The Strategy Unit.

Health service use in the last two years of life

Lincolnshire STP

1 October 2020

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1. Introduction

Health and care services get just one opportunity to support people at the end of their life. When this support is compassionate and appropriate, unnecessary suffering can be avoided and grieving can be eased. When this is not the case, harm and distress can result. The difference in these experiences can be profound.

Providing the best possible end of life care, within the limited resources available, is not a simple task. It requires a dispassionate assessment of the current situation; it demands detailed insight into the local population; and it needs the perspectives of professionals and the people they serve. Good care is founded on the intelligent use of this information.

This report gives decision makers an understanding of death and dying in Lincolnshire Sustainability and Transformation Partnership (STP) area. It looks at how services are currently used in the last two years of people's lives; it shows how the future might evolve.

The report was produced by the Strategy Unit and jointly funded by NHS England/Improvement (Midlands) and NHS Midlands and Lancashire Commissioning Support Unit. Individual reports have been produced for every STP area in the Midlands – and for the region as a whole. The aim is to provide insights that can be used to improve care.

The analysis presented here is based on linking different datasets[1]. These datasets cover hospital care (including critical care), mental health contacts, psychological therapies and 111 calls. Data are drawn from the national register of all people who died in Lincolnshire STP in 2018/19. Each deceased person is linked to their service use in the two-year period prior to their death. In all, this data linkage involved processing 4.2 million records across thirteen different datasets.

This analysis advances the conversation, but it is not exhaustive. For reasons of availability it excludes data on community services, social care, GP practices, and ambulance services. Data used in the analysis also precedes the Covid-19 pandemic. At the time of writing, this had claimed over 40,000 lives in the UK - predominantly of older people. This is a terrible toll. It will have some effect on the size of population groups considered in this analysis and the Strategy Unit is doing further work to understand this. But the broader context – of around 600,000 deaths annually in the UK – and the long-term nature of the issues considered means that the conclusions of the analysis stand.

The report is structured to set out the story of the population who die and their journey through services. Analysis therefore starts by describing all deaths, before progressing in increasing detail

[1] All datasets are via NCDR pseudonymised specific datamart

towards the final weeks and days of life; it ends by considering what resources future decedent populations will require.

Broad conclusions are drawn, but no recommendations are made. Analysts can show ‘what is’, but they have no special standing in saying what ought to be. This requires the expert inputs of those providing and commissioning care, blended with the insights of the population supported. The aim of what follows is therefore to inform conversations about improving the deaths of people in Lincolnshire.

2. Summary of key findings

This report provides a description of end of life care in Lincolnshire Sustainability and Transformation Partnership (STP). It is part of a suite of reports produced by the Strategy Unit for all STPs in the Midlands region.

Drawing on an analysis of individual level linked datasets, the report outlines the current and likely future situation. The aim is to equip decision makers – in all parts of the STP – with insight that can be used to improve outcomes.

The value of this analysis is therefore in its detail. Nonetheless, several main points emerge that help provide a broad sense of the findings. These are that:

- 66% of people say they would like to die at home. In Lincolnshire just 23% do so.
- People from deprived areas are more likely to die in hospital than people from affluent areas. The reverse is true for deaths in care homes.
- 35% of people in Lincolnshire who die do so after being admitted to hospital as an emergency. Their length of stay in hospital is often short. The most common experience is a terminal episode of two days.
- If patterns of care follow those observed nationally, then as many as a third of palliative patients (around 2,000 people) in Lincolnshire may have died with their pain not properly controlled.
- Over 80% attend A&E at least once in the two years prior to their death. 88% have at least one emergency admission. Around two-thirds call 111.
- 30% of those dying are in contact with mental health services. This is higher than for the Midlands region (25%).
- Patterns of service use differ radically by cause of death. People dying from cancer access all types of service (except critical care) more than those dying of other causes; this is especially true for planned care.
- People's use of urgent care starts low and increases slowly for much of the last two years of life. There is a rapid increase a few months prior to death. The same is true for use of hospital beds.
- Use of planned care rises steadily over the last two years of life. There is then a sharp peak in the months or weeks prior to death, at which point use declines. There is a consistently lower rate of planned care use in Lincolnshire compared to the Midlands. People dying from cancer account for much of this use.

- Not all treatment adds value. Palliative chemotherapy, for example, can be associated with worsening quality of life, often without commensurate gains in survival. In Lincolnshire, people receiving chemotherapy in the last four weeks of life started their treatment later than those that did not. Their use of chemotherapy increased sharply six months prior to death. People with haematological cancer feature significantly in this group.
- Use of emergency admissions and A&E attendances does not differ greatly by age at death. What drives use of these services is not age, but proximity to death.
- Use of hospital beds is dominated by stays following an emergency admission. This increases as age at death increases. In the final year of life, the oldest decedents spend an additional seven days in hospital compared to the youngest decedents.
- In the last two years of life around £97 million is spent on hospital services for decedents in Lincolnshire. Urgent service events account for around two-thirds of this.
- Spend per decedent on hospital services was around £13,500; the lowest in the Midlands.
- Having declined for decades, the number of deaths has begun to rise and is set to continue. The greatest number of deaths is among those aged 85 and above. This is also the group with the largest expected increase.
- If patterns of care do not change, the current growth in deaths per annum suggests that 200 additional beds will be needed in the STP by 2040.

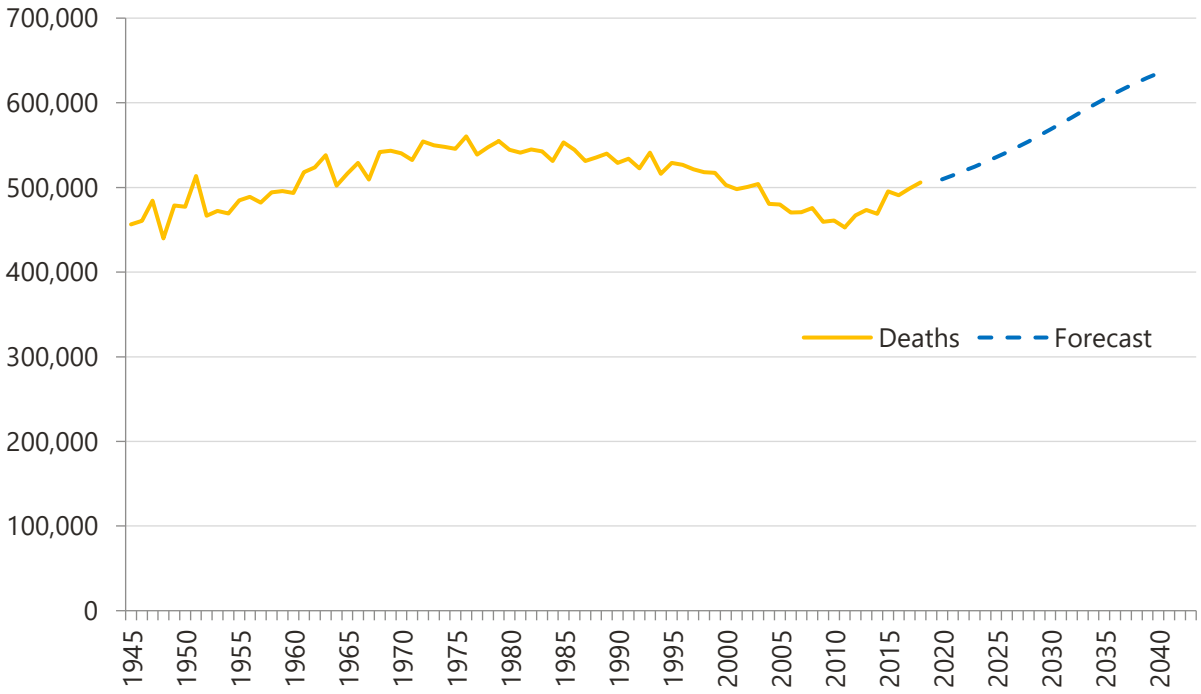
3. How many deaths have there been? How many will there be?

Trends in the number of expected deaths and age at death are driven by broader demographic changes, including the gains in life expectancy seen throughout the 20th century[2]. While dramatic in a broader historical context, these changes have unfolded slowly over decades. It is possible to predict and plan for deaths in the local population. This section therefore provides a basic scaling of historic and forecast numbers of deaths by gender and age group.

3.1 Having declined for decades, deaths are set to increase

The population of England has grown almost every year since the end of the Second World War. Figure 1 shows that until the late 1970s the number of deaths per annum also grew although at a slower rate than the population. Since the early 1980s the number of deaths per year has fallen and the number of deaths in 2009 were the lowest that had been seen since 1952. This continued until 2010 when the trend reversed sharply.

Figure 1 : Deaths in England, long term trends and forecasts



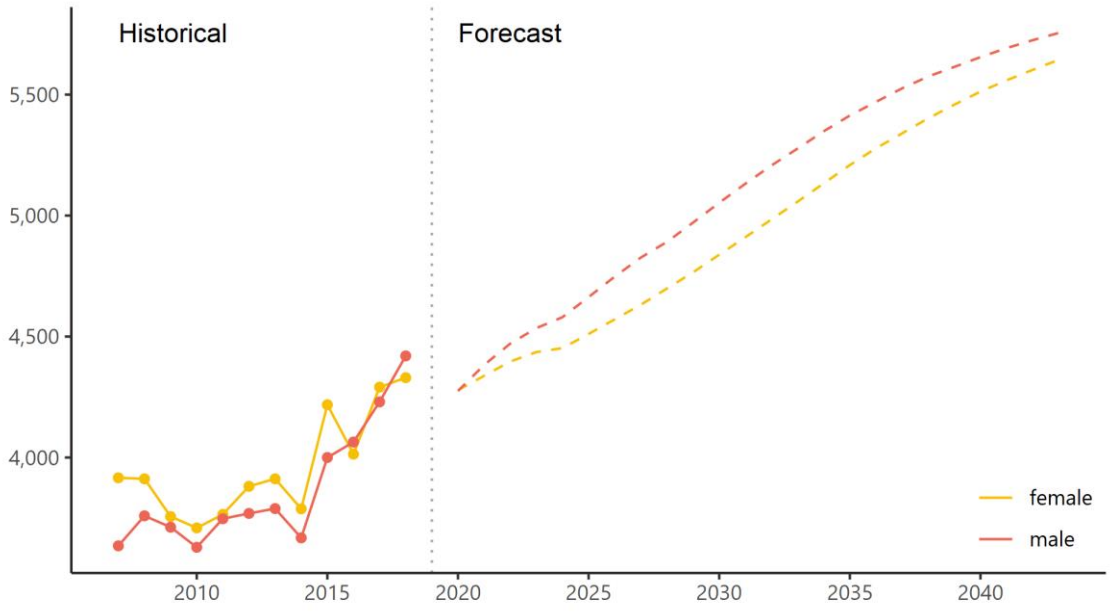
[2] The Health Foundation: Mortality and life expectancy trends in the UK https://www.health.org.uk/publications/reports/mortality-and-life-expectancy-trends-in-the-uk

3.2 Deaths will increase for both males and females

Trends and forecasts in Lincolnshire reflect those in England. Figure 2 shows the annual increase in all deaths over the last decade. In 2018/19 8,169 adults died in Lincolnshire. Between 2020 and 2030 the number of deaths is expected to grow 16% to 9,891 per annum. As the size of the decedent population grows so too will demand on services.

There has also been a shift towards increasing numbers of deaths in males, narrowing the gap between genders. In future years deaths for males are predicted to be consistently higher than deaths for females.

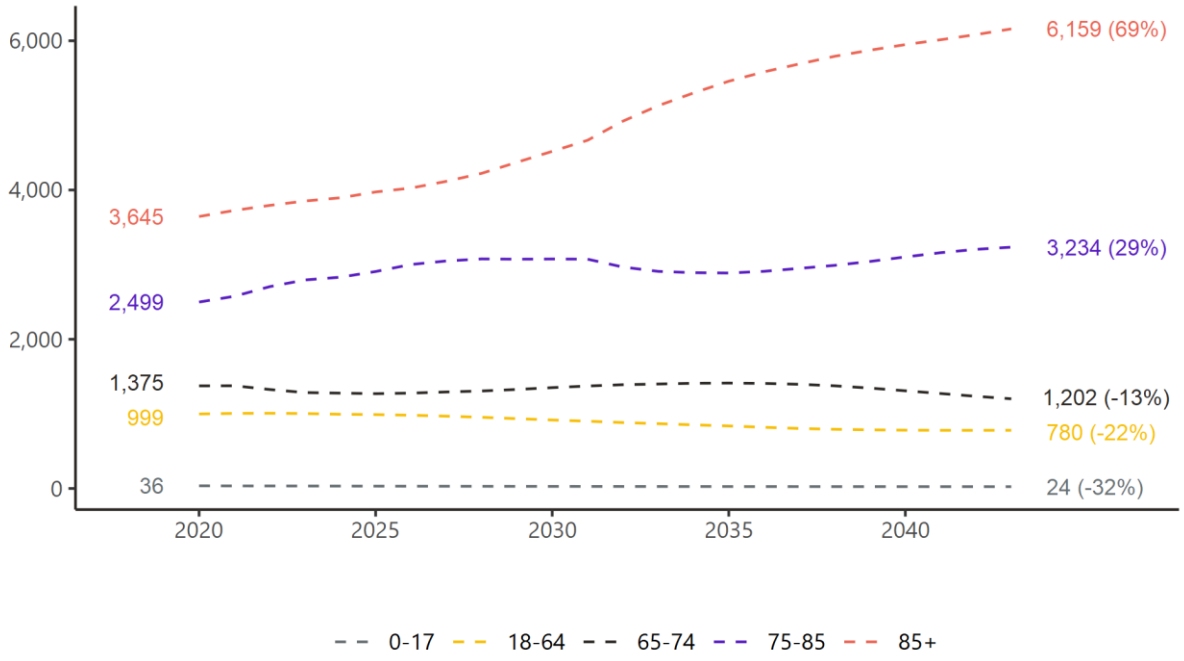
Figure 2 : Historical and forecast deaths by gender - Lincolnshire STP



3.3 The oldest decedents account for most of the increase

Figure 3 shows forecast deaths by age group. The greatest number of deaths is in those aged 85+. This is also the age group with the most significant expected increase. The needs of these older decedents will therefore have a greater impact on future demand.

Figure 3 : Forecast deaths by age group - Lincolnshire STP



4. Where do people die?

The previous section described historic and forecast numbers of deaths. Yet *where* people die is important to the quality and experience of their death. This section therefore examines place of death. It begins by considering how place of death varies by cause, before moving on to consider differences by deprivation and by gender. It also considers the length of stay in hospital for those who die in hospital. Concluding by exploring how place of death is a factor in the level of unrelieved pain for palliative patients, calculating the number of palliative patients dying with their pain not fully relieved.

4.1 How place and cause of death are recorded and assigned

When a person dies a doctor involved in their care completes a medical death certificate which is used to formally register the death. This contains detailed information about the individual, their place of death and underlying cause of death[3].

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 Network[4]. They are:

- Home;
- Care home;
- Hospice;
- Hospital[5]; and,
- Elsewhere.

The underlying cause of death is assigned to one of the five cause groups below. These groups are based on research by Dr June Lunney and Dr Joanne Lynn[6].

- Cancer;
- Frailty;
- Organ failure[7];
- Sudden death; and,
- Other terminal illness.

It can however be difficult to assign deceased patients 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)[8]. This work additionally assigns patients by age groups 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.

[3] Death registrations are collated by the Office for National Statistics who produce an anonymised mortality dataset
[4] https://www.gov.uk/government/publications/classification-of-place-of-death
[5] Where palliative care beds are in community hospitals, deaths in these beds are counted as 'hospital'
[6] JAMA. 2003 May 14;289(18):2387-92. & J Am Geriatr Soc. 2002 Jun;50(6):1108-12.
[7] Primarily decedents with congestive heart failure or chronic lung disease
[8] http://www.endoflifecare-intelligence.org.uk/end_of_life_care_models/cohort_model

4.2 Fewer die at home than would like to

Although 66%[9] of people say they would like to die at home, just 23% of people in Lincolnshire do so.

Figure 4 shows that place of death differs significantly by cause, in that:

- Frailty is the single largest underlying cause of death, accounting for close to half of all deaths. Frailty has the largest proportion of deaths in a care home setting;
- Cancer is the cause of death for around a fifth of the population. 14% of cancer patients die in a hospice setting. This is considerably higher than other causes;
- Organ failure and sudden death have a large proportion of deaths in a hospital setting although there are still a substantial number of deaths occurring at home for both these groups; and,
- Other terminal illness (OTI) represent the smallest cause of death group within the population, but this category has a large proportion of deaths in a hospital setting.

If hospice care for organ failure patients could be organised along similar lines as for cancer care an additional 158 people could die in a hospice rather than a hospital.

When compared to the Midlands (Figure 5) profiles by cause are generally similar. However, in Lincolnshire there are a lower proportion of deaths in hospital for all causes

Figure 4 : Proportion of decedent population by cause and place of death - Lincolnshire STP

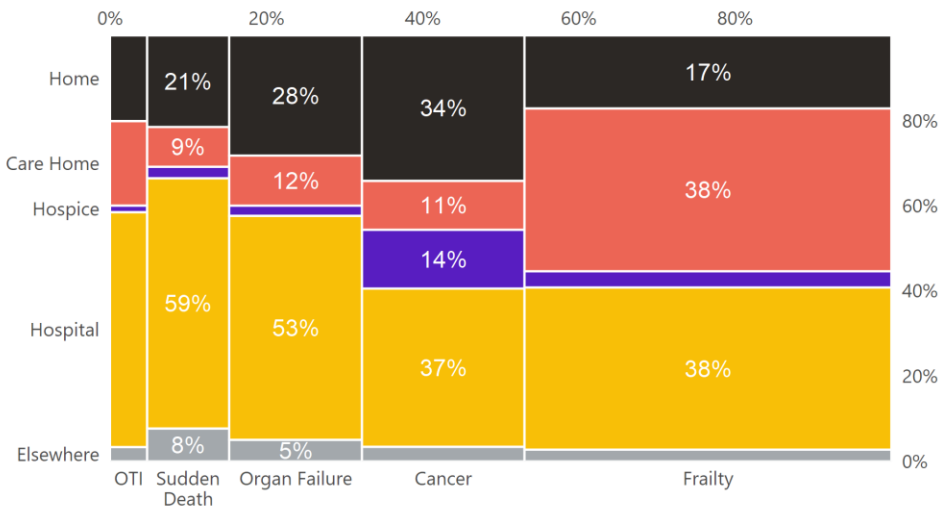
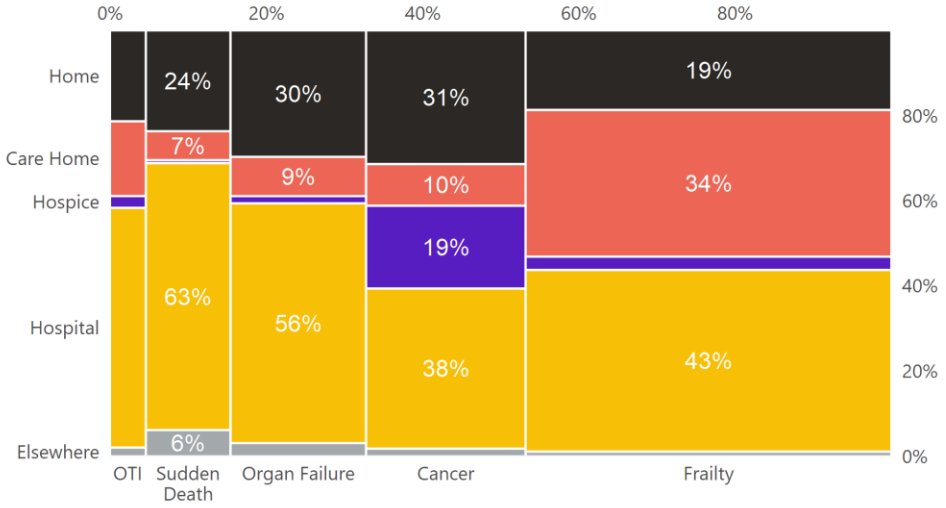


Figure 5 : Proportion of decedent population by cause and place of death - Midlands region



[9] PRISMA survey data, as published in 'Local preferences and place of death in regions within England 2010' Gomes, B, Calazani, N, and Higginson, IJ. Cicely Sounders International. 2011 https://www.kcl.ac.uk/cicelysaunders/attachments/keyreport-Local-preferences-and-place-of-death-in-regions-within-England.pdf

4.3 People from deprived areas are more likely to die in hospital

Figure 6 shows that for decedents living in more deprived areas there were a higher proportion of deaths in hospital. This is offset by smaller proportion of deaths taking place in care homes for these decedents. Proportions differ but this is the same profile seen for the Midlands in Figure 7.

