either in or out of scope based on three service bands. If a care home offers one of these services, regardless of which other services it also offers, it is deemed to be in scope. If it does not offer one of these services then it is deemed out of scope and excluded.

- Older People
- Dementia
- Physical Disability

The excluded care homes equate to 5% of care homes beds being excluded and 20% of care home sites. For a list of all excluded services please see appendix 2.

Care home locations are further broken down into the categories of nursing or residential. Some locations do provide both types of care. Where this is the case then locations are categorised as nursing.

In the CQC data eight care homes (0.07%) were found have to have zero beds and were excluded⁴².

The full list of excluded service bands flagged for a care home and where the care home does not also offer the service user bands of Older People, Dementia or Physical Disability are:

- Children 0-18 years
- Learning disabilities or autistic spectrum disorder
- Mental Health
- People detained under the Mental Health Act
- People who misuse drugs and alcohol
- People with an eating disorder
- Sensory Impairment
- Whole Population
- Younger Adults

⁴¹ <https://www.cqc.org.uk/about-us/transparency/using-cqc-data>

⁴² The Martins, The Warren, Orchard Cottage, Rockley Core Unit, Robertson Road Core Unit, Glenhurst Lodge, Cambeck Close and Amberley Core Unit

7.4.4 Processing

As an aid to understanding data, we describe here some specific instances in the data processing which it might be help assist in interpretation.

Deaths in Usual Place of Residence are those deaths taking place in a care home, hospice, or home.

The flag for Emergency Admissions Via A&E Out of Hours is calculated as admissions via A&E admitted on weekdays between 6:30pm and 8:00am or admitted any time at on Saturdays and Sundays. Since this uses the time information recorded on A&E activity it will not include all emergency admissions – only those admitted through A&E. It will however identify the vast majority as A&E is the primary route for emergency admissions.

Days in Hospital is intended to describe the burden on decedents of having to attend hospital. It includes the following types of activity:

- Stay in a hospital bed overnight
- Daycase admissions admitted and discharged on the same day
- Regular night and day attenders
- A&E attendances
- Outpatients seen face to face

Each type of activity is given the same weight. This means that a day in hospital carries the same weight as a face to face outpatient appointment. In line with the intention to describe the burden on people, any days with more than one activity is counted only once. For example, if on a particular day a patient attended a face to face appointment whilst also an inpatient then Days in Hospital is set to 1.

The average number of patients on a palliative care register is calculated against the number of deaths and not practice list size.

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