



End of life care  
**Together**

# Supporting end of life care in NHS Highland:

## Accounting for Value Report



One person. One plan.  
One chance to get it right.

## Foreword

It is a great privilege to be able to support an individual, their family and friends at the end of life. Health and care systems across the world have made great strides to improve end of life care over the span of my fifty-five-year career, often led by the persuasive leadership of the hospice movement and organisations like Macmillan and Marie Curie.

Despite this leadership and these improvements, the lure of the acute hospital and desire of clinicians to provide interventions where they can, has meant that we have seen the medicalisation of the end-of life. Emergency admissions have increased and there is a sense that care is provided, often when it might be considered futile.

Rarely do we look at people at the end-of -life as a population group- what would happen if we were to organise the people concerned with end-of-life care from bureaucracies and institutions into networks focussed on providing the best value care to people at the end of life? Those networks would endeavour to deliver four aims:

- That we are achieving the goals and outcomes that matter to people at the end of life (and their family and friends), including involving them in critical decisions.
- That we are providing end-of-life care fairly (equitably).
- That we are making best use of resources for the population group of people at the end of life.
- That in providing end of life care we benefit society in Highland, Argyll and Bute

This report starts to ask questions about how well NHS Highland is doing regarding these first three of these four aims (the last is beyond the scope of our analysis). In doing so, it builds the case for increasing the value of end-of-life care through establishing a network charged with delivering on the four aims.

I believe the report is of national and international importance and the people served by the NHS Highland should be proud of the insight and commitment of their health service.

Professor Sir Muir Gray CBE

## Preface

This is the first Accounting for Value report prepared for NHS Highland, and the first report of its kind to take a methodical look through a value-lens at dying and death from both an individual and system perspective for a defined local population in Scotland.

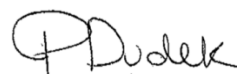
This is the culmination of several years' work in NHS Highland to improve end-of-life care.

Scotland's Chief Medical Officer, Professor Sir Gregor Smith, reminds us in his action plan for Value based health and care that:

*“care is human. It is about personal interaction, uncertainty, co-creation and compassion in managing risk, anxiety and hope. It is about the power of the relationship and being able to jointly identify issues that affect us, our preferences and our goals. It is as much about alleviating as it is about fixing, but always with honesty, kindness and consideration of others life experience. Care is not just biomedical, it is biographical too. The desire is to provide **careful and kind care**, that people really value.”<sup>[1]</sup>*

This Accounting for Value report generates a hypothesis that the single best way to deliver what it is that people value at the end-of-life is to use resources better. In doing that we would need reinvestment in end-of-life care by reducing unnecessary and often reactive, emergency admissions to hospital toward the end of people's lives. Then the main ways to achieve this would be through reducing referrals to hospital by understanding, recording and sharing an individual's preferred outcomes, allowing us to anticipate their likely care needs, and planning and putting in required measures accordingly. We need to increase support to keep people in their preferred place of care by building general practice, and community, capacity and capabilities.

The conclusions from this report and proposed next steps will I hope will provide a firm foundation for the implementation of a fully realised population approach to end of life care in NHS Highland with great potential for shared learning and scalability across Scotland.



Pamela Dudek  
Chief Executive  
NHS Highland



<sup>[1]</sup> Smith G. Value based health and care: action plan. Available at <https://www.gov.scot/publications/value-based-health-care-action-plan/pages/1/> (accessed October 2023)

## Acknowledgement

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## Executive Summary

More people in NHS Highland are dying, they are doing so at an older age (especially over the age of 85) and from more complex conditions such as dementia and with multiple conditions. This trend is predicted to continue over the next twenty years, greatly increasing the need for support at the end of life (palliative care).

A survey in Scotland showed that 61% of people would prefer to die in their usual place of residence. Fewer than 10% wish to die in hospital or a care home. Over the last 20 years, the number and proportion of people dying at home has increased, and the number and proportion of people dying in hospital has decreased. In NHS Highland, the place a person dies is highly impacted by the area in which they live, especially the degree of remoteness. The cause of death impacts the place where people die. People dying with dementia are more likely to die in a care home and much less likely to die in hospital; those dying of cancer are less likely to die in hospital and more likely to die at home; and those dying of organ failure are more likely to die in hospital and less likely to die at home.