Figure 6 : Proportion of decedent population by deprivation quintile and place of death - Lincolnshire STP

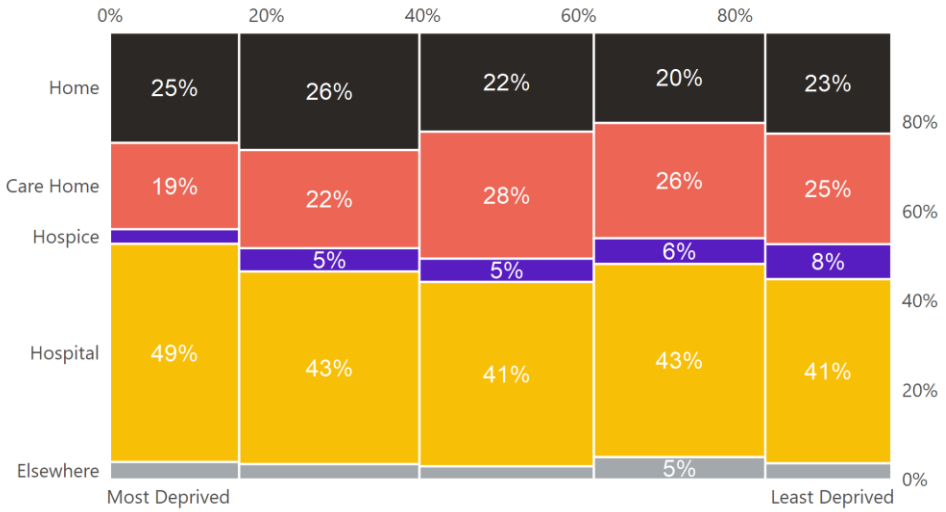
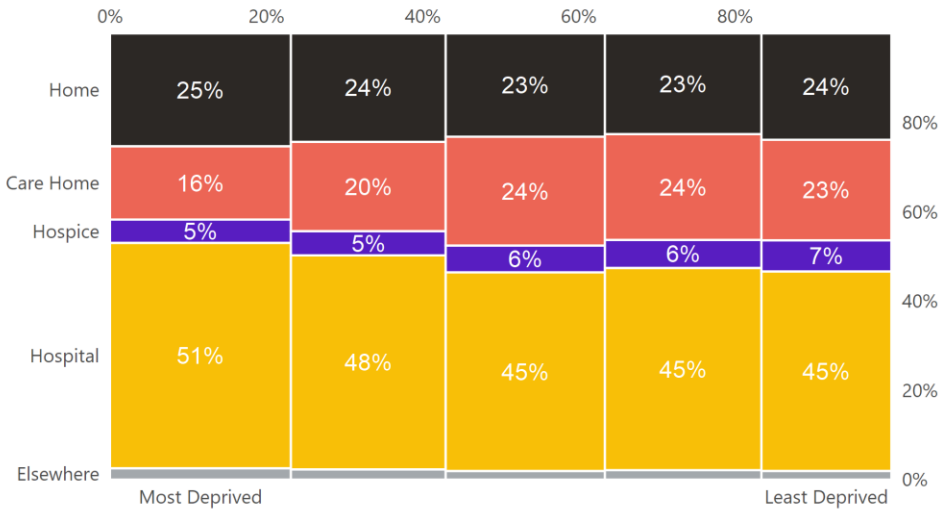


Figure 7 : Proportion of decedent population by deprivation quintile and place of death - Midlands region



4.4 Fewer male deaths take place in care homes

Comparing between genders in Figure 8 there were a higher proportion of males dying either in hospital or at home. The proportion of males dying in a care home was much lower when compared to females. Proportions differ but again this is the same profile seen for the Midlands in Figure 9.

Figure 8 : Proportion of decedent population by gender and place of death - Lincolnshire STP

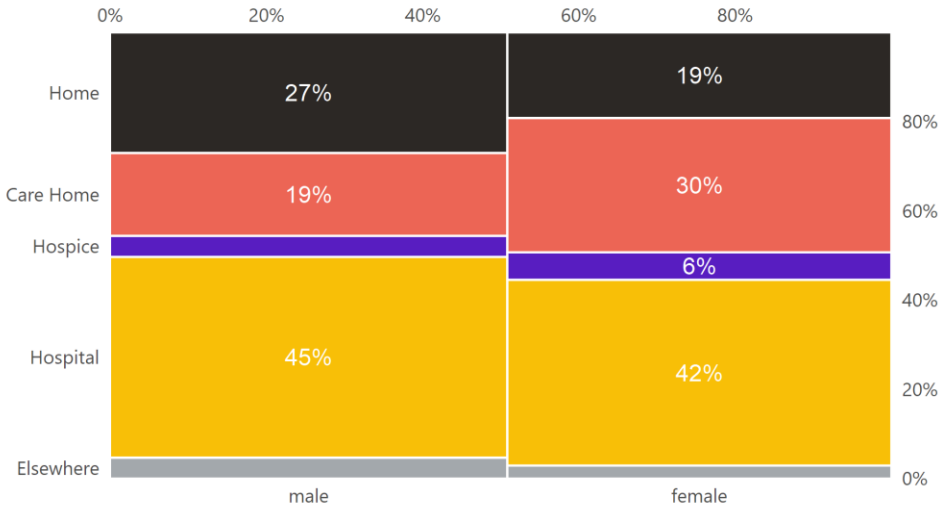
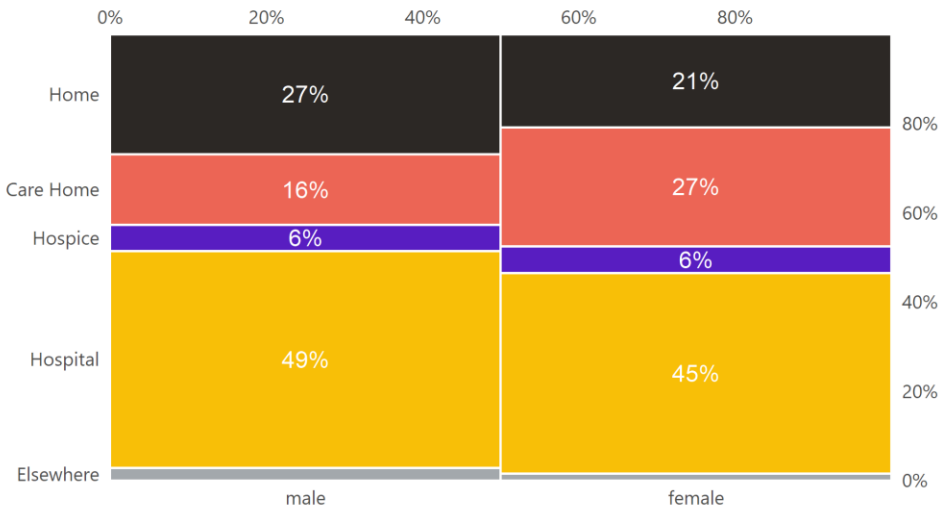


Figure 9 : Proportion of decedent population by gender and place of death - Midlands region

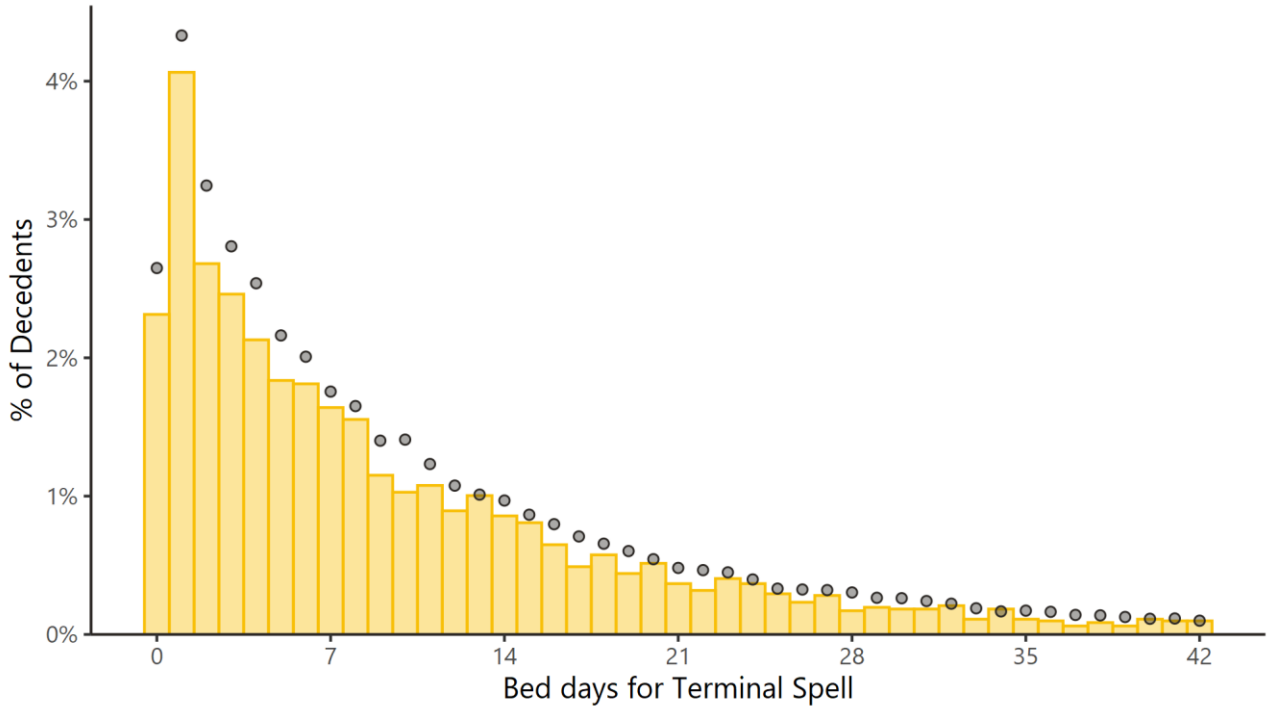


4.5 For deaths in hospital length of stay is often short

Of all decedents in Lincolnshire 35% die in hospital after being admitted as an emergency. For the Midlands the same figure is 41%. Figure 10 shows, for entire decedent populations, the proportions by terminal episode length of stay[10]. Proportions for Lincolnshire are shown as bars. Proportions for the Midlands are shown as dots.

The length of stay for a terminal episode is often short. In Lincolnshire, as in the wider Midlands, there are a higher proportion of decedents with the shortest stays (terminal episodes of 6 days or less). However, proportions are noticeably lower when compared to the Midlands. This reflects the overall lower proportion of the decedent population in Lincolnshire dying in hospital as an emergency.

Figure 10 : Proportion of decedent population by emergency terminal episode length of stay - Lincolnshire STP indicated by bars, Midlands region indicated by dots



[10] Length of stay is calculated as the number of midnight bed stays

4.6 Place of death influences the likelihood of experiencing pain

Previous research has found a relationship between place of death and experience of pain[11]. People who die in a hospice report the lowest level of pain at end of life compared to other settings. Applying research from the Office of Health Economics[12] to those receiving, or in need of, palliative care in Lincolnshire (Table 1 and Table 2) suggests that in total a third of palliative patients (2,072 people - using central estimate) may have died with their pain uncontrolled.

From these estimates; rates of unrelieved pain are highest for those palliative patients who die at home; they are lowest for those who die in a hospice setting. This represents an opportunity to explore the local picture of palliative care service provision and patient end of life experience to ensure interventions to maximise pain control for people wherever they die.

Table 1 : By setting, the number of people at end of life whose pain is not relieved

	No. of Palliative Care Deaths	Pain Not Relieved					
		%			No. of People		
		LCL	Central Est.	UCL	LCL	Central Est.	UCL
Home	1,418	7.6	8.2	8.8	108	116	125
Hospital	2,656	3.6	4.0	4.4	96	106	117
Care home	1,486	1.8	2.2	2.6	27	33	39
Elsewhere/Other	234	1.8	2.2	2.6	4	5	6
Hospice	332	0.8	1.4	2.0	3	5	7
Total	6,126				237	265	293

Table 2 : By setting, the number of people at end of life whose pain is only partially relieved

	No. of Palliative Care Deaths	Pain Partially Relieved					
		%			No. of People		
		LCL	Central Est.	UCL	LCL	Central Est.	UCL
Home	1,418	43	43.6	44.6	604	618	633
Hospital	2,656	27	27.6	28.5	709	733	757
Care home	1,486	23	24.2	25.4	342	360	377
Elsewhere/Other	234	23	24.2	25.4	54	57	59
Hospice	332	10	12	13.5	35	40	45
Total	6,126				1,743	1,807	1,871

[11] Office of National Statistics, 2016. National Survey of Bereaved People (VOICES): England, 2015 [Online]. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015

[12] Zamora, B., Cookson, G. and Garau, M., 2019. Unrelieved Pain in Palliative Care in England. OHE Consulting Report, London: Office of Health Economics. https://www.ohe.org/publications/unrelieved-pain-palliative-care-england

5. Which services are accessed before death?

In the two years before they die most people access some form of healthcare. In this section we describe these patterns of use and how they vary by cause of death.

The datasets used in this section have been grouped into four different healthcare activity types[13]:

ACTIVITY TYPE	SERVICE GROUP
Urgent service event	Emergency Admissions A&E Attendances Calls to 111
Planned contact	Planned Outpatient Attendances Mental Health Contact IAPT Appointments
Planned admission	Daycases Elective Admissions Regular Day/Night Admissions
Bed days	Critical Care All Other Bed Types

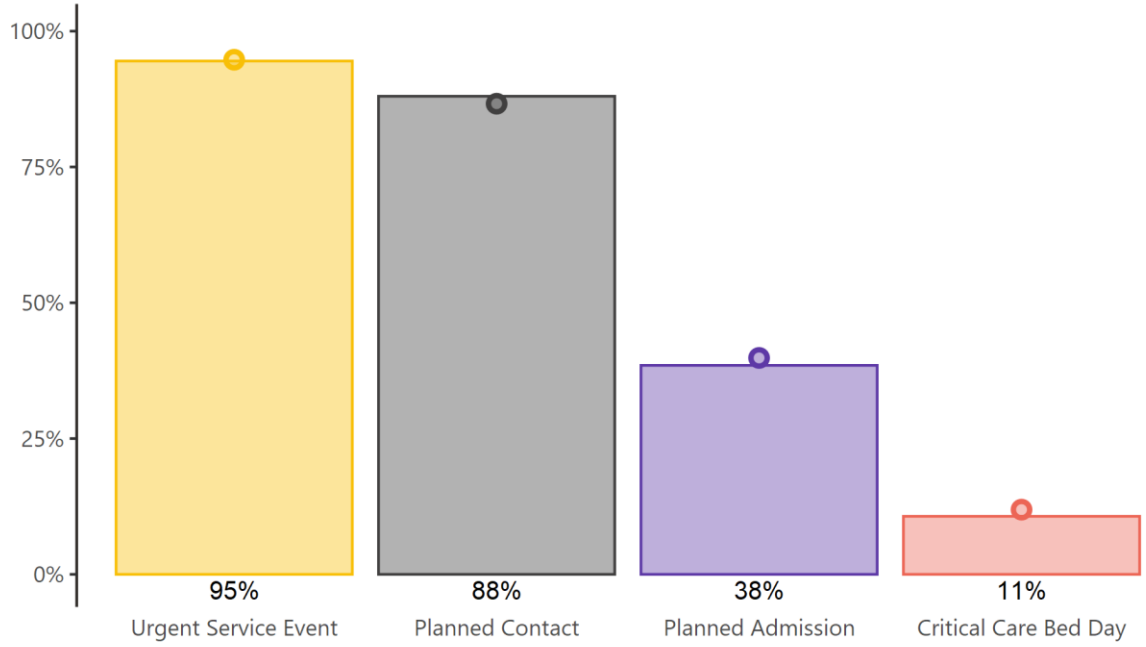
[13] A&E attendances include applicable urgent same day consultant outpatient appointments. Outpatient appointments include planned follow-up A&E attendances

5.1 Nearly all decedents access urgent care

Figure 11 shows that 9 in 10 people dying in Lincolnshire access urgent care services in the two years prior to death. A similar but slightly smaller proportion also access planned care. Access is lower for planned admissions (4 in 10) and much lower for critical care (1 in 9).

Access levels for Lincolnshire are shown as bars. Access levels for the Midlands are shown as dots. Proportions are similar compared to the Midlands.

Figure 11 : Proportion of decedent population accessing healthcare activity types in two years prior to death - Lincolnshire STP indicated by bars (with percentage at bottom), Midlands region indicated by dots

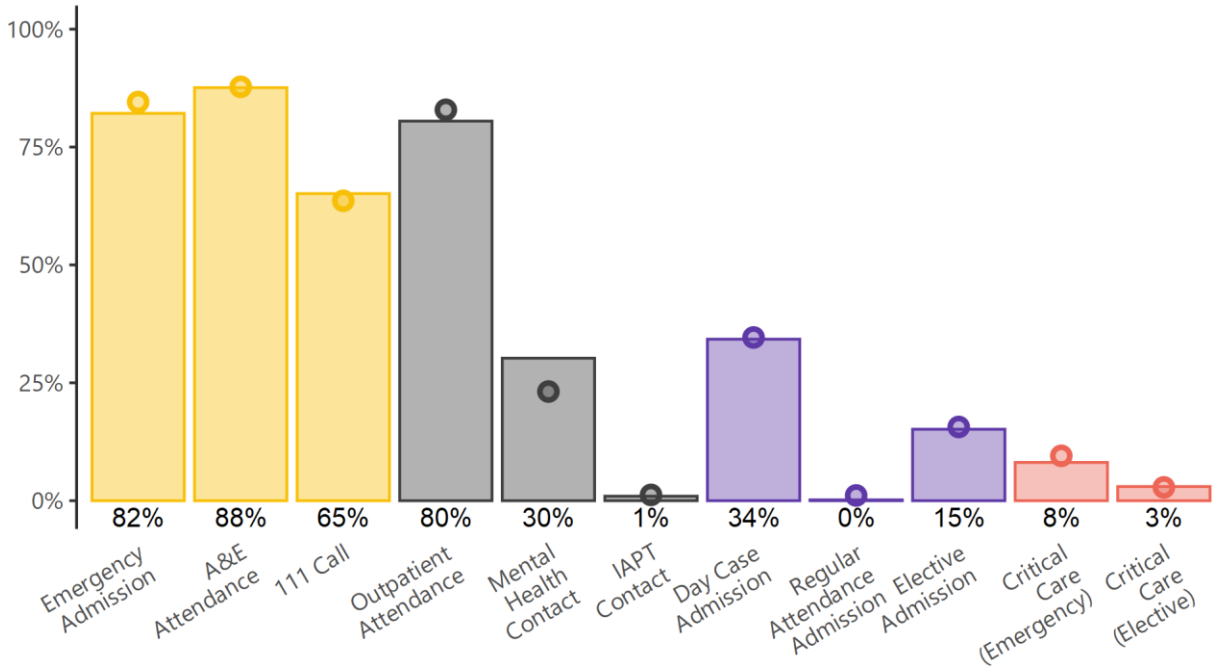


5.2 Most decedents access emergency admissions, A&E and outpatient clinics; few access mental health services

The proportion of people accessing different types of care in the last two years of life is shown in Figure 12. It highlights radical differences by service type:

- For urgent service events:
  - Over 80% of the decedent population have at least one emergency admission;
  - 88% of the decedent population have at least one A&E attendance; and,
  - Around two-thirds call 111.
- For planned contacts, 80% access an outpatient appointment. 30% are in contact with mental health services; this is much higher than the Midlands (25%);
- Planned admissions are largely accounted for by day case admissions (34% of people); around half that proportion access elective admissions (15%); and,
- For critical care access is mainly as the result of an emergency admission. Only 3% of the decedent population accessed critical care as part of an elective admission.

Figure 12 : Proportion of decedent population accessing healthcare service types in two years prior to death - Lincolnshire STP indicated by bars (with percentage at bottom), Midlands region indicated by dots

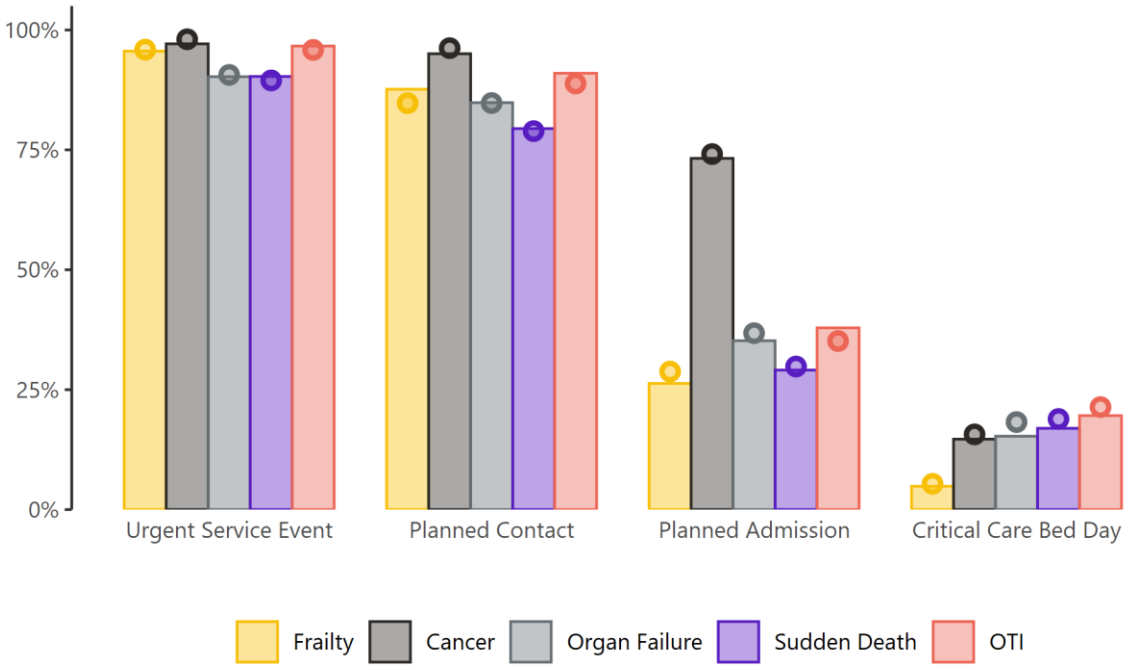


5.3 Most cancer patients access planned admissions

Figure 13 looks at access to different service types by cause. This shows that:

- People dying from cancer access all types of service (except critical care) more than those dying of other causes. Their access to planned admissions is significantly higher;
- Critical care access is much lower for people dying from frailty than from other causes; and,
- Access to urgent service events and planned contacts are broadly similar between causes of death.

Figure 13 : Proportion of decedent population accessing healthcare activity types by cause in two years prior to death - Lincolnshire STP indicated by bars, Midlands region indicated by dots

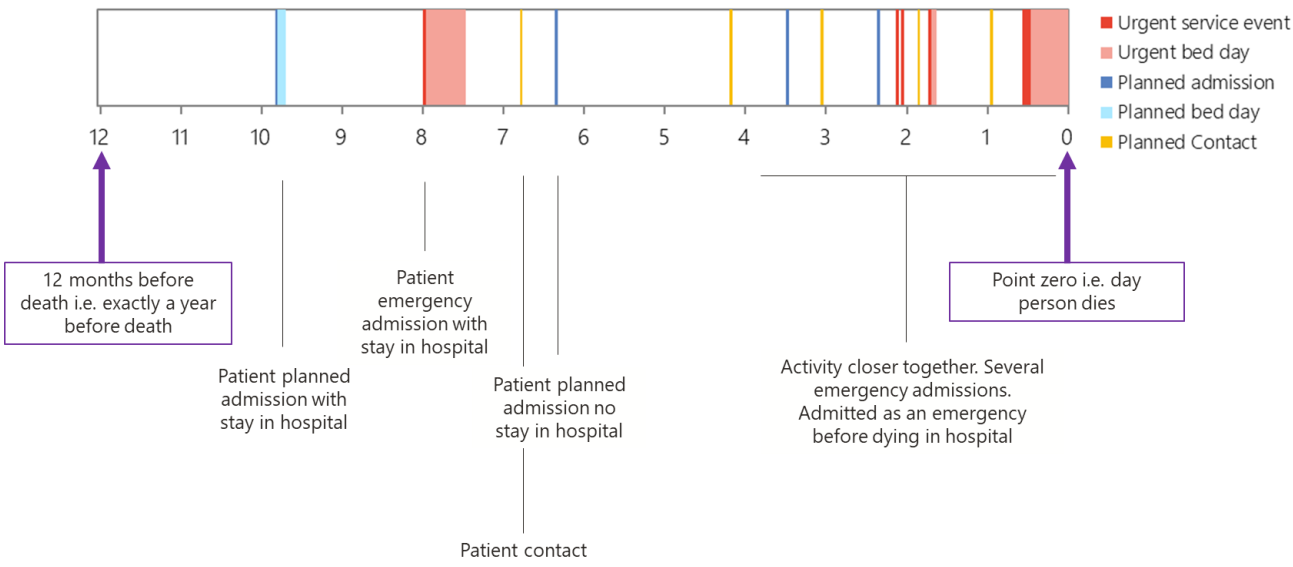


5.4 Service use differs radically by cause of death

Behind headline levels of access examining patients' interactions with services can reveal significantly different patterns. These patterns can then suggest specific areas for improvement. To illustrate this, we now investigate the service interactions of a small sample of fifteen random decedents. We do so for each cause of death, focusing on their last year of life.

Figure 14 shows the format used for this analysis. It does so here using a 'fictional' example of a decedent's service use in the last year of life. The chart shows different service events, starting at day 365 and ending at death. This format is applied below to look at samples of decedents for different causes of death.

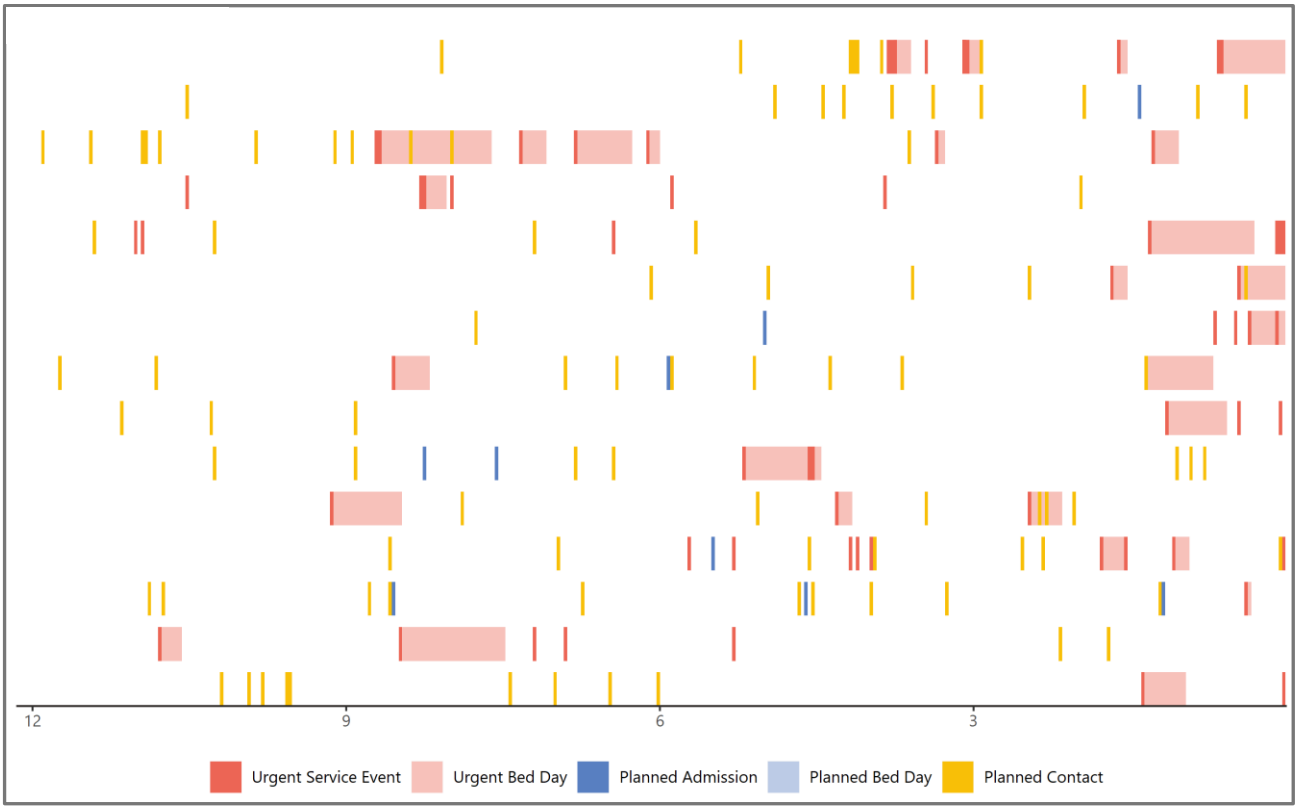
Figure 14 : Fictional example explaining patterns of service use charts



5.4.1 Most of those dying from frailty access urgent care

Analysis of the sample of those dying from frailty (Figure 15) suggests that a large proportion of people experience an emergency admission, plus an associated bed stay, at some point in their last year. The likelihood of this increases the closer people are to death.

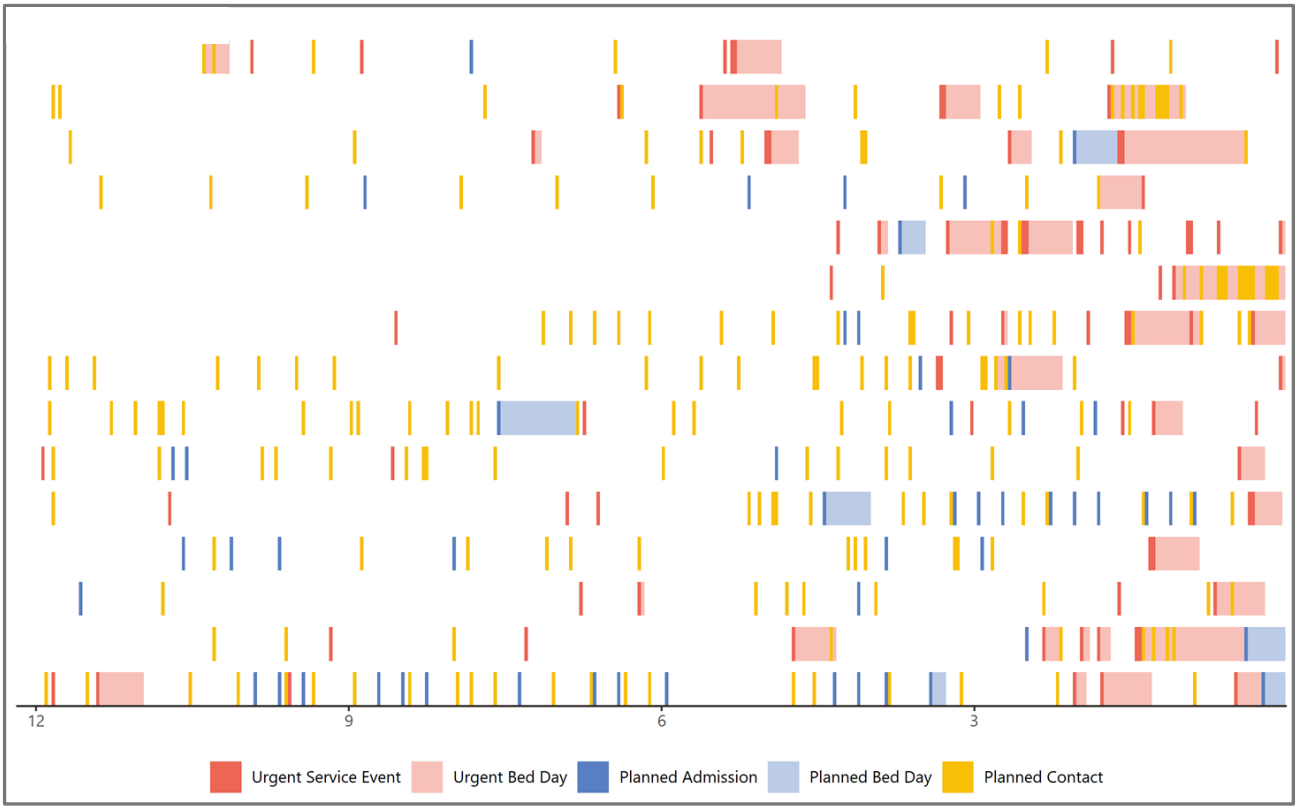
Figure 15 : Patterns of service use for people dying from frailty



5.4.2 Planned care features highly for those dying of cancer

Analysis of the sample of those dying from cancer (Figure 16) suggests frequent planned contacts and planned admissions. This group is also more likely to have a planned stay in hospital and experience more planned bed days than other cause of death groups. Urgent events and associated urgent bed stays are more likely to occur in the last six months of life.

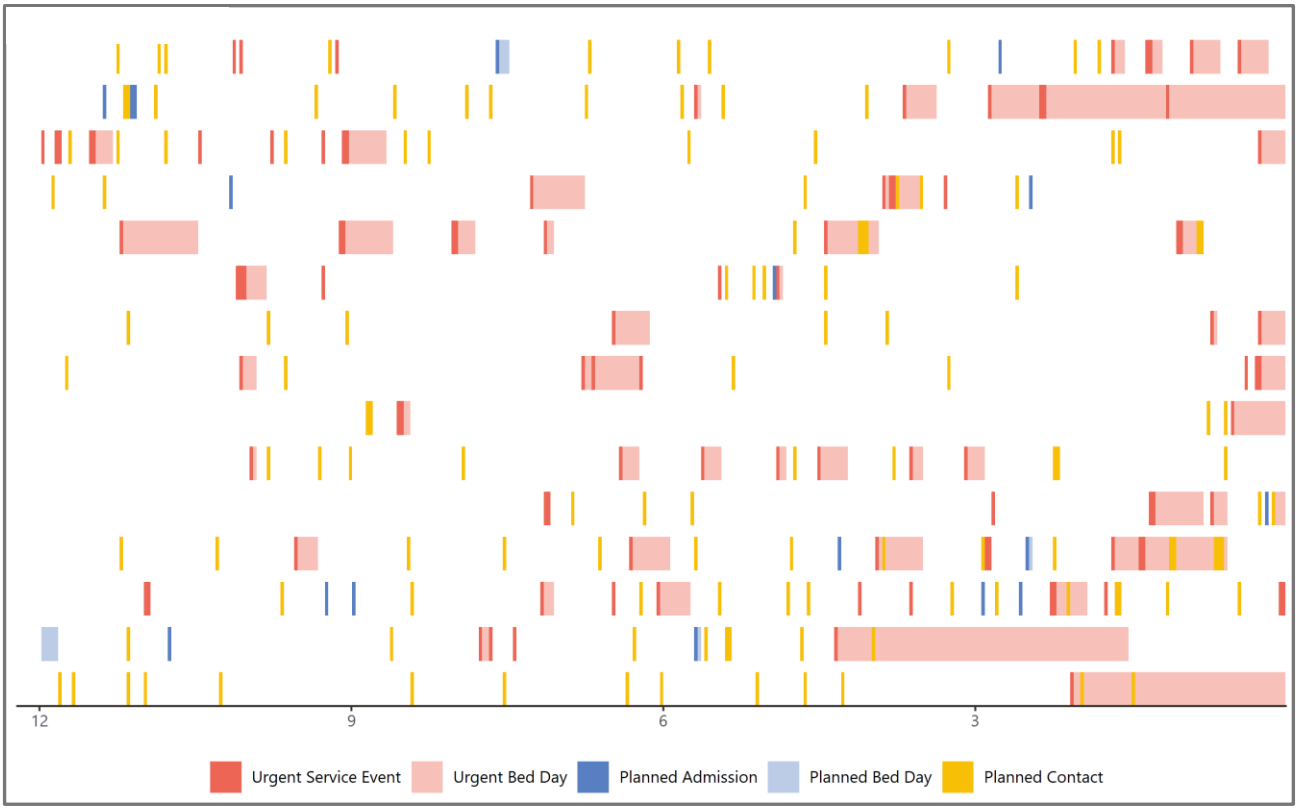
Figure 16 : Patterns of service use for people dying from cancer



5.4.3 People dying from organ failure experience multiple urgent stays

Figure 17 illustrates service use for people dying of organ failure. Here there are multiple urgent events with an associated bed stay in the last year of life. The closer this population are to death, the longer these stays tend to become.

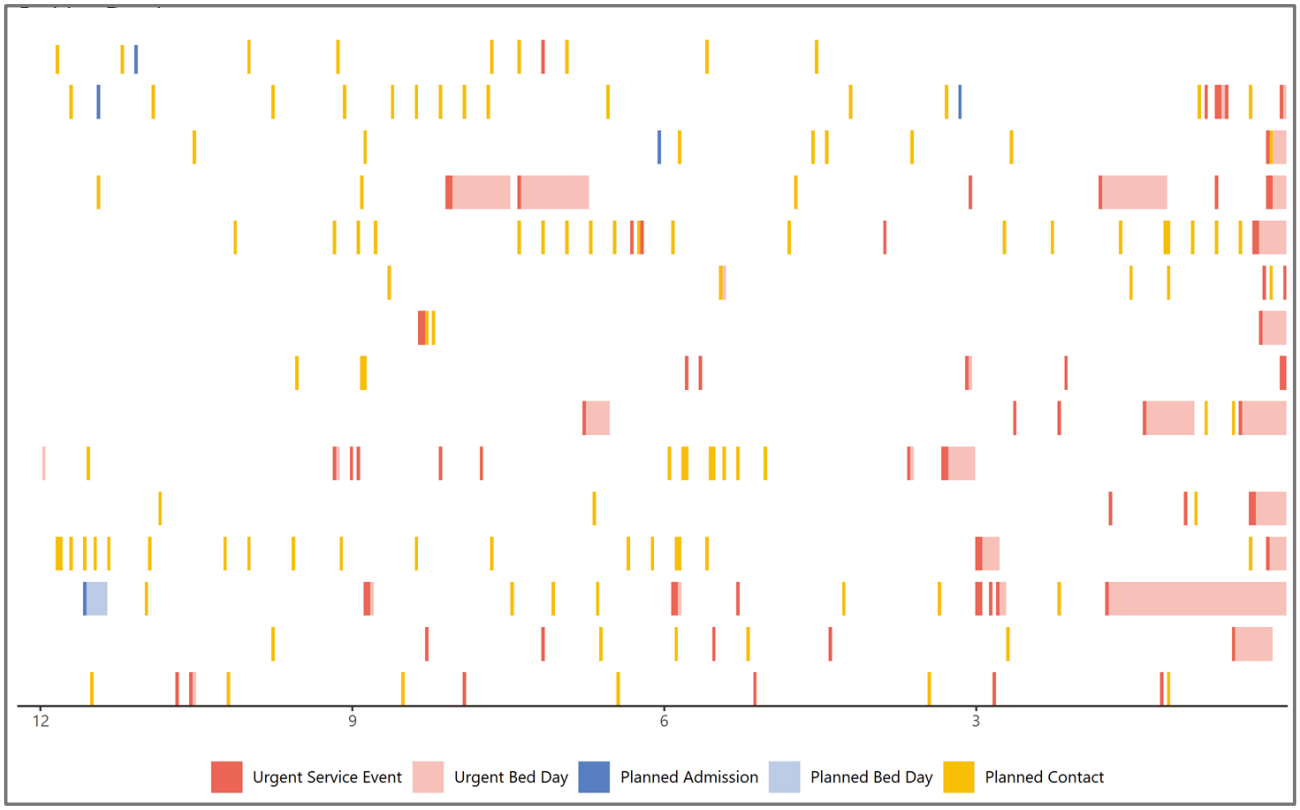
Figure 17 : Patterns of service use for people dying from organ failure



5.4.4 People dying a sudden death tend to experience urgent care

Figure 18 shows the sample of people experiencing sudden death. Here there are planned contacts throughout the last year of life. A large proportion experience an urgent event with associated urgent bed stay in their final month - often then going on to die in hospital after a short period.

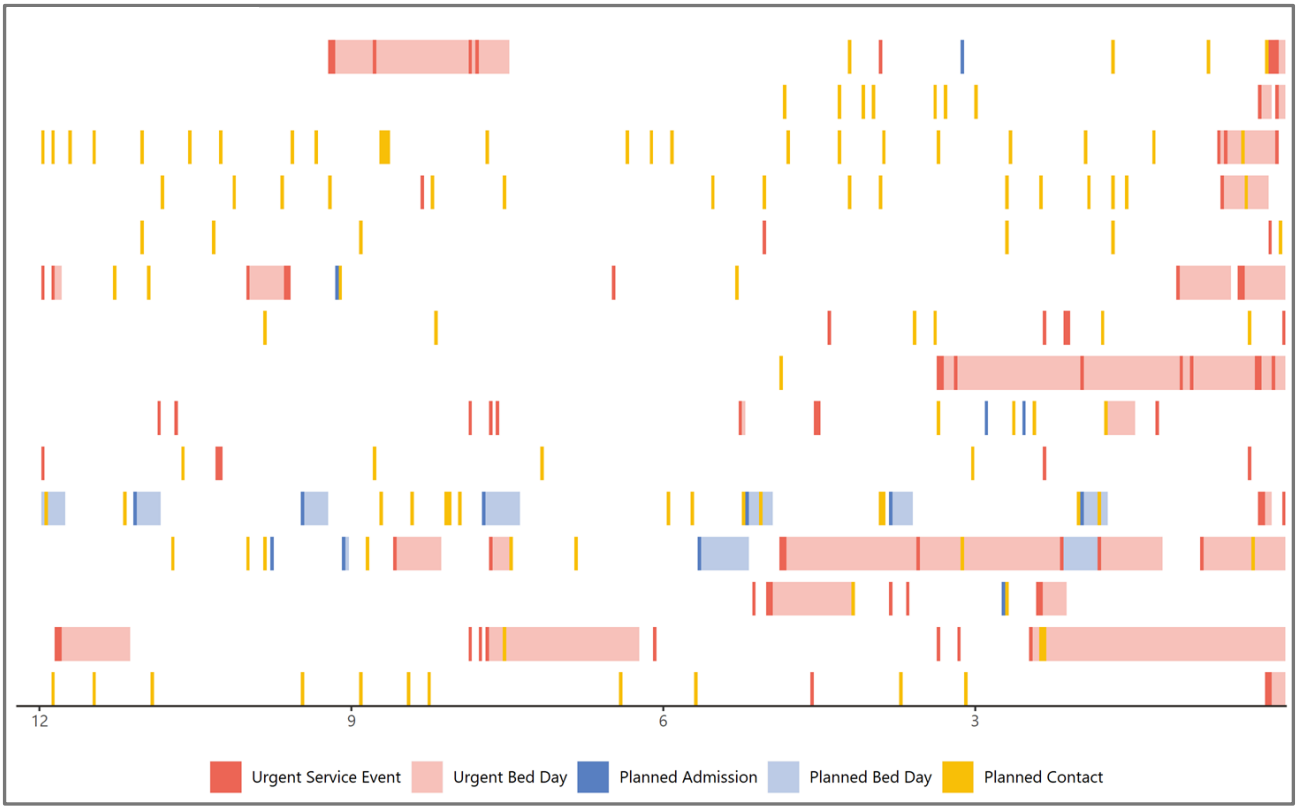
Figure 18 : Patterns of service use for people dying a sudden death



5.4.5 Those dying from other terminal illness experience long lengths of stay

Analysis for people dying of 'other terminal illness' (Figure 19) presents a mixed picture. A large proportion experience an urgent service event with long bed stays. When charts show urgent bed days intersected by another urgent event this represents patients being transferred between different hospitals.