People who reside in more deprived neighbourhoods are less likely to die in a care home- this might be due to a lower life expectancy or fewer care homes being available in more deprived neighbourhoods. People who reside in more deprived neighbourhoods are more likely to die in hospital, possibly due to reduced access to alternative out of hospital services.

Emergency hospital admissions are a significant feature in the last year of life, with only 32% of people not experiencing any emergency admission of any kind. The number of emergency admissions increases in the last few months of life. In the last month of life, there is a sharp increase in the number of people experiencing an emergency admission, but a fall in the length of stay per admission.

Bereavement services have undergone several changes during and after the Covid-19 pandemic. In 2022-23 there 167 referrals and 490 sessions for bereaved people. People living in the south area of Highland are more likely to receive bereavement services compared to those living in more remote areas.

Many aspects of spending on the last year of life are unknown, including informal care from family and carers, social services, community nursing and core general practice. Of the spend we do know about, the amount spent on people in the last year of life in NHS Highland Health has remained much the same over the period 2017-18 to 2019-20, with £44 million being spent in 2019/20. 71% (£31 million) of that £44 million is spent on emergency admissions. Bed occupancy related to emergency admissions for people at the end of life has increased from 25.2% of all emergency beds in January 2016 to 29.7% in July 2022. Spending on GP out of hours services for people in the last year of life increased by 18% Hospice

charitable service spending has increased by 27% over the period 2017-18 to 2019-20 (in line with 23% increase of inpatient activity, and 124% increase in outpatient hospice activity).

Although we have good data about where people died in NHS Highland, we know almost nothing about the quality of life leading to their death, nor the nature of their death. We have information from local focus groups on the kind of activities that might promote better, or worsen, outcomes at the end of life. We have an agreed set of outcomes that matter, and measures for each of these. We need to put these into a dashboard, and alongside measures of resource use, adopt this as a tool for value improvement activities.

Based on this report, the End of Life Together Board concluded these are the key issues that we will address:

- People who die in NHS Highland possibly experience inequities, especially from the impact of rurality and accessibility;
- We are not systematically identifying NHS Highland residents at the end of their life, nor are we capturing or sharing their preferences in order to be able to fulfil them;
- We do not know the outcomes people in NHS Highland experience at the end-of-life;
- The number of people who would benefit from end-of-life support is increasing, and the causes and the age of death are changing;
- Emergency hospital admissions are a major feature as people in NHS Highland approach death- reflected in the way resources are used.

We think there are four key actions we want to take to improve the value of health and care for people at the end of life in NHS Highland:

- Build a movement for change by communicating the findings of this report, in an appropriate format, within the NHS and wider, including with the public.
- Identify people at the end-of-life, listen to them and share their preferences so we can fulfil them.
- Take our agreed outcomes, measure them, and reflect and act on them on a regular basis to enable us to track improvements in value.
- Trial a rolling series of projects to impact the number of emergency hospital admissions, whilst better fulfilling people's end of life preferences, reducing possible inequities of outcomes and using resources more efficiently.

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## **Note on the methodology used in this document**

In this document we have tried to differentiate between adults (18 years and older) who died from conditions that would benefit from end-of-life support (or palliative care) from people who would not benefit from such support.

We have further classified people who died into broad groups, namely people who would benefit from end-of-life support and who died from:

- All forms of cancer
- Organ failure (e.g., heart failure, renal failure, COPD)
- Dementia
- Other conditions, including neurological, stroke, HIV (often referred to as other palliative care in this document)

The methodology we used is described further in appendices 1 and 2, and in the paper by Finucane *et al* (2021)<sup>i</sup> and is based on the underlying cause of death.