Figure 19 : Patterns of service use for people dying from other terminal illness



6. How and when is care used by the dying?

The previous section showed which services people accessed. We now consider how *much* healthcare is used. We consider this by proximity to death, by cause and by age.

6.1 How much care and when; service use by proximity to death

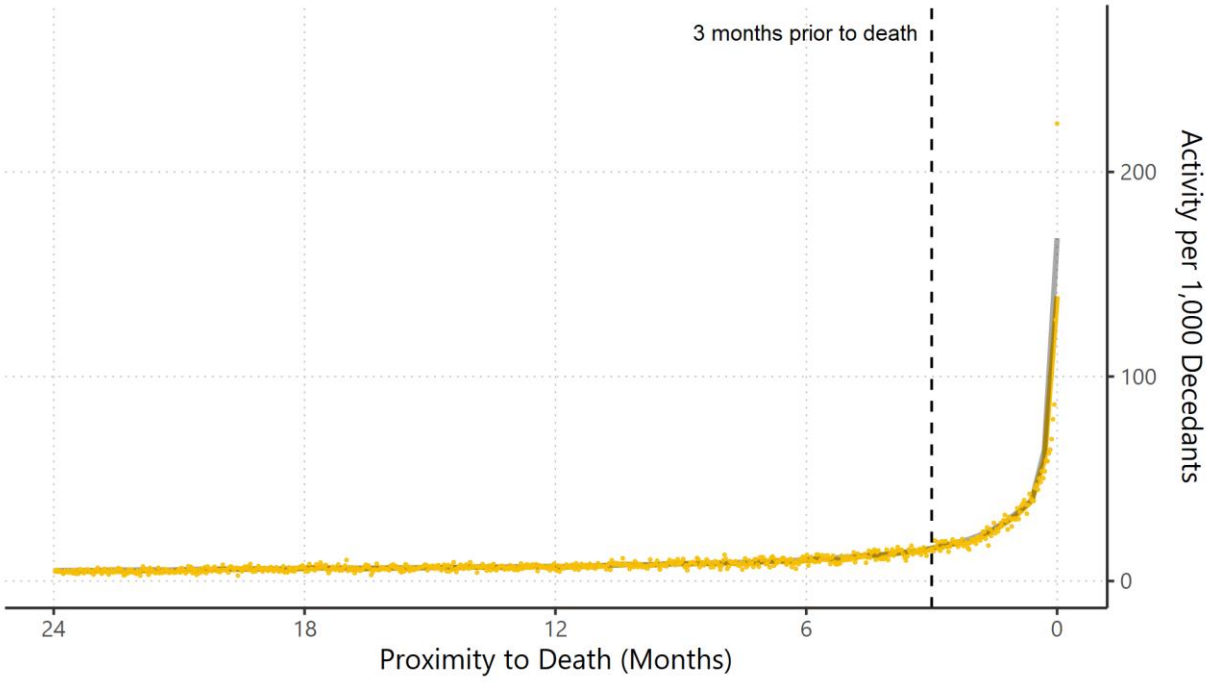
In this sub-section we consider how use of care changes over time, as people approach death. For each type of activity, we show how service use increases, decreases and at what point a peak is reached. Time here means 'time before death', regardless of any actual calendar date. Activity taking place on the day of death is a time of 0 days, taking place the day before death is 1 day etc.

In the two year period prior to death we show rates of service use for those dying in Lincolnshire (yellow dots); the utilisation curve for Lincolnshire (yellow line); and the utilisation curve for the Midlands as a whole (dashed grey line).

6.1.1 Urgent care use rises rapidly and peaks on day of death

Urgent service events start low and increase slowly for much of the period until a few months prior to death when there is a rapid rate of increase, rising to a sharp peak at the point of death. The rate and pattern of service use in Lincolnshire is the same as the Midlands.

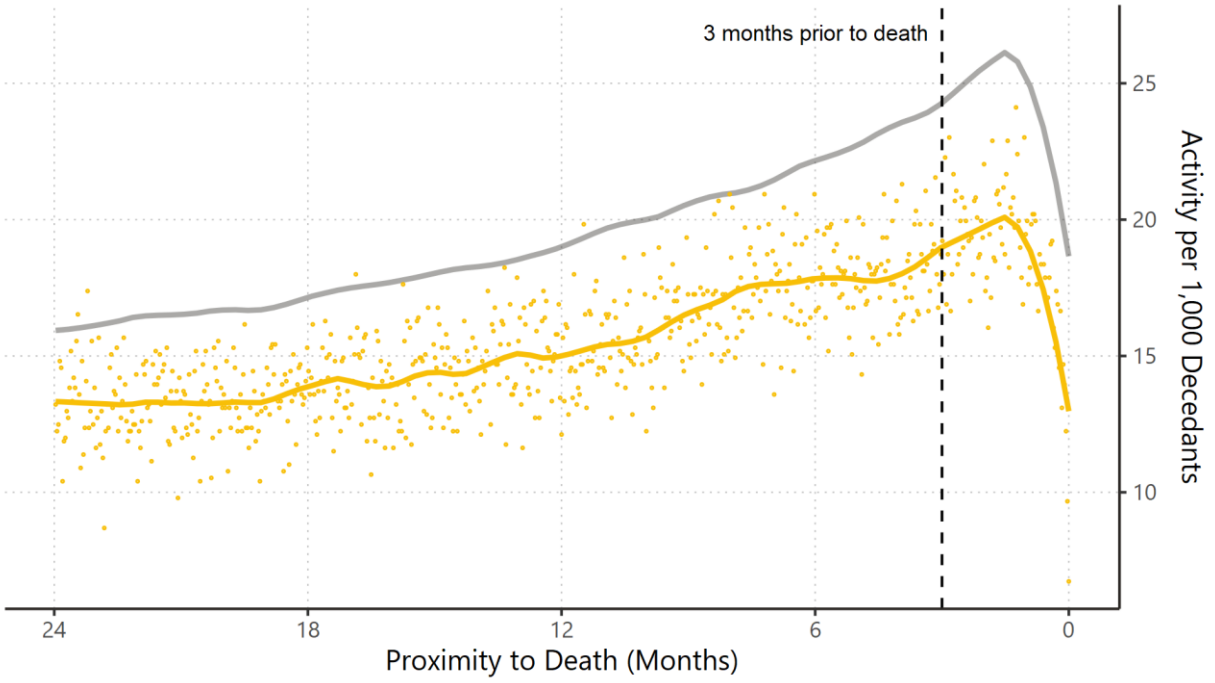
Figure 20 : Urgent service events per 1,000 decedents by proximity to death in days - Lincolnshire STP (yellow dots and line) relative to Midlands region (grey line)



6.1.2 Use of planned contacts increase steadily, peaking in weeks before death

Planned contacts rise steadily throughout the period until a sharp peak in the weeks prior to death, at which point they decline. Although the pattern of service use is similar there is a consistently lower rate in Lincolnshire when compared to the Midlands.

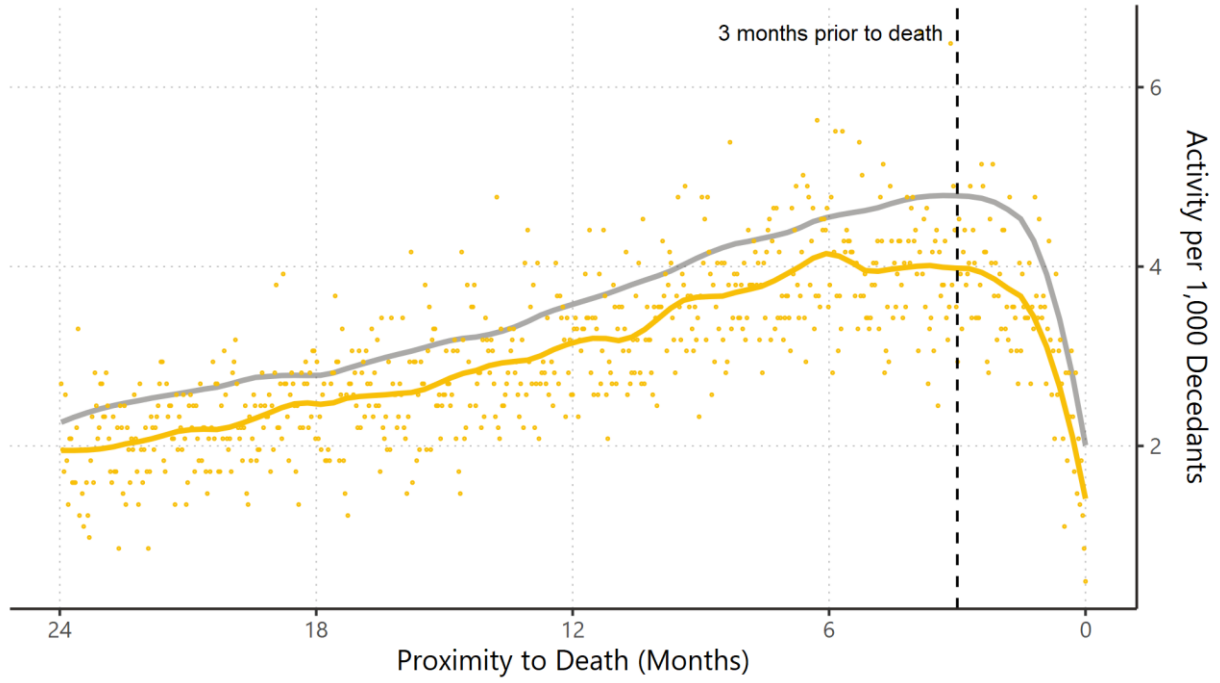
Figure 21 : Planned contacts per 1,000 decedents by proximity to death in days - Lincolnshire STP (yellow dots and line) relative to Midlands region (grey line)



6.1.3 Use of planned admissions increases steadily, peaking in months before death

Planned admissions also rise steadily throughout the period with a rounded peak a matter of months prior to death, at which point they decline. Although the pattern of service use is similar there is a consistently lower rate in Lincolnshire when compared to the Midlands.

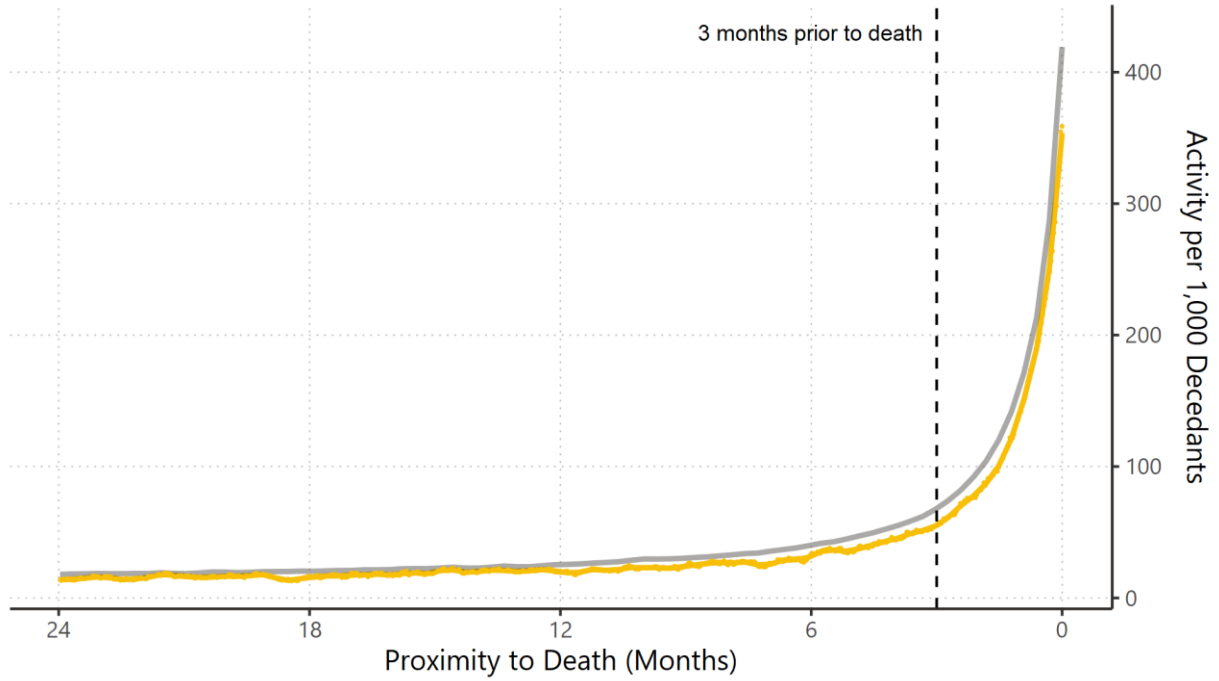
Figure 22 : Planned admissions per 1,000 decedents by proximity to death in days - Lincolnshire STP (yellow dots and line) relative to Midlands region (grey line)



6.1.4 Use of hospital beds rises rapidly and peaks on day of death

Use of bed days, created when an admission to a bed takes place, closely follows the pattern seen in urgent service events. This is because, as seen in analysis of patterns of service use (in sub-section 5.4), bed occupancy for the decedent population usually follows an emergency admission. Therefore, these patterns of service use in Lincolnshire is the same as the Midlands but rates are slightly lower.

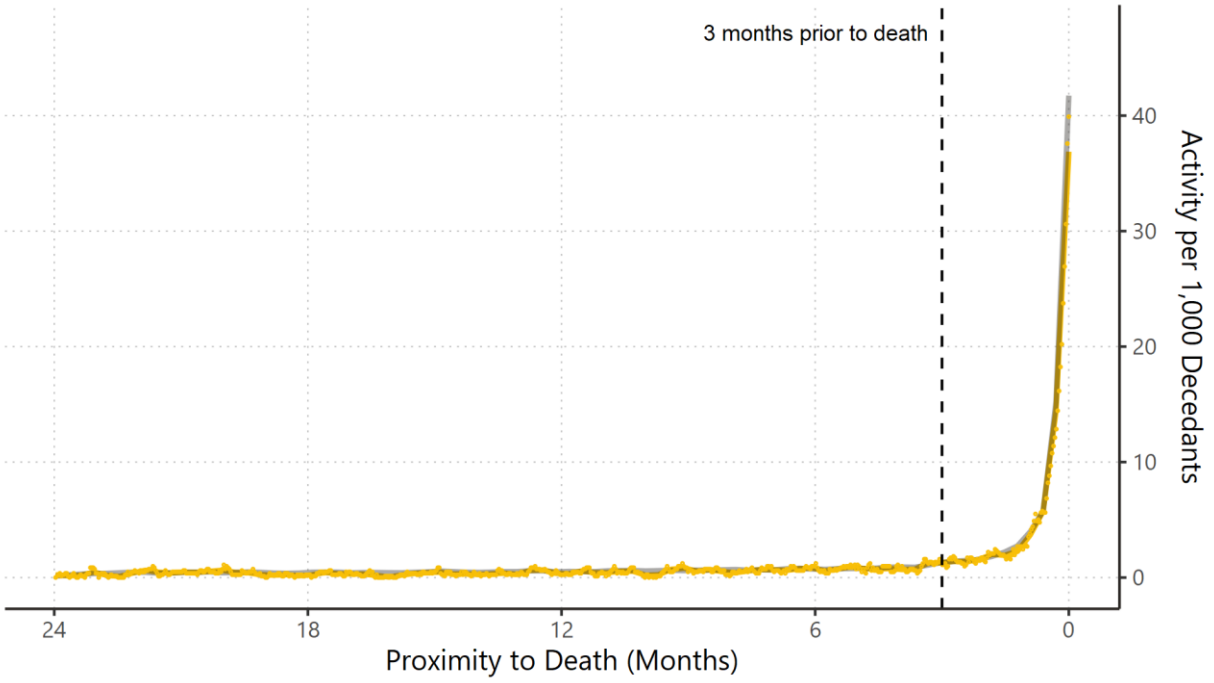
Figure 23 : Bed days per 1,000 decedents by proximity to death in days - Lincolnshire STP (yellow dots and line) relative to Midlands region (grey line)



6.1.5 Critical care days are concentrated in the last month of life

Again, this closely follows the pattern seen in urgent service events. The rate and pattern of service use in Lincolnshire is the same as the Midlands.

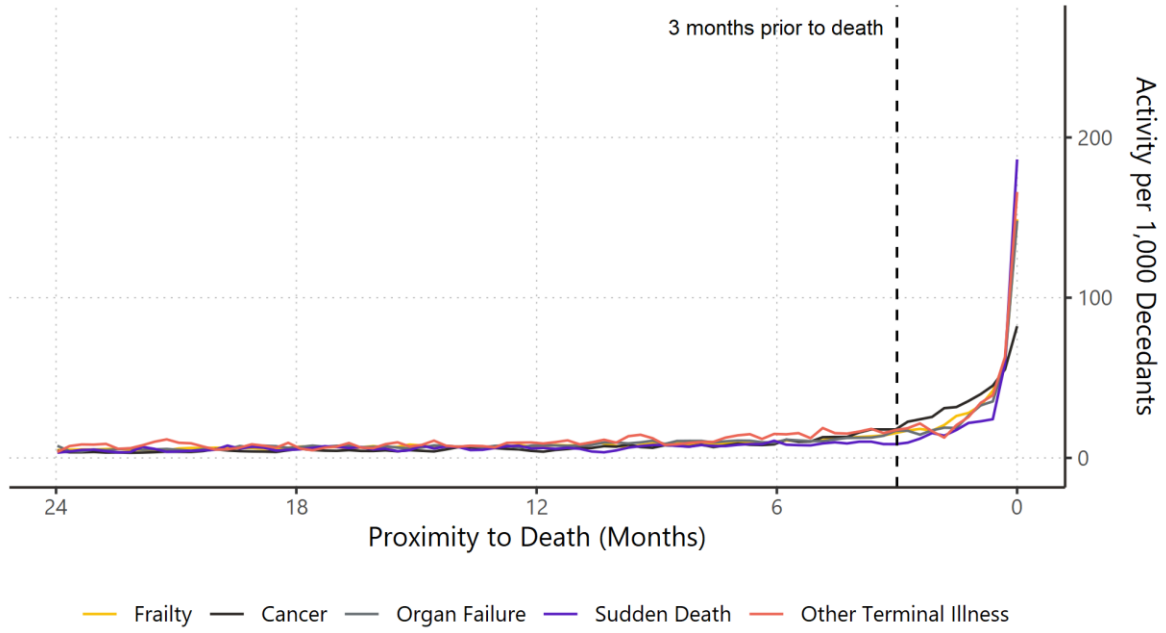
Figure 24 : Critical care days per 1,000 decedents by proximity to death in days - Lincolnshire STP (yellow dots and line) relative to Midlands region (grey line)



6.1.6 Use of urgent service events show similar patterns by cause

Utilisation curves by cause show patterns which are very similar for urgent service events (Figure 25). Where curves do diverge, this occurs in the last 3 months of life.

Figure 25 : Urgent service events per 1,000 by cause and proximity to death in days - Lincolnshire STP

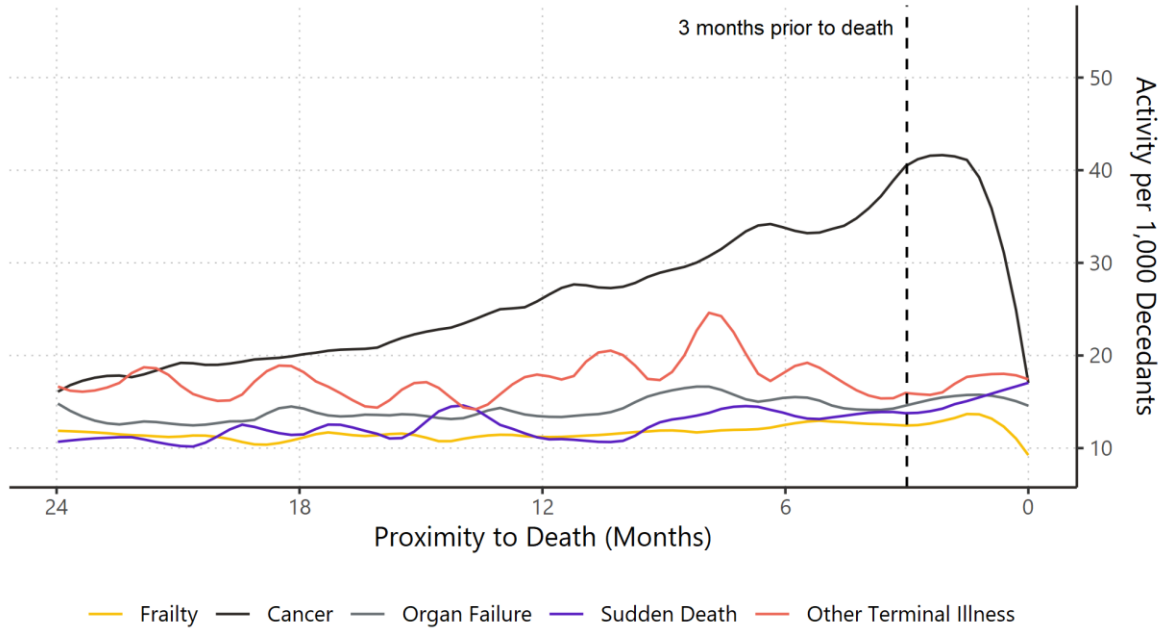


6.1.7 Use of planned contacts and admissions is much higher for those dying from cancer

Utilisation curves by cause of death in Figure 26 show that those dying from cancer dominate use of planned contacts. Whilst only a fifth of deaths are due to cancer we have seen that people in this group experience a relatively high volume of planned contacts (sub-section 5.4.2).

Cancer patients will experience a high volume of planned care due to cancer treatment regimens. These regimens require a regular sequence of multiple hospital visits, leading to the high volumes of planned care for cancer patients. Many planned contacts are outpatient attendances, a setting used for delivering radiotherapy regimens.

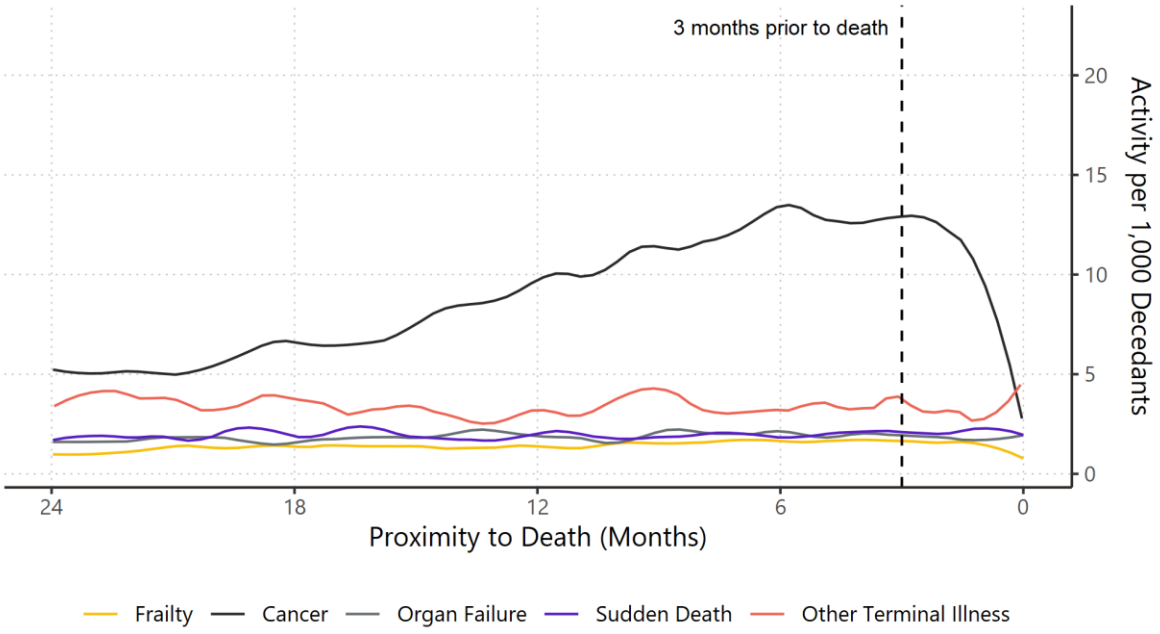
Figure 26 : Planned contacts per 1,000 by cause and proximity to death in days - Lincolnshire STP



Utilisation curves by cause of death in Figure 27 show that those dying from cancer also dominate the use of planned admissions. We have seen that people in this group also experience a relatively high volume of planned admissions (again, in sub-section 5.4.2).

As mentioned in above, cancer patients will experience a high volume of planned care due to cancer treatment regimens. These regimens require a regular sequence of multiple hospital visits, leading to the high volumes of planned care for cancer patients. Many planned admissions are daycases, a setting used for delivering chemotherapy regimens.

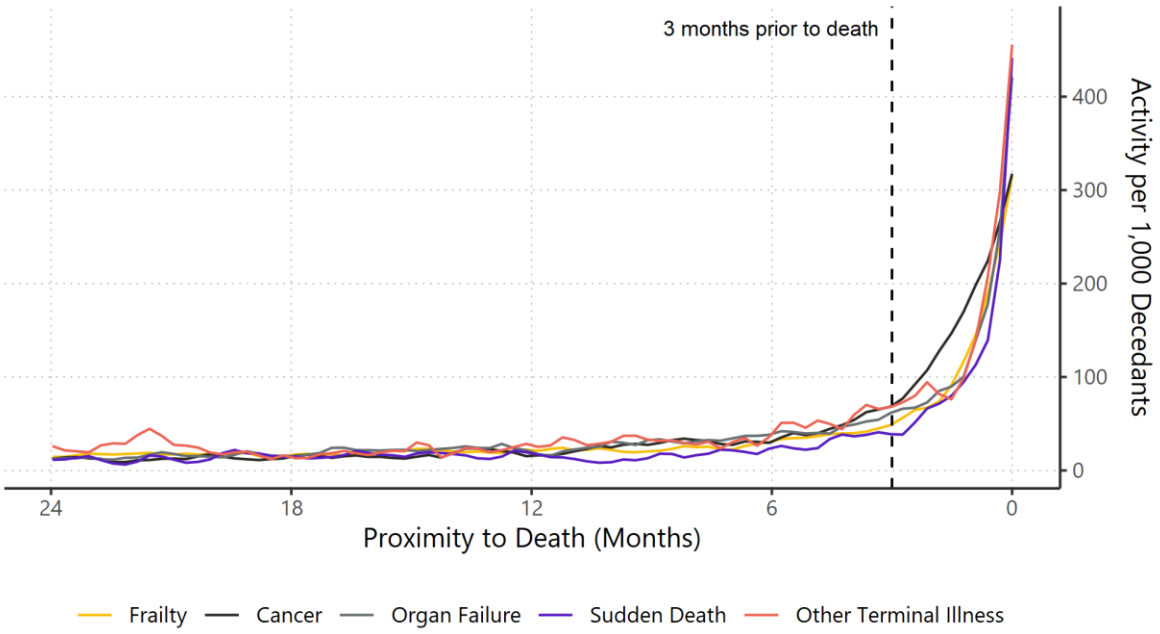
Figure 27 : Planned admissions per 1,000 by cause and proximity to death in days - Lincolnshire STP



6.1.8 Use of bed days – and critical care bed days - show similar patterns by cause

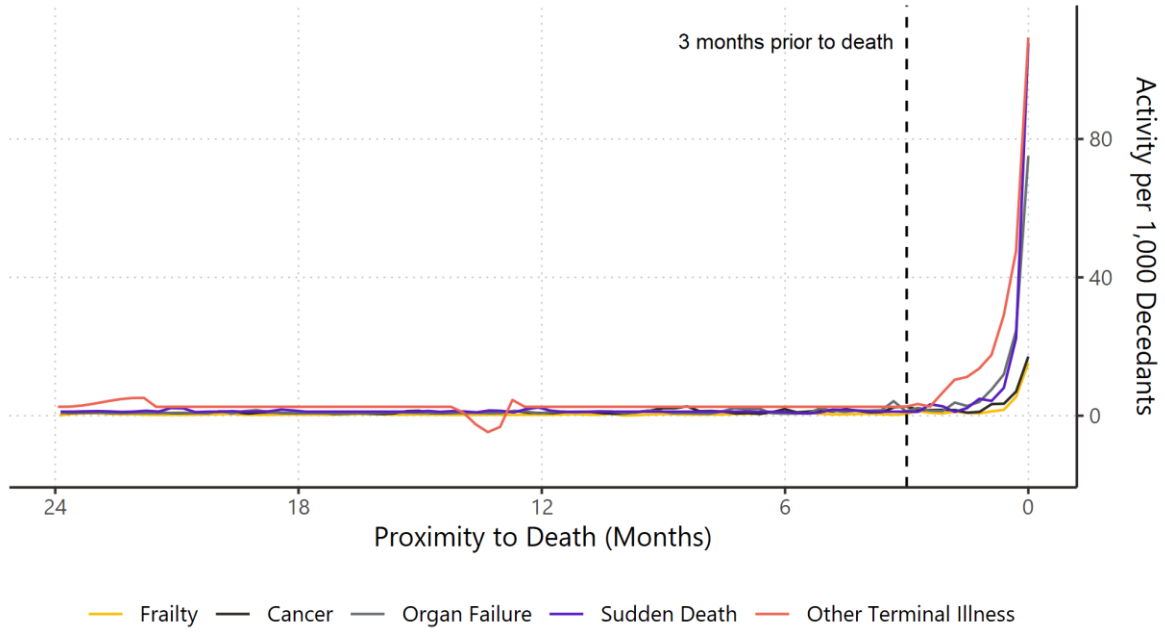
Utilisation curves by cause show patterns which are very similar for bed days (Figure 28). Where curves do diverge, this occurs in the last 6 months of life.

Figure 28 : Bed days per 1,000 by cause and proximity to death in days - Lincolnshire STP



Utilisation curves by cause also show patterns which are very similar for critical care bed days (Figure 29). Where curves do diverge, this occurs in the last 3 months of life.

Figure 29 : Critical care days per 1,000 by cause and proximity to death in days - Lincolnshire STP



6.2 Does age at death influence service use?

In this sub-section we consider the use of care by age at death[14,15]. We do this for each service within an activity type.

We consider this for two periods:

- the final year of life (0-12 months before death); and,
- the penultimate year of life (12 – 24 months before death).

[14] Age specific utilisation is summarised here but was calculated by age, gender and proximity to death year.
[15] Due to high variability from the small numbers all people aged 50 or under were grouped together, as were people aged 90 or over.

6.2.1 Use of urgent service events is not influenced by age at death

Age specific use of urgent service events in Figure 30 shows that:

- Largest areas of use are emergency admissions and A&E attendances. Use of these services does not differ greatly by age at death. Use is however much higher in the final year of life than in the penultimate year of life. This signifies that what drives utilisation of these services is not age, but proximity to death;
- Calls to 111 are used less often than the other urgent services. For those dying aged 70 and over, as age increases so does use of 111. Use is again higher in the final year of life; and,
- Age patterns and levels of use are similar compared to the Midlands (Figure 31).

Figure 30 : Urgent service event use by age at death in final and penultimate year of life - Lincolnshire STP

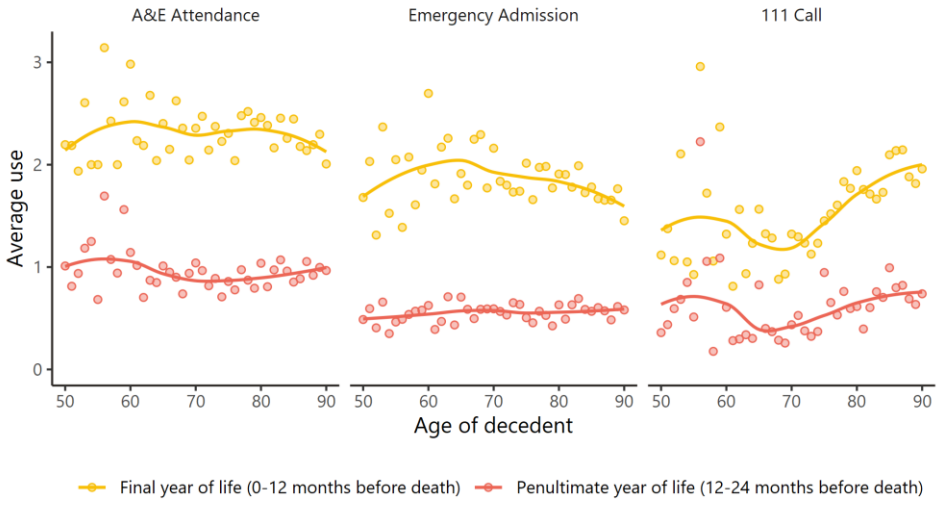
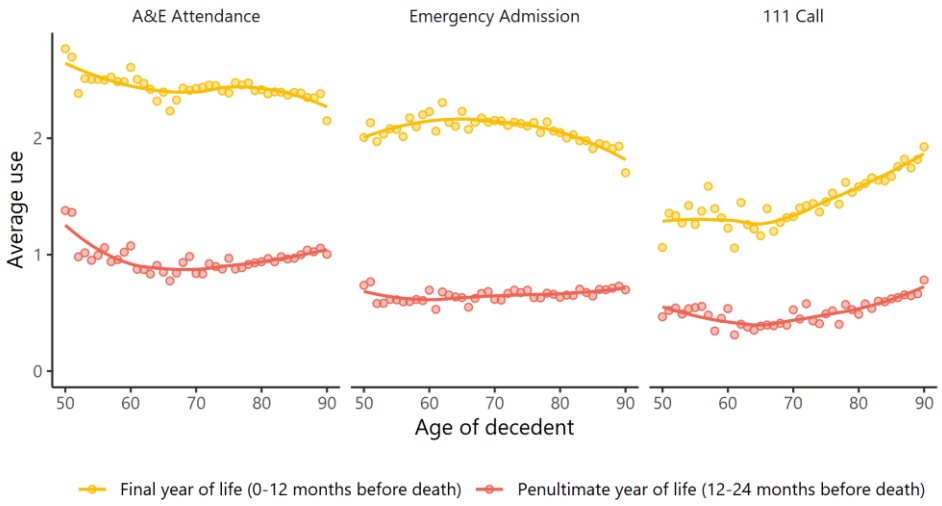


Figure 31 : Urgent service event use by age at death in final and penultimate year of life - Midlands region



6.2.2 Use of planned contacts decreases for older decedents

Age specific use of planned contacts in Figure 32 shows that:

- Largest use is for outpatient attendances. As age at death increases use of outpatient attendances decrease;
- Use of outpatient attendances is higher in final year of life than in the penultimate year. However, the difference between years diminishes as age increases;
- Age patterns and levels of use are similar compared to the Midlands (Figure 35).

Figure 32 : Planned contact use by age at death in final and penultimate year of life - Lincolnshire STP

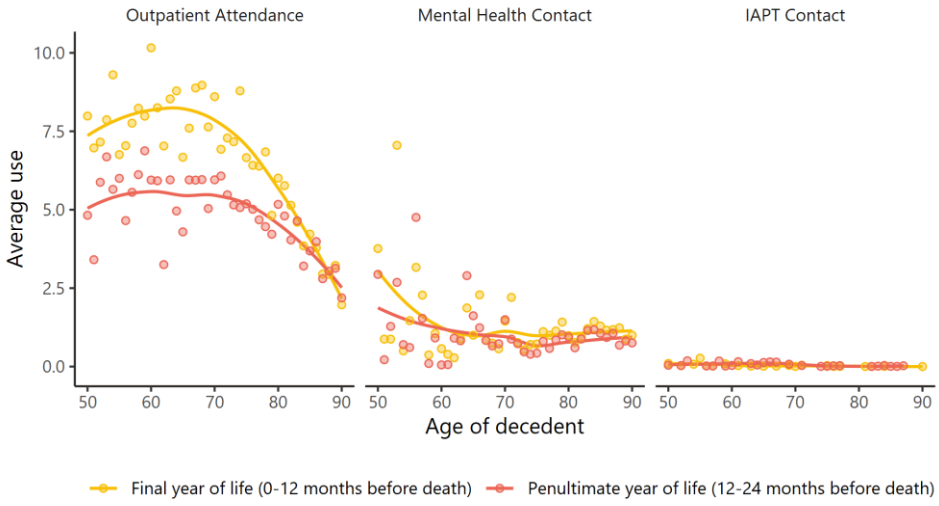
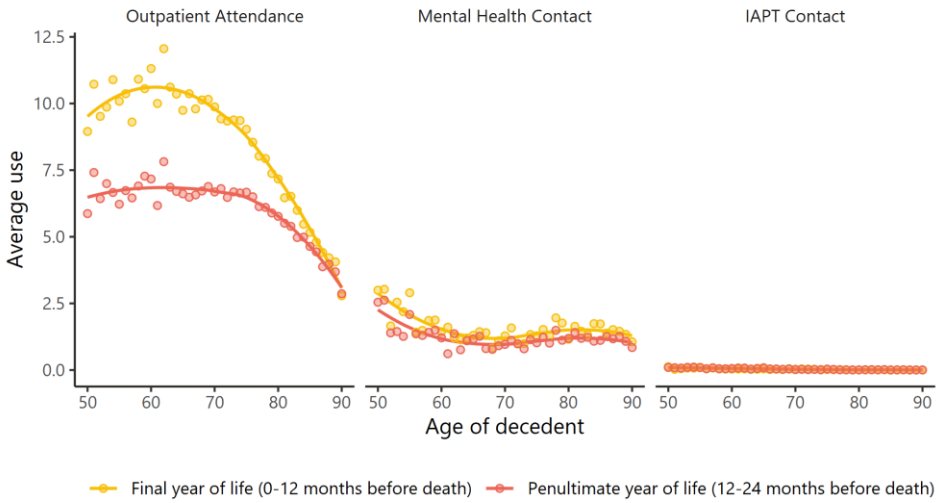


Figure 33 : Planned contact use by age at death in final and penultimate year of life – Midlands region



6.2.3 Use of planned admissions also decreases for older decedents

Age specific use of planned admissions in Figure 34 shows that:

- Largest area of use is day case admissions. Generally, as age at death increases use of these services decreases;
- There is a variable pattern of use for regular attendances. This is due to the low volume of this type of activity.