## Commonly used abbreviations

EoL	End of Life support (a death potentially needing palliative care)
CHI	Community Health Index
CIS	Continuous Inpatient Stay
NRS	National Records of Scotland
PHS	Public Health Scotland
PLICS	Patient Level Information and Costing System
SPIRE	Scottish Primary Care Information Resource

## Introduction

This document provides *an Accounting for Value report* of the support we are providing to adults (18 years and older) in the last year of life, and to their bereaved family and carers.

*Our:* because it is the collective view of all the various organisations involved in end-of-life support, not just a single team or institution. It also incorporates feedback from people, and their families and carers, who are at the end of life and from various interested groups.

*Accounting for value:* as Mark Carney outlined in his recent Reith lectures, value is subjective and ultimately should reflect our values.<sup>ii</sup> So, our perspective reflects the definition of value developed for universal health systems by the EU, and later adopted by G20 group of nations<sup>iii</sup>:

- fair access to end-of-life support based on need (allocative value),
- providing the best possible experience at the end of life for the dying individual and the family and carers (personal value),
- using the resources we have available for end of life support as efficiently as possible (technical value) and
- in doing so benefiting society in Highland, Argyll and Bute.

Further, access to end-of-life support is also considered a human right. In compiling this report, we have been influenced by the focus groups we have conducted with people at the end of life, their friends and families, carers, and other interested groups- in other words the report is shaped by the people we serve.

It is not definitive, there are many gaps in the data that we will seek to fill in the coming years, allowing us to further improve the support we provide. We know little about the resources and activity in core general practice and community nursing, even though they form 90% of NHS activity. We also know very little about the outcomes that people who die, and their family and carers, experience. We capture proxies in the hope that they reflect the real outcomes. These gaps must be rectified.

However, using the knowledge we have, alongside the data in this report, we have enough to help guide us as we start to improve the value of care for people at the end of life, making it fairer, optimising their quality of life and using resources wisely.

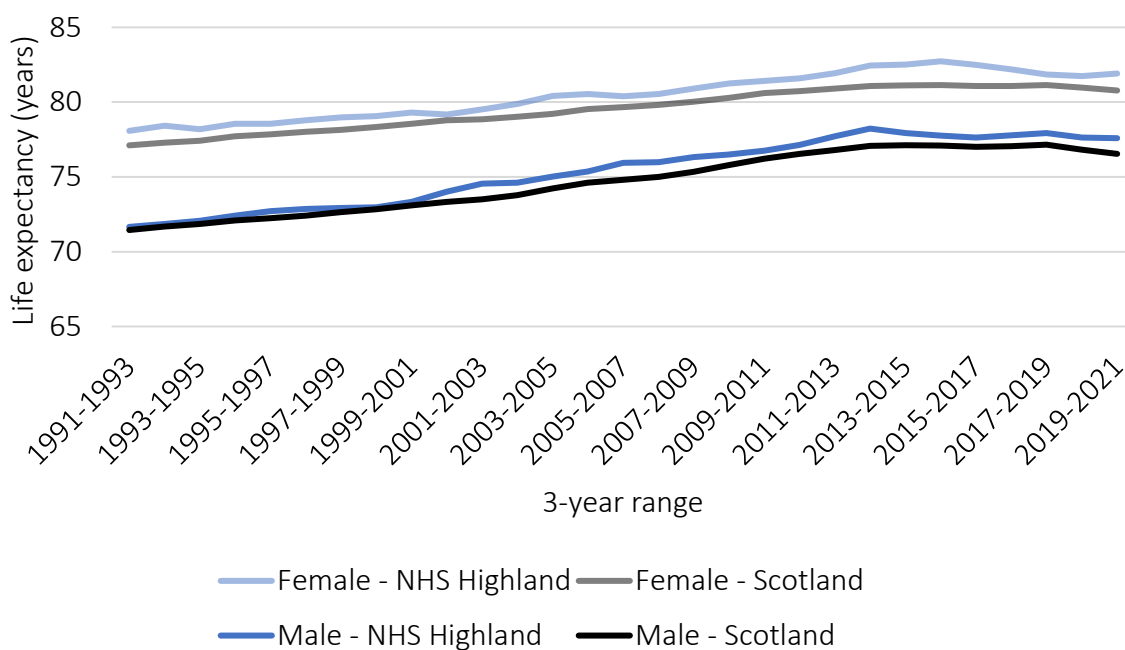
# People at end of life (adult residents dying in NHS Highland)