Figure 34 : Planned admission use by age at death in final and penultimate year of life - Lincolnshire STP

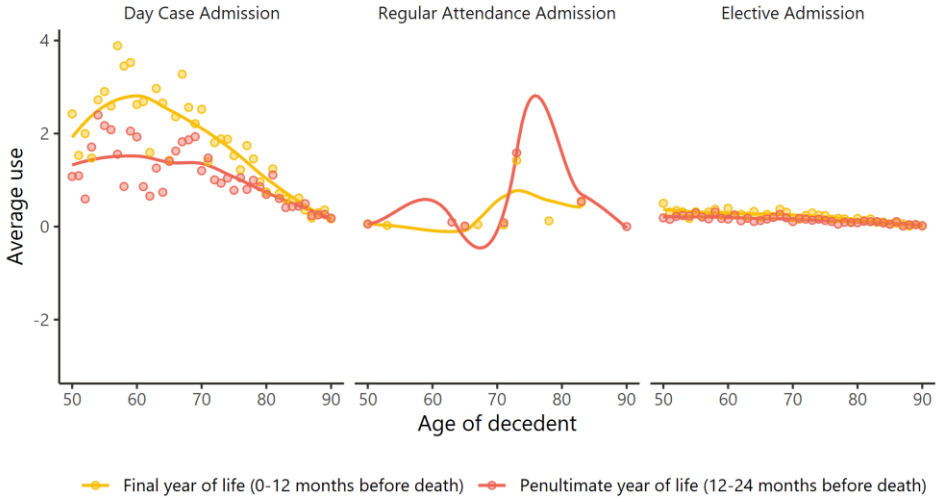
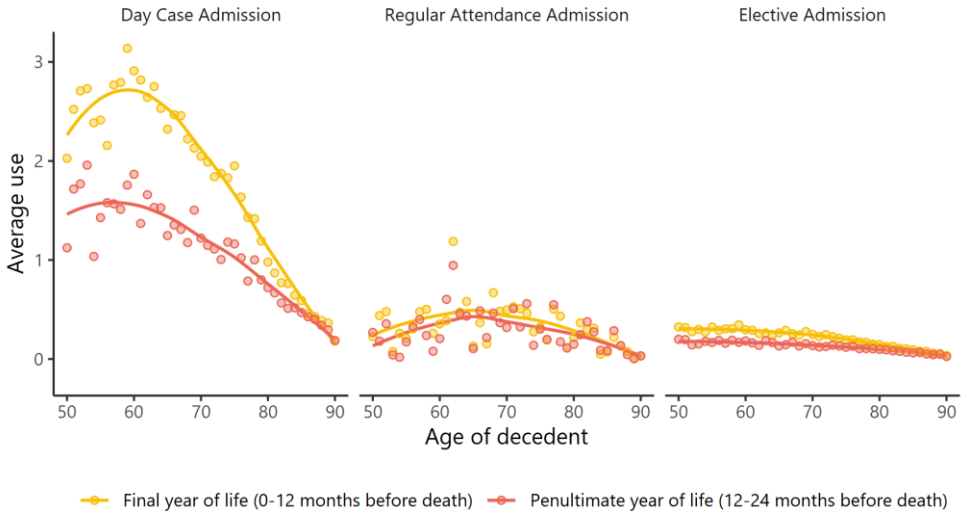


Figure 35 : Planned admission use by age at death in final and penultimate year of life - Midlands region



6.2.4 Older decedents stay in hospital longer

Age specific use of bed days in Figure 36 shows that:

- Use of bed days is dominated by emergency admission bed stays. Use of emergency bed days increases as age at death increases. We have seen in earlier sub-section (6.2.1) that age does not influence use of emergency admissions. However, we see here that age does influence length of stay. And that when admitted, the older the decedent the longer the length of stay;
- In the final year of life, the oldest decedents spend approximately an additional seven days in hospital than the youngest decedents; and,
- Volume and age patterns of use are similar to the Midlands (Figure 37).

Figure 36 : Bed day use by age at death in final and penultimate year of life - Lincolnshire STP

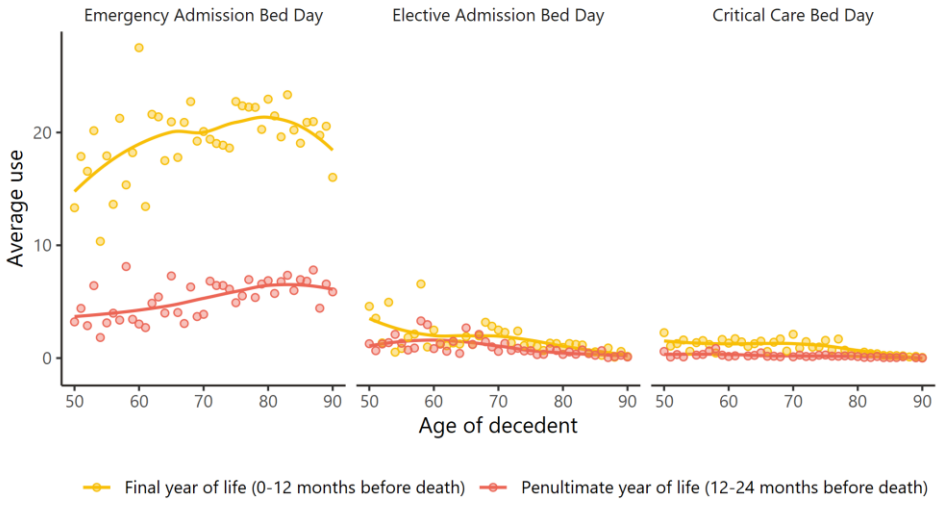
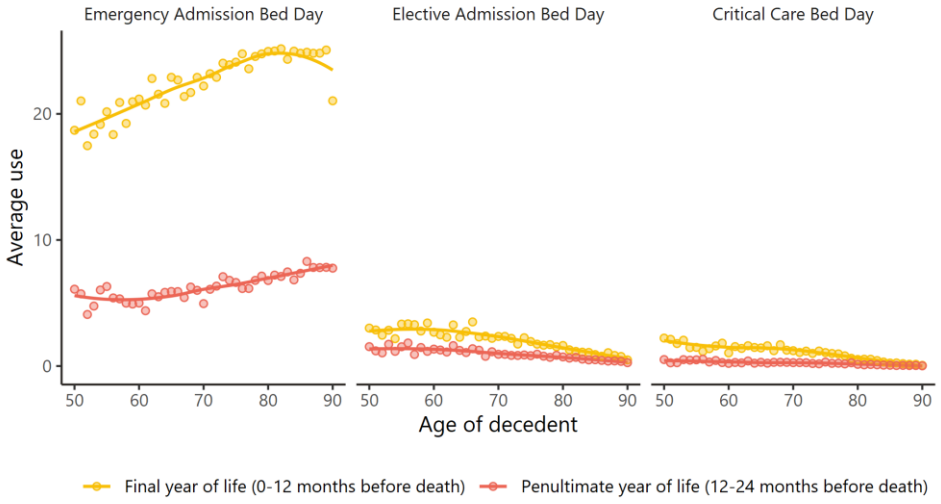


Figure 37 : Bed day use by age at death in final and penultimate year of life - Midlands region



7. Is there evidence of non-beneficial treatment in the final few weeks of life?

For those who are dying time is an increasingly precious and scarce resource. What happens in the final few weeks of life is of paramount importance. In this section we consider non-beneficial treatments in the final few weeks of life. A systematic review of non-beneficial treatments[16], describes these as "a treatment that was administered with little or no hope of it having an effect, largely because of the underlying state of the patient's health and the known or expected poor prognosis regardless of treatment". In this section we consider non-beneficial treatments in the following two areas:

- chemotherapy in the period four weeks prior to death
- use of critical care by the decedent population

7.1 Is there evidence of non-beneficial use of chemotherapy?

Chemotherapy overuse close to the time of death has been suggested as a potential indicator of poor quality of care[17]. Additionally, a recent study found that palliative chemotherapy can in some cases both shorten and reduce quality of life[18].

In the following sub-sections we consider chemotherapy decedents (those decedents who received chemotherapy treatment[19] in the two years prior to death). We consider how many received chemotherapy close to death, where 'close to death' is defined as the period four weeks prior to death. Moving on to consider patterns of chemotherapy service use and start date of treatment before investigating differences by demographic and clinical subgroups.

[16] Definitions of non-beneficial treatment and a review of extent and quantification: M Cardona-Morrell, JCH Kim, RM Turner, M Anstey, IA Mitchell, K Hillman, Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem, *International Journal for Quality in Health Care*, Volume 28, Issue 4, September 2016, Pages 456–469, https://doi.org/10.1093/intqhc/mzw060

[17] 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.

[18] https://jamanetwork.com/journals/jamaoncology/fullarticle/2398177

[19] https://hscic.kahootz.com/gf2.ti/f/762498/27838501.1/PDF/-/ChemRegClinCodingStandGuidApl2017.pdf

7.1.1 One in six of those receiving chemotherapy did so in the last month of life

Of 867 chemotherapy decedents in Lincolnshire 130 (15%) received chemotherapy in the last four weeks of life. The remaining 737 (85%) did not receive chemotherapy their last four weeks. Characteristics of these two groups are compared in the following sub-sections.

7.1.2 Pattern of service use differs for those who have chemotherapy close to death

Patterns differ significantly between the two groups. Figure 38 shows that for much of the two years those receiving chemotherapy in the last four weeks of life use comparatively less chemotherapy than those who do not. Their use of chemotherapy starts to increase more rapidly around the same time that use by the other group declines. It then peaks close to death. This is the same pattern as seen in the Midlands (Figure 39).

Figure 38 : Chemotherapy use per 1,000 chemotherapy decedents by proximity to death in days - Lincolnshire STP

Figure 39 : Chemotherapy use per 1,000 chemotherapy decedents by proximity to death in days - Midlands region

7.1.3 People having chemotherapy close to death start treatment later

Those receiving chemotherapy in the last four weeks of life start chemotherapy much later. Figure 40 shows the cumulative proportion of chemotherapy decedents by start of chemotherapy date. It shows that at the point twelve months prior to death 31% of people receiving chemotherapy in the last four weeks of life have started chemotherapy. By the same point in time many more people in the other group, the group who do not receive chemotherapy in their last four weeks, have started chemotherapy (54%). Four weeks prior to death 83% of those people receiving chemotherapy in the last four weeks of life have started. The remaining 17% start chemotherapy in their last four weeks. Again, this is the same pattern as seen in the Midlands (Figure 41).

Figure 40 : Cumulative proportion of chemotherapy decedents by start date - Lincolnshire STP

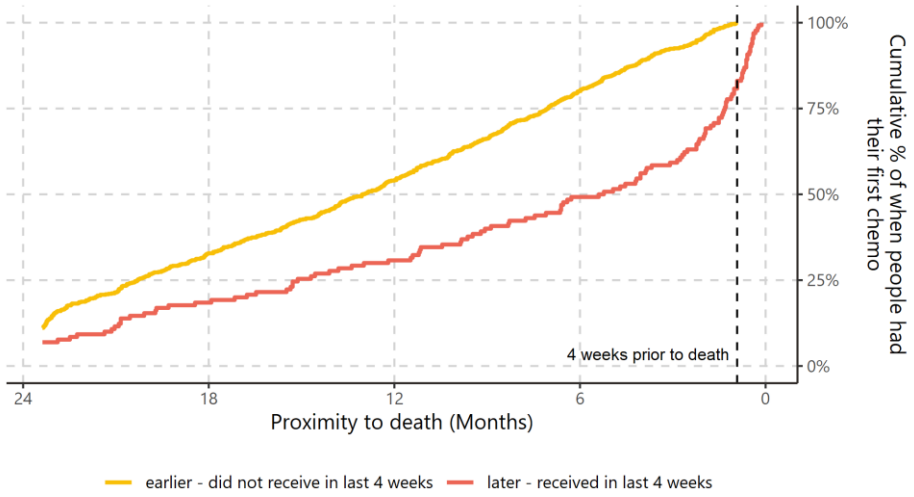
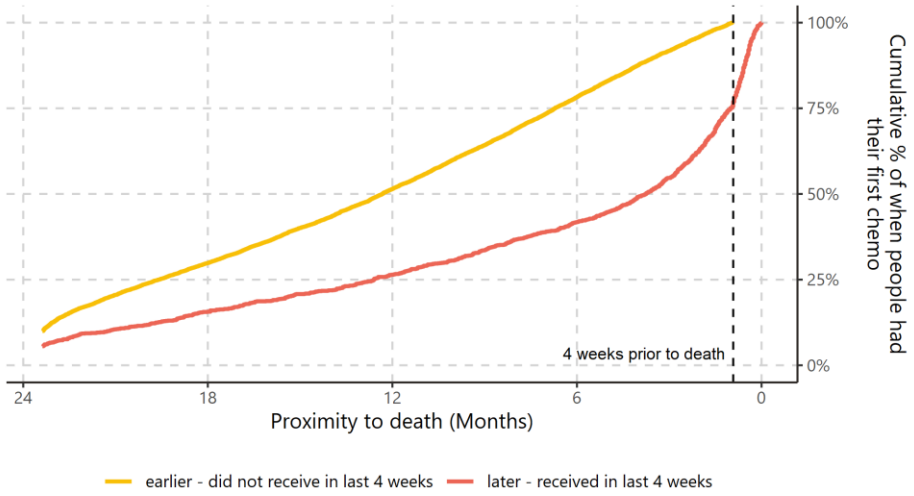


Figure 41 : Cumulative proportion of chemotherapy decedents by start date - Midlands region



7.1.4 People having late chemotherapy tend to be younger

Figure 42 shows composition by age group of those in Lincolnshire receiving chemotherapy in the last four weeks of life. The proportion is highest for the younger chemotherapy decedents (18 to 64 year olds, and 65 to 74 year olds). However, this lacks significance as do the other age groups. The Midlands does show some significant differences by age group due to larger sample size.

Figure 42 : Proportion by age group receiving chemotherapy in the last four weeks of life - Lincolnshire STP

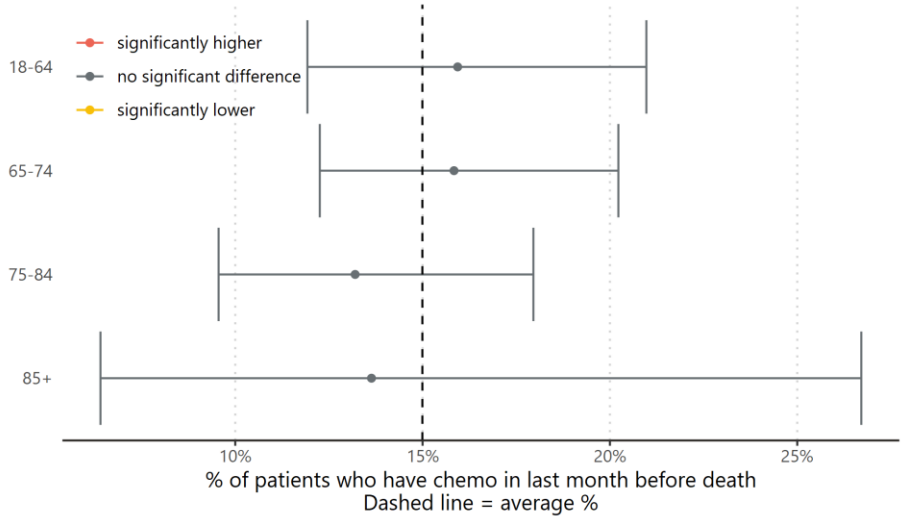
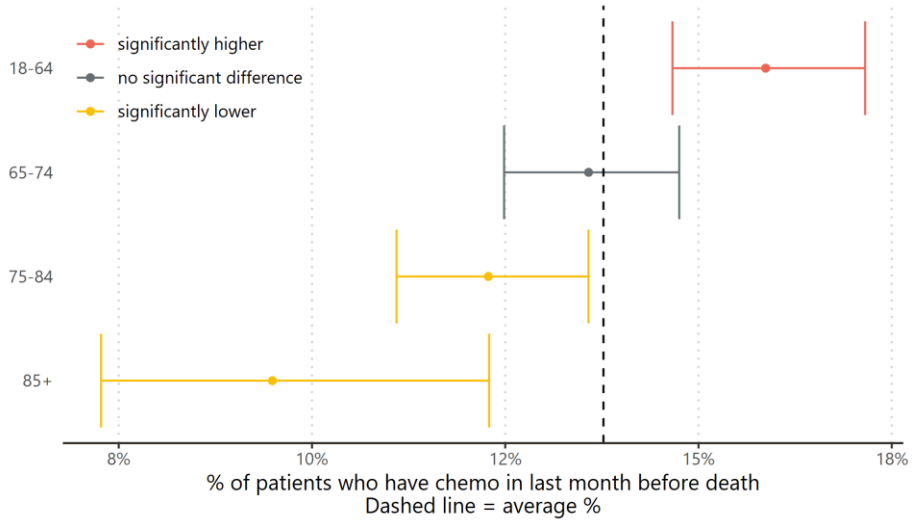


Figure 43 : Proportion by age group receiving chemotherapy in the last four weeks of life - Midlands region



7.1.5 People having late chemotherapy have certain types of cancer

There are a significantly greater proportion of those with haematological cancer. There are significantly fewer with lower gastrointestinal cancer.

Cancer type proportions and ranking are similar to the Midlands but due to larger sample size, the level of significance varies.

Figure 44 : Proportion by cancer type receiving chemotherapy in the last four weeks of life - Lincolnshire STP

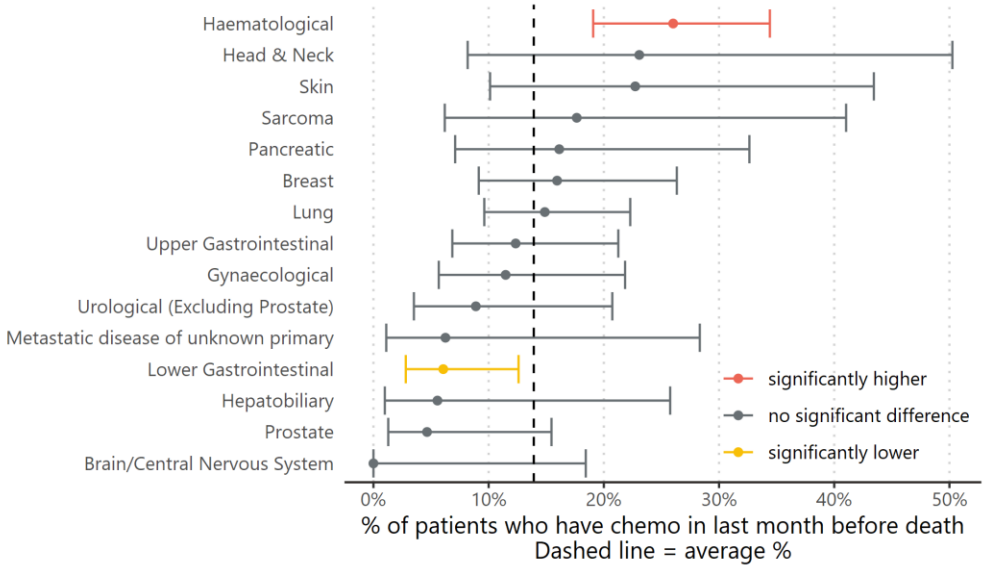
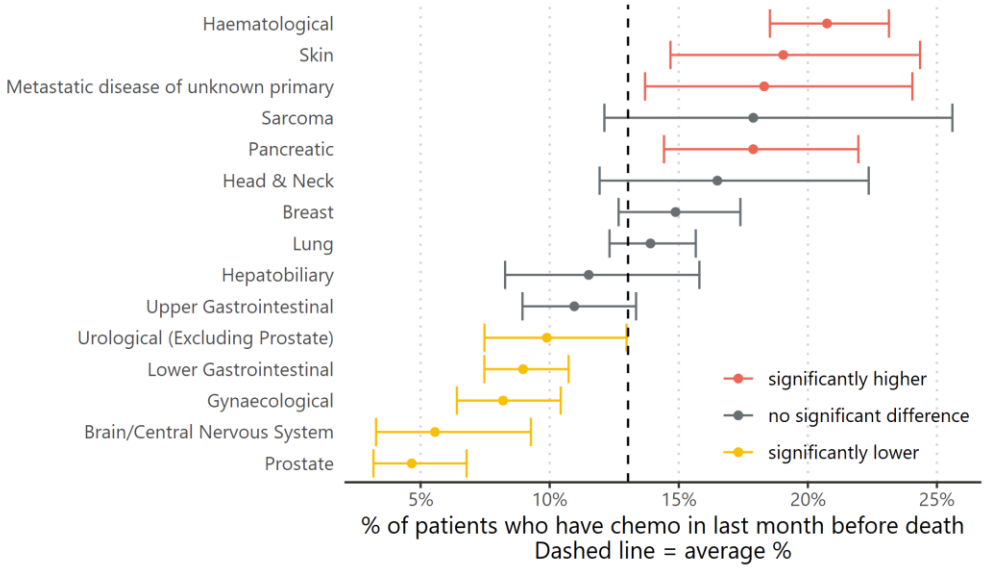


Figure 45 : Proportion by cancer type receiving chemotherapy in the last four weeks of life - Midlands region



7.2 How is critical care used at end of life?

Critical care units are crucially important, they are highly specialist wards that provide treatment and monitoring for people who become very unwell or are recovering from major surgery. 1 in every 9 decedents (sub-section 5.1) spend some time in critical care in the two years before they die. For some decedents, particularly when close to death, critical care may be non-beneficial. It is also a costly resource. This is important because in addition to a lack of benefit to patients use of critical care also has substantial resource implications for services.

We now consider critical care in detail. We investigate how days in critical care are used by decedents and for how many decedents it is their place of death.

7.2.1 Critical care bed days are usually part of emergency care

Critical care is usually a component of a longer hospital stay. Some decedents who spend time in this setting do so after elective surgery whilst others do so following emergency admission. For those decedents using critical care Figure 46 shows the amount of critical care days by source. It shows that:

- Most days are used by decedents with organ failure or cancer;
- More critical care bed days used by the decedent population are part of an emergency admission. Critical care days after elective admission are few but cancer is an exception, over half of critical care days for cancer decedents are part of an elective admission; and,
- When compared to the Midlands (Figure 47) profiles of critical care days by type of admission and cause are very similar.

Figure 46 : Proportion of critical care bed days by cause and source of admission - Lincolnshire STP

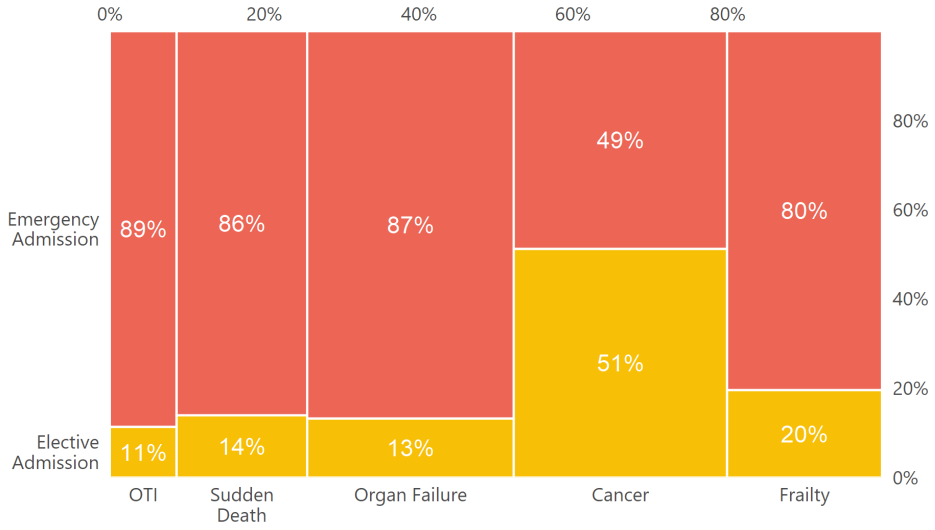
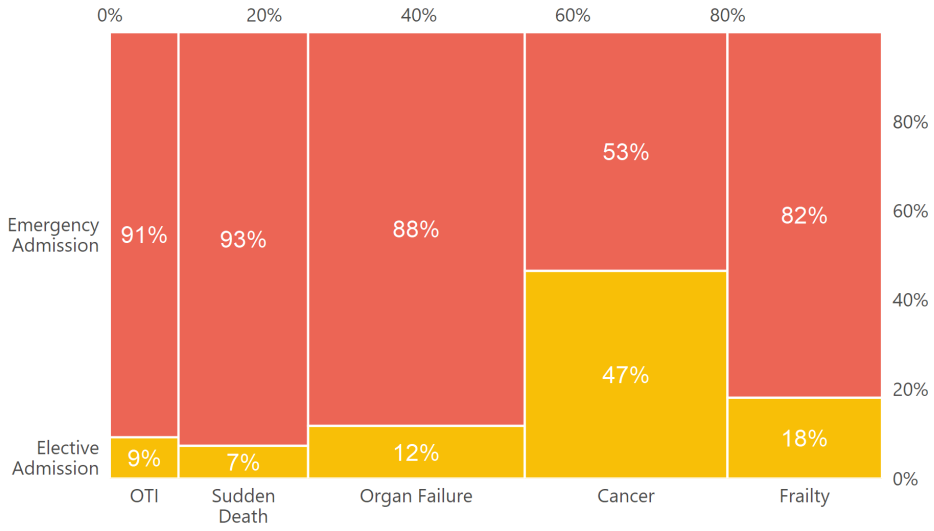


Figure 47 : Proportion of critical care bed days by cause and source of admission - Midlands region



7.2.2 Death in critical care varies greatly by cause of death

Critical care stays end when a patient leaves critical care, either because they have recovered enough to be moved to another ward or because they have died in critical care. Figure 48 shows the amount of days spent in critical care by the eventual outcomes of:

- Did not die in critical care – moved to non-critical care ward; or,
- Died in critical care.

It shows that for sudden death more than half of critical care days are for a stay which ends with death in critical care. The proportions are similarly high for other terminal illness and organ failure. Cancer has the smallest proportion of days in critical care ending in death. When compared to the Midlands (Figure 49) profiles of critical care days by cause are similar.

Figure 48 : Proportion of critical care bed days by cause and outcome - Lincolnshire STP

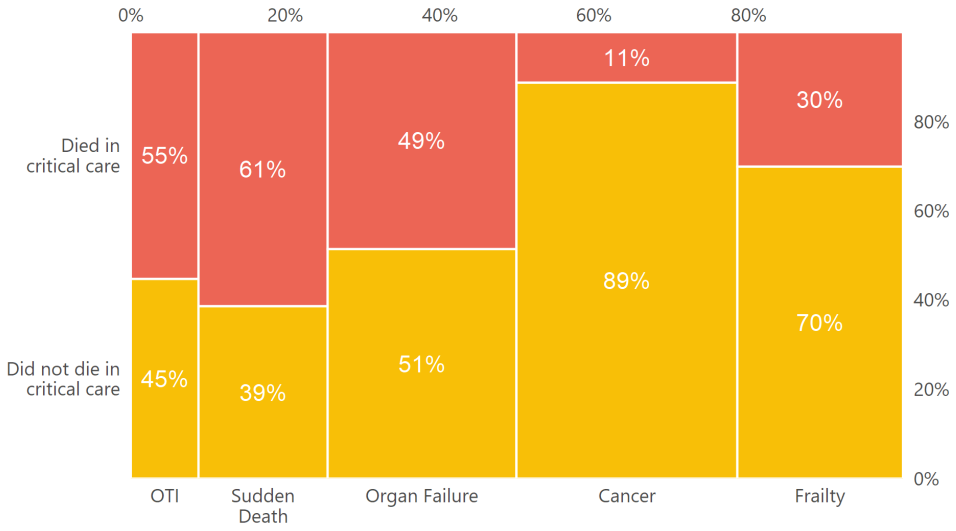
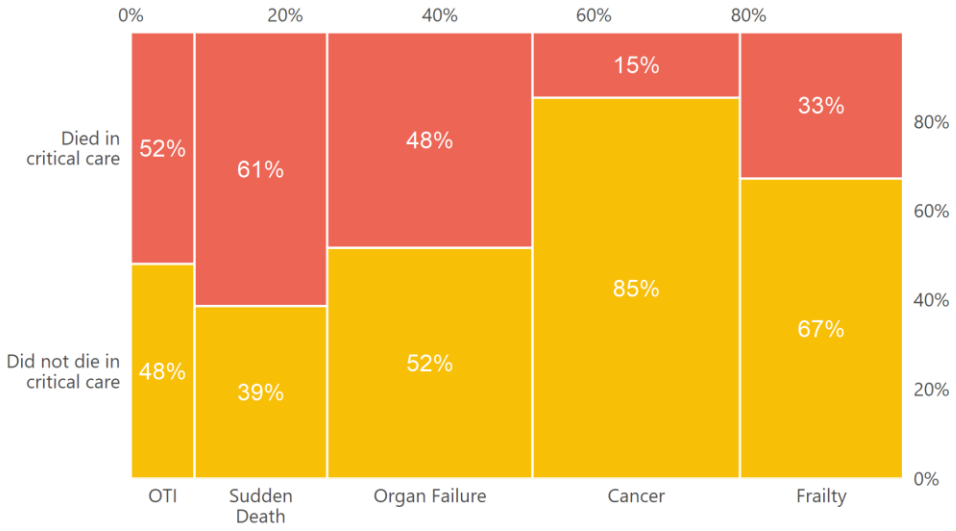


Figure 49 : Proportion of critical care bed days by cause and outcome - Midlands region

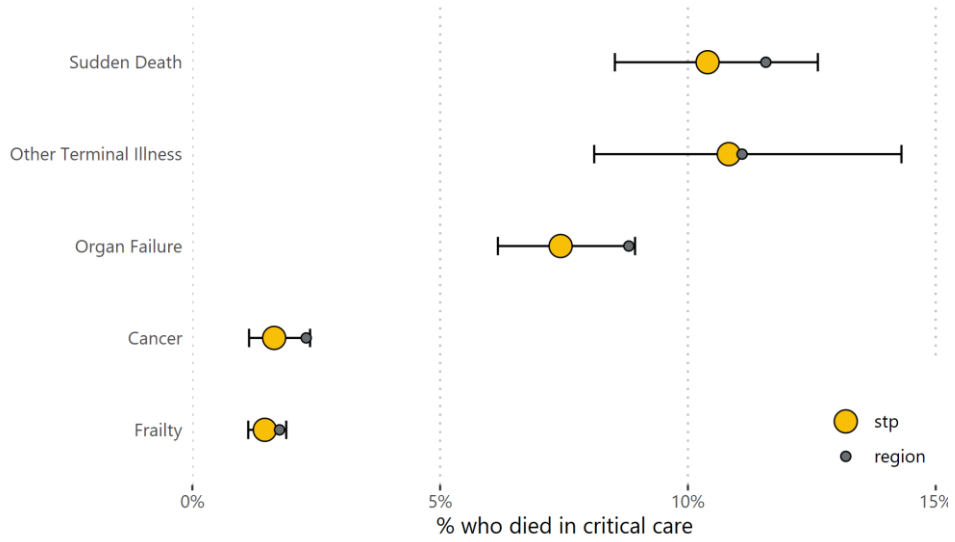


7.2.3 Fewer frailty and cancer deaths happen in critical care

We now consider stays, rather than days, in critical care. We investigate the proportion of critical care stays ending in death as a proportion of all decedent critical care stays. Figure 50 shows the proportions by cause. Lincolnshire are shown as larger yellow dots (with confidence interval – the range in which we can be reasonably confident that the true proportion lies); the Midlands is shown as smaller grey dots. It can be seen that:

- Proportionally fewer critical care stays end in death for cancer and frailty patients. This reflects the nature of cancer and frailty patients who, with advanced incurable disease or pre-existing limitations of treatment, are less likely to benefit from critical care;
- Proportionally more critical care stays end in death for the causes of other terminal illness, sudden death and organ failure; and,
- Lincolnshire has proportionally fewer critical care stays ending in death than the Midlands for all causes. However, these are within confidence intervals and are therefore not considered significantly different.

Figure 50 : Proportion of critical care spells ending in death, confidence intervals indicated by whiskers – Lincolnshire (yellow dots), Midlands (grey dots)



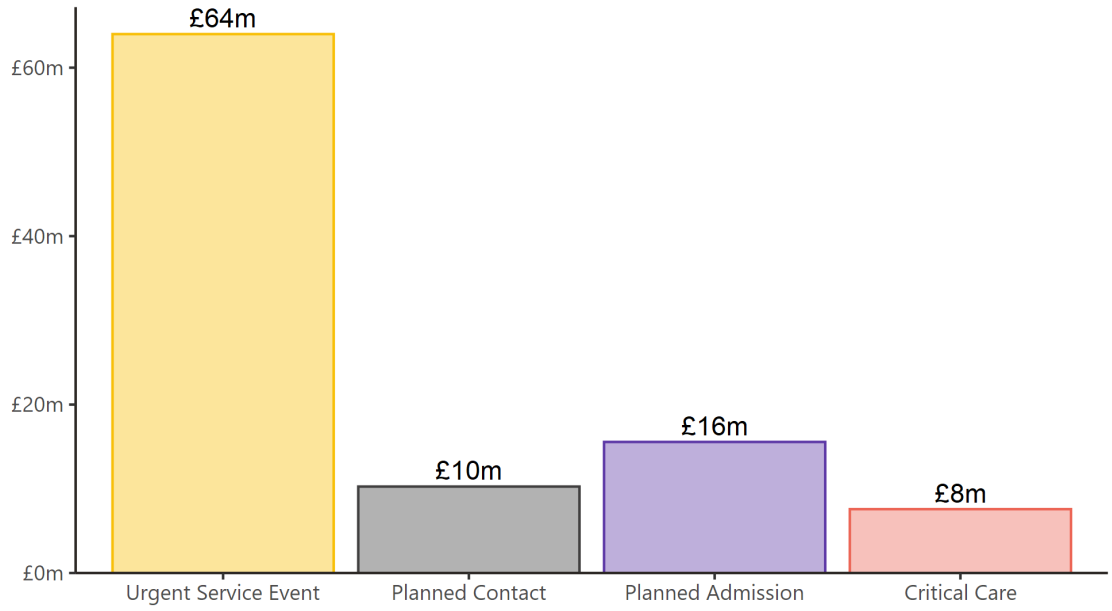
8. How much is spent and what level of resource will be required in future?

In earlier section (section 6) we have examined use of services from the perspective of activity. Now we consider use in terms of spend for Lincolnshire STP decedents in the two years before they die[20]. We then move on to consider the level of resources required by future decedent populations from perspective of activity, spend and beds.

8.1 Urgent care accounts for two-thirds of expenditure

The calculated total hospital spend in the last two years of life in Lincolnshire is £97 million. Figure 51 shows spend by activity type. Urgent services dominate spend, consuming two-thirds of end of life resource.

Figure 51 : Total spend by activity type in two years prior to death – Lincolnshire STP



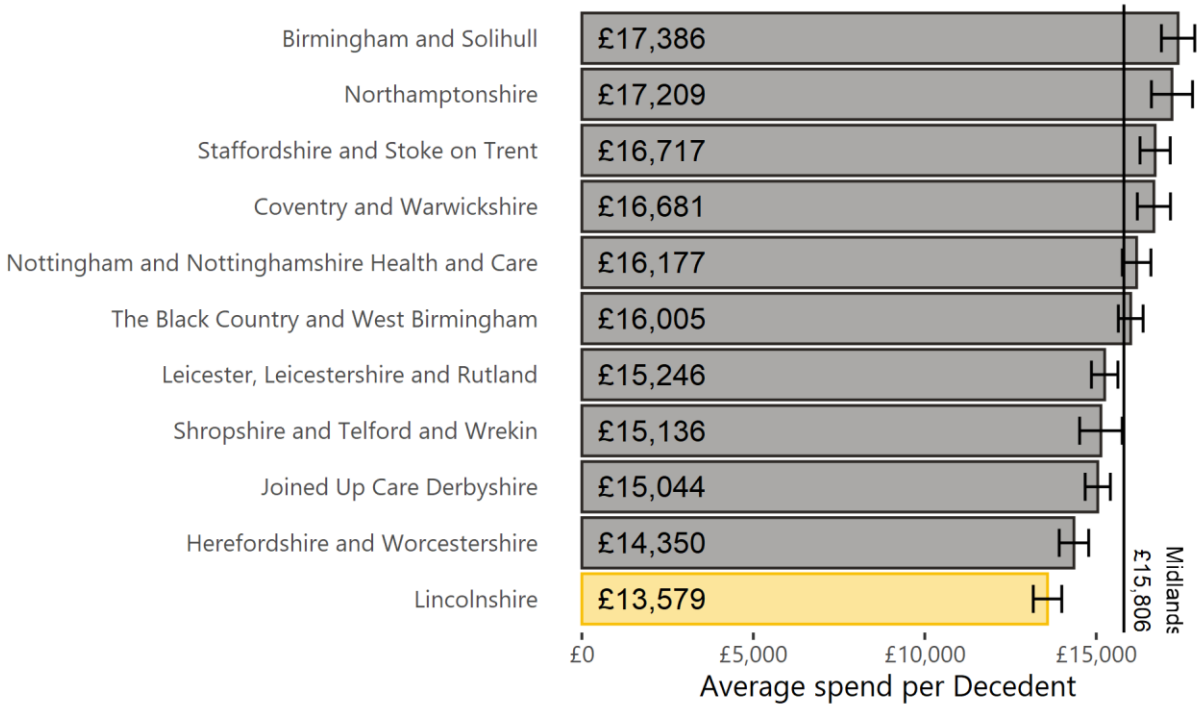
[20] Costs are for hospital activity in the two years before death. Where applicable they are calculated using national tariff, where this does not exist reference costs have been used. They include CCG and specialised services commissioned costs.

8.2 STP expenditure differs widely in the Midlands

The average spend in the last two years of life in Lincolnshire is £13,579 per decedent. To put this into context, government spend on hospital care per year per head[21] is £1,225.

Figure 52 shows for each STP average spend and confidence interval – the range in which we can be reasonably confident that the true average lies. For Lincolnshire the average spend per decedent is significantly lower than the Midlands.

Figure 52 : Average spend per decedent in two years prior to death – by STP with Midlands regional average and STP confidence intervals indicated by whiskers



21 https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/datasets/healthaccountsreferencetables

8.3 Spend increases as death nears, but reduces in the final days

The spend curve by proximity to death shown in Figure 53 is similar to the utilisation curve of urgent service events seen in sub-section 6.1.1. There is however one key difference noticeable when we zoom in on the final month of life in Figure 54. This shows that for the Midlands, unlike service use where activity peaks on day of death, spend peaks a few days before death. Activity still takes place but the investigations, treatments and procedures which drive costs start to reduce. Across the two years the rate and pattern of spend in Lincolnshire is slightly lower than the Midlands. In final few days the peak of spend in Lincolnshire also drops more sharply.

Figure 53 : Average daily spend per decedent over two years - Lincolnshire STP (yellow dots and line) and the Midlands region (grey line)

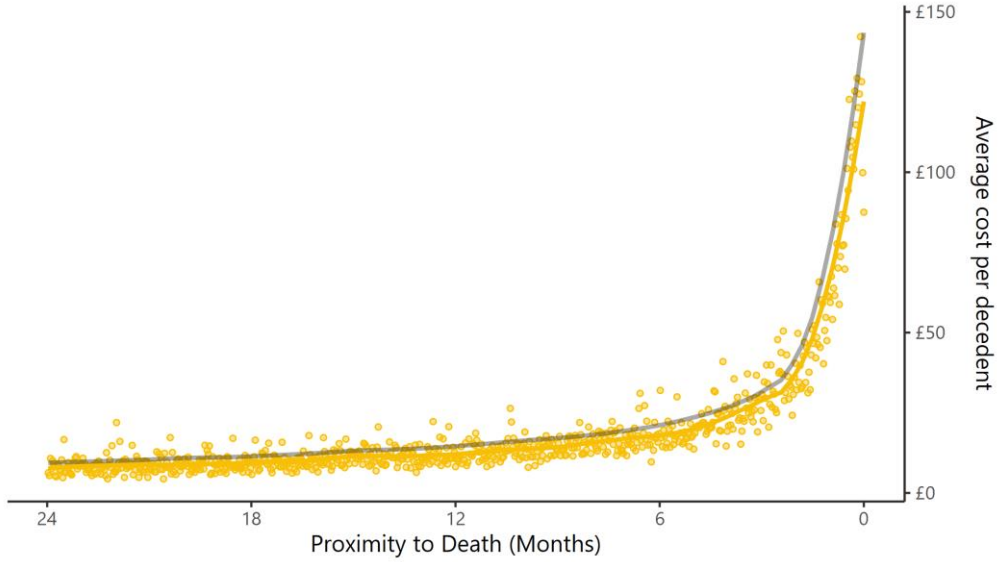
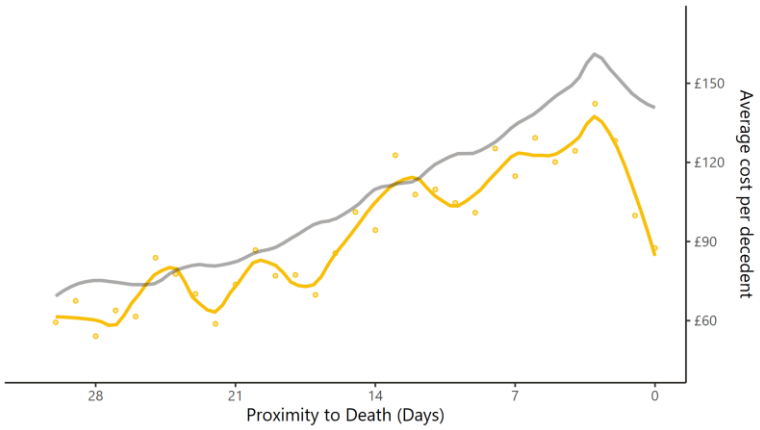


Figure 54 : Average daily spend per decedent in final month - Lincolnshire STP (yellow dots and line) and the Midlands region (grey line)



8.4 How will service use and expenditure evolve in future?

The earlier section (section 6) showed how much service use there was for those who died. Now we consider how much will be used in *future*. We examine what levels of future use will be *if current patterns of service and resource use continue*. We view these at five-year intervals and by age group for activity, spend and beds.

Future levels of service use in Lincolnshire were predicted by applying the current utilisation rates[22] to future expected decedent populations. If utilisation rates were to change then so too would the predicted levels.

[22] Future use and spend are summarised here but were calculated by age, gender, and proximity to death year. No account is taken of other factors such as inflation or future changes in technology.

8.4.1 Urgent services activity and expenditure is set to increase

By 2030 urgent service events will have increased by 17% for activity (Figure 55) and 18% for spend (Figure 56). Older decedents (those aged 85+) are the largest share of urgent services and growth is driven by increasing number of decedents in this age group.

Figure 55 : Urgent service events future use at five-year intervals by decedent age group (percentages relative to 2020)

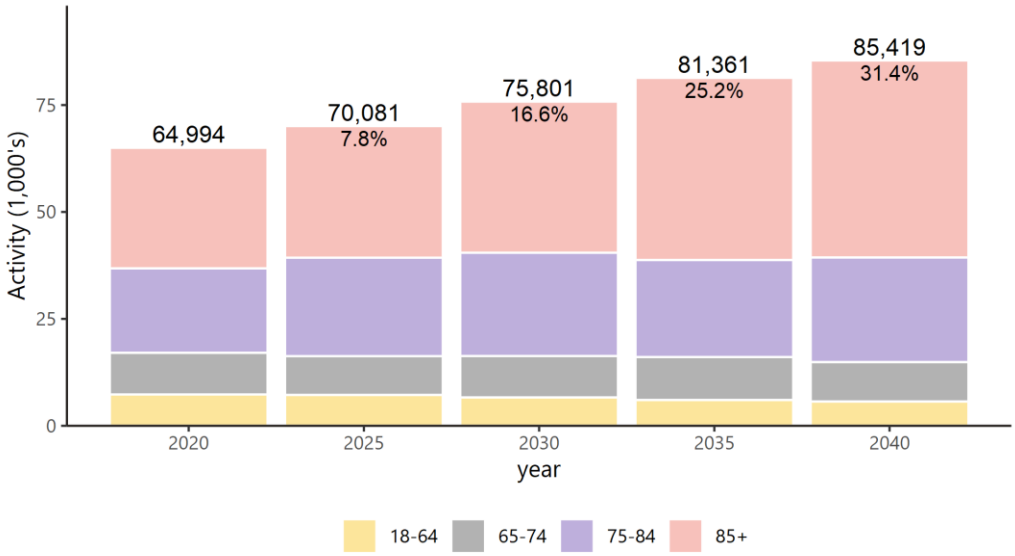
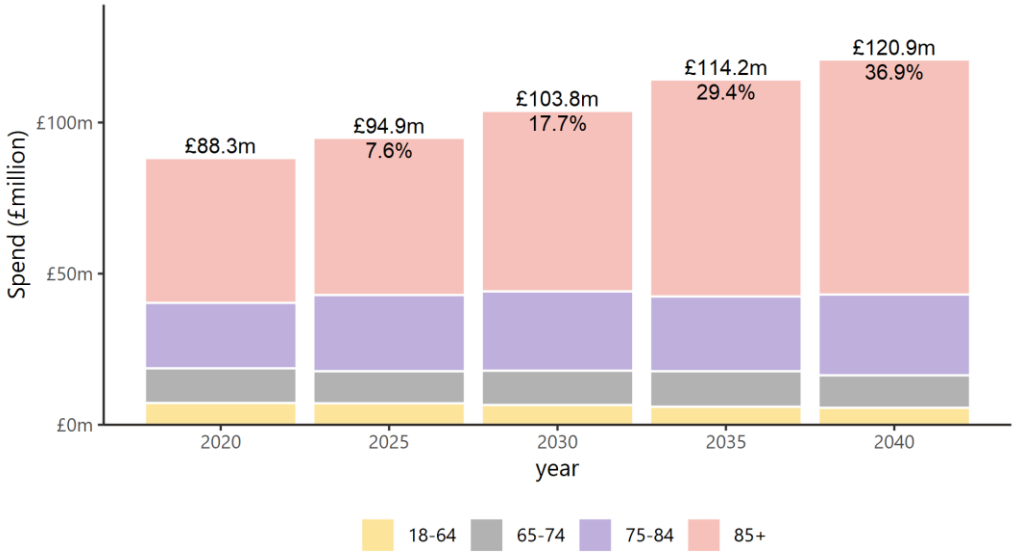


Figure 56 : Urgent service events future spend at five-year intervals by decedent age group (percentages relative to 2020)



8.4.2 Future use and spend grow steadily for planned contacts

Jointly the two oldest age groups (those 75-84 and those aged 85+) are responsible for over half of planned contacts. For both activity (Figure 57) and spend (Figure 58). Growth is driven by increasing number of decedents in the oldest age group.

Figure 57 : Planned contact future use at five-year intervals by decedent age group (percentages relative to 2020)

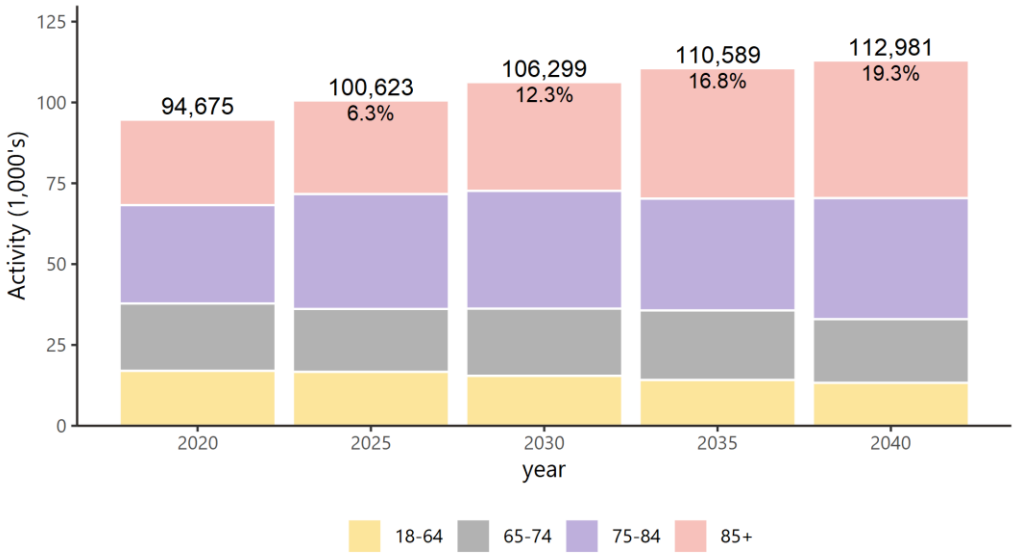
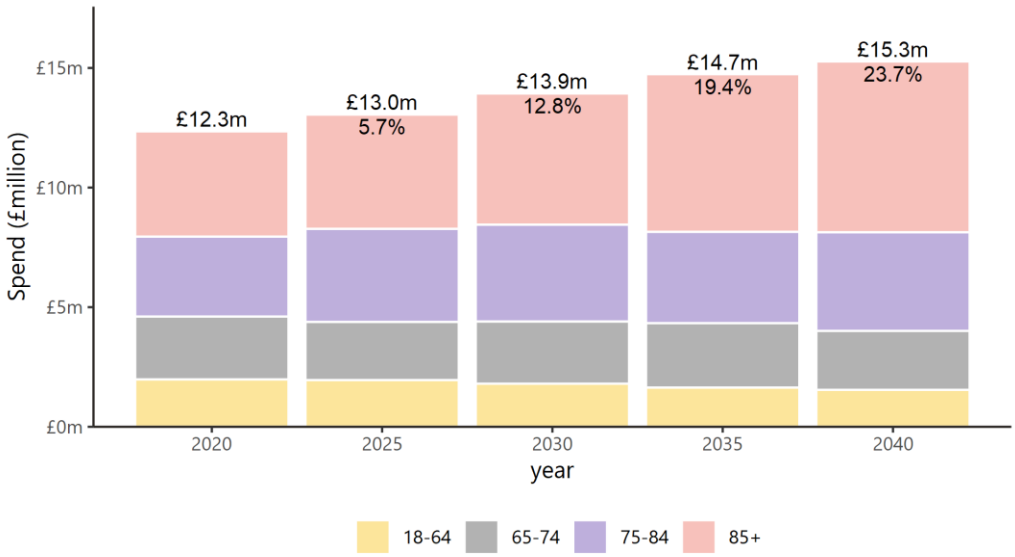


Figure 58 : Planned contact future spend at five-year intervals by decedent age group (percentages relative to 2020)



8.4.3 Future use and spend remain steady for planned admissions

Future levels of planned admissions grow for activity (Figure 59) and spend (Figure 60). The increase in spend is proportionally more than the increase in activity. Although younger age groups feature more heavily in planned admissions the growth in spend is driven by decedents in the oldest age group.

Figure 59 : Planned admission future use at five-year intervals by decedent age group (percentages relative to 2020)

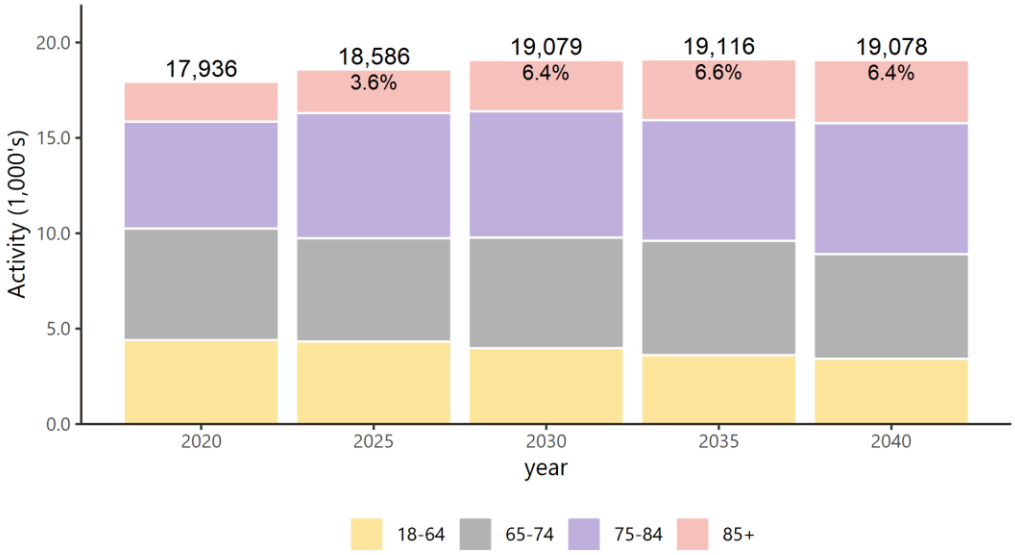
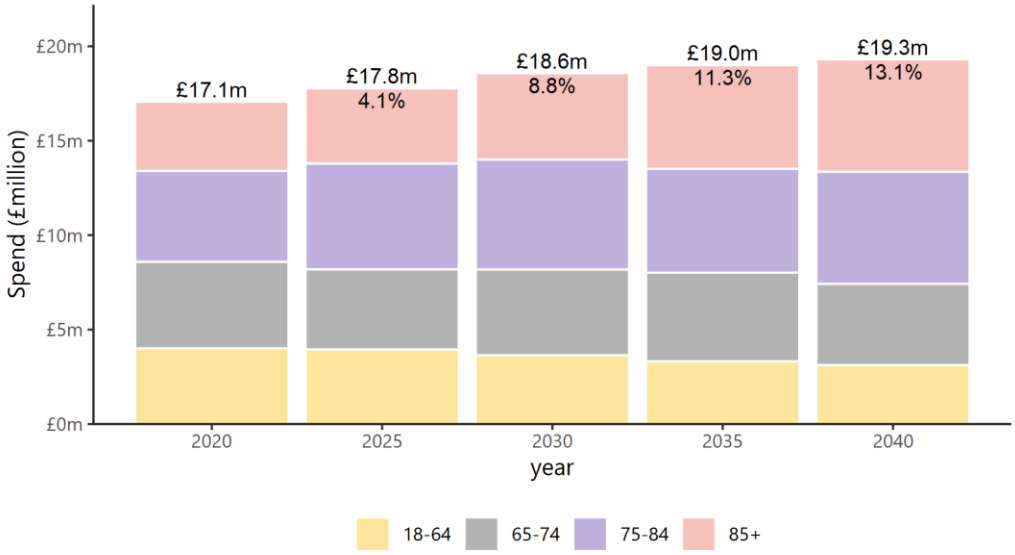


Figure 60 : Planned admission future spend at five-year intervals by decedent age group (percentages relative to 2020)



8.4.4 Increased demand for bed days will put pressure on capacity

Future bed days have similar growth to urgent service events. By 2030 they will have increased by 17% (Figure 61). Older decedents (those aged 85+) are responsible for the largest share of bed days and growth is also driven by the increasing number of decedents in this age group. By 2030 to meet growth in bed days Lincolnshire will require an additional 112 beds[23] (Table 3).

Costs for future bed days are not calculated separately. They are included in cost of admission.

Figure 61 : Bed day future level of use at five-year intervals by decedent age group (percentages relative to 2020)

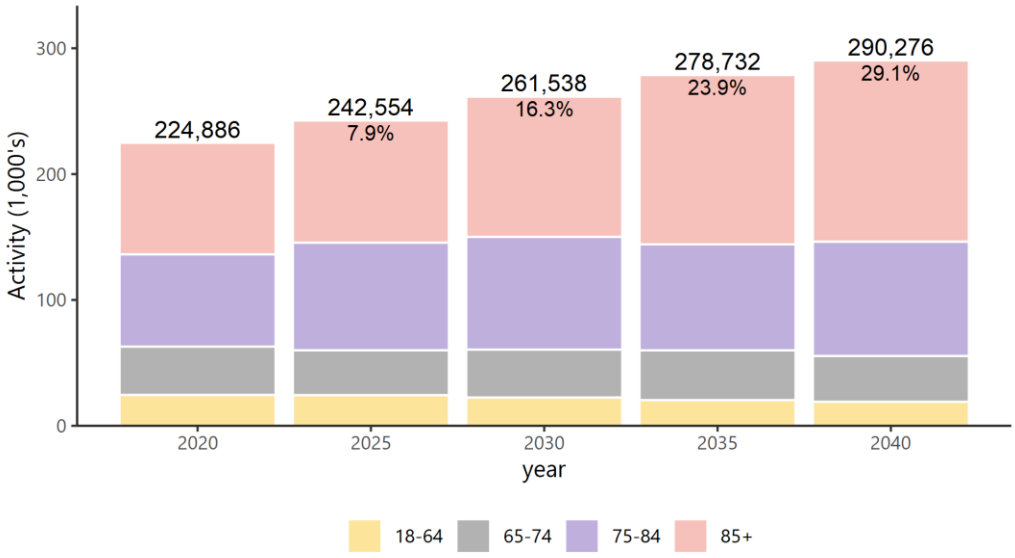


Table 3 : Additional beds required to meet future growth in bed days

Year	2025	2030	2035	2040
Extra Beds	54	112	164	199

[23] Number of beds are calculated with the assumption of 90% occupancy

8.4.5 Future use and spend remain steady for critical care

Future levels of critical care days grow slowly for activity (Figure 62) and spend (Figure 63). Although the youngest group in the decedent population (aged 18-64) feature more heavily in critical care growth is again driven by the oldest decedents.

Figure 62 : Critical care bed day future use at five-year intervals by decedent age group (percentages relative to 2020)

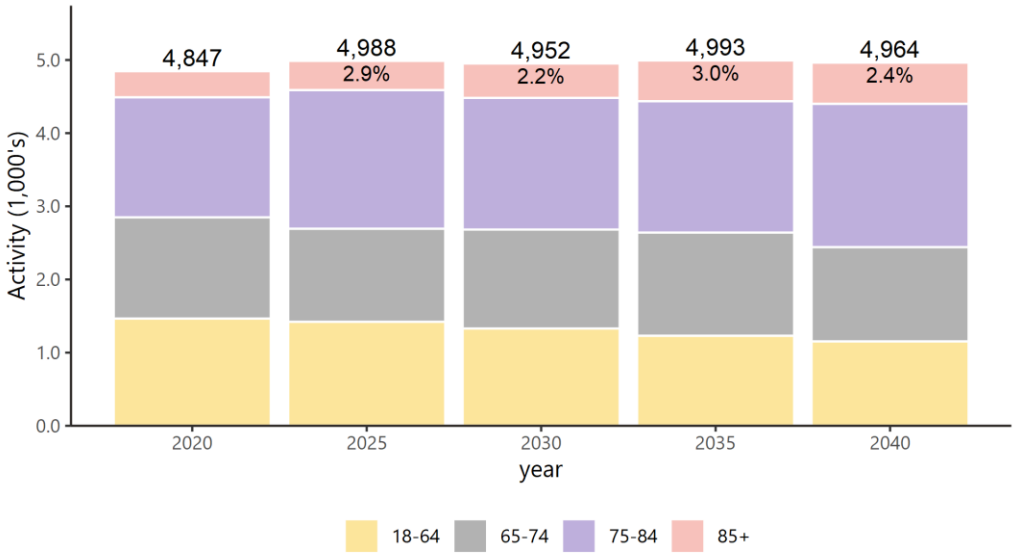
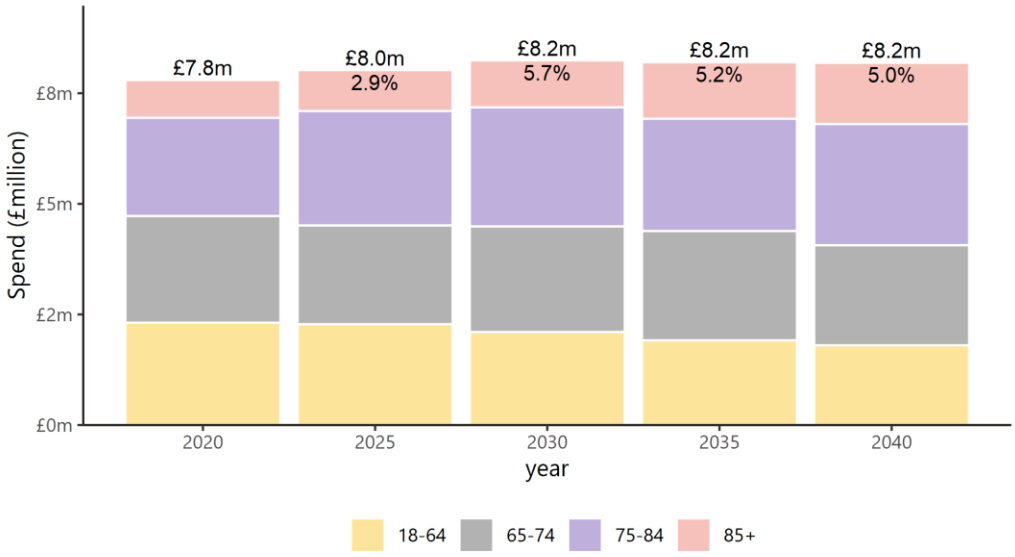


Figure 63 : Critical care bed day future spend at five-year intervals by decedent age group (percentages relative to 2020)



9. Discussion

The aim of this report is to equip decision makers, in all parts of the STP, with insight into people's use of healthcare services as they approach the end of their lives. These insights can be used to spur action and improve outcomes.

The report's main messages are challenging. The analysis is detailed and takes multiple angles; it presents subtlety, difference and nuance. Yet the overall conclusion is clear: too few people in Lincolnshire experience a 'good death'.

There is no single explanation for this. The analysis suggests that services are often reactive and uncoordinated, with patterns of use that seem undesirable. Most people say they want to die at home, but this intention is frequently lost in the interaction with – and between - the services supporting them. Expenditure also does not seem to support this desire to die at home: around two thirds of investment in hospital services is spent on urgent care.

Inequality is a clear part of the story. Experiences at the end of life differ radically according to factors such as age, gender, class and cause of death. There are also geographic differences, with a consistently higher rate of planned care use in Lincolnshire compared to the Midlands, for example.

The current situation has evolved during a decades-long trend of falling deaths. This trend is now set to change and the number of deaths is forecast to increase. Demographic change means that this growth is largely concentrated among those aged 85 and above. As well as adding to the overall scale of need, the average case is also therefore likely to become more complex.

This change in the nature and scale of demand casts a different light on the current situation. Faced with this more challenging future, decision makers may want to consider more ambitious options in response.

This report presents a detailed account of 'what is'. Moving on from this and deciding 'what ought to be' is a more complex undertaking. It involves professional judgement, evidence and clinical standards. But it also involves personal preference, values and cultural differences. Combining such diverse perspectives requires care, humanity, and skill.

Seen in this context, the analysis presented here is just one input (albeit an essential one) into a broader set of conversations. These conversations are the place to generate detailed plans for improvement.

We therefore stop short of making specific recommendations. But, as a bridge into these conversations, we note that:

- Local citizens have the main stake in better end of life care. People living in the STP area will have views on the analysis presented here; they will be a source of first-hand evidence from experience; they will have a sense of what outcomes are desirable and of what better care

would look like. As friends, neighbours and family members, they are also current providers of care: a source of solutions as well as of 'demand'.

- Professionals and organisations involved in providing care – clinical and non-clinical, health and social care, statutory and voluntary sector – also have a clear stake. They will see the practice that leads to the situation described in this analysis; they will know where there are gaps between professional standards and current provision; they will have the clearest sense of the opportunities to reduce non-beneficial treatments. Professionals will also be a source of solutions for improving communication and coordination between different services.
- NHS and Local Authority commissioners hold responsibility for patterns of investment and service provision. They have a stake in ensuring that outcomes for their population are improving and that inequalities are reducing. Acting on behalf of citizens, they are stewards of a collective resource, balancing out competing claims and perspectives. Commissioners must therefore ask whether citizens are well-served by the picture presented in this report. Given the projections presented here, they should also consider the needs of future populations.

In approaching these conversations, it is perhaps helpful to reflect that many of the underlying trends - demographic change for example - are long-term and amenable to strategic planning. This is an opportunity to take advantage of foresight.

Any successful way forward will draw on a combination of perspectives and insights from the different groups noted above. Their reactions and responses to the analysis presented here will determine the direction, nature and ambition of efforts to improve the deaths of people in Lincolnshire.

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