## Summary

- After many years of decline the number of people dying in NHS Highland is rising, even after accounting for Covid-19.
- In line with projections across Scotland, the number of deaths is likely to continue to increase over the next two decades.
- Between 0.9%-1.2% of the population in NHS Highland have end-of-life support (palliative care) needs (2790 to 3520 people). 0.4% have been identified on GP end-of-life registers.
- The cause of death is changing, notably away from circulatory disorders (especially ischemic heart disease) and towards people dying of (or with) dementia and multiple co-morbidities.
- The age at which people die is increasing with more people dying over the age of 85.
- These changes mean two things: that we need to change the way we support people at the end of life, and we need to build capacity now and, in the future, to be able to support the increasing numbers of people at the end of life.

One of the great successes in the 20<sup>th</sup> century has been the rapid increase in life expectancy. This has stalled in recent years, and NHS Highland, as in Scotland, has experienced a decrease in both male and female life expectancy (see Figure 1). These changes started prior to the Covid-19 pandemic.

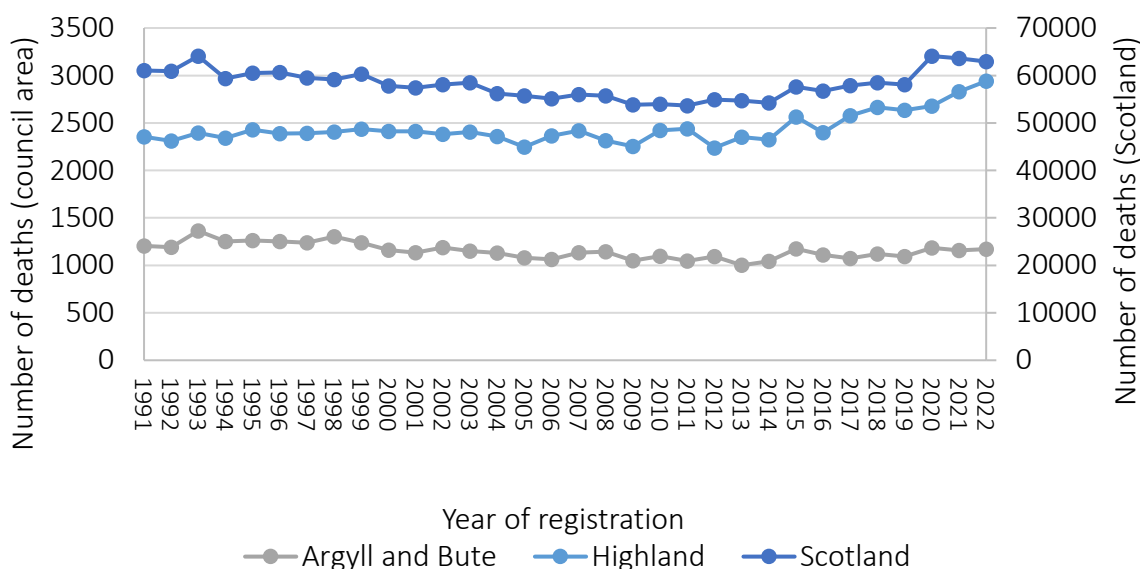
Figure 1: Life expectancy at birth, NHS Highland and Scotland, 1991-93 to 2019-21



Source: National Records of Scotland (NRS), see appendix 3

From 1990 and until 2013, there was a slow decline in the number of people dying in NHS Highland (Highland and Argyll and Bute council areas). However, since then the number of deaths has increased (from 3,321 in 2013 to 3,861 in 2020). 2020 is obviously impacted by the Covid-19 pandemic, but it is consistent with a general trend upwards over the last seven years. This trend (a fall then increase) is very similar to that seen across Scotland as a whole. Argyll and Bute has seen a more modest trend in the absolute number of deaths (see Figure 2).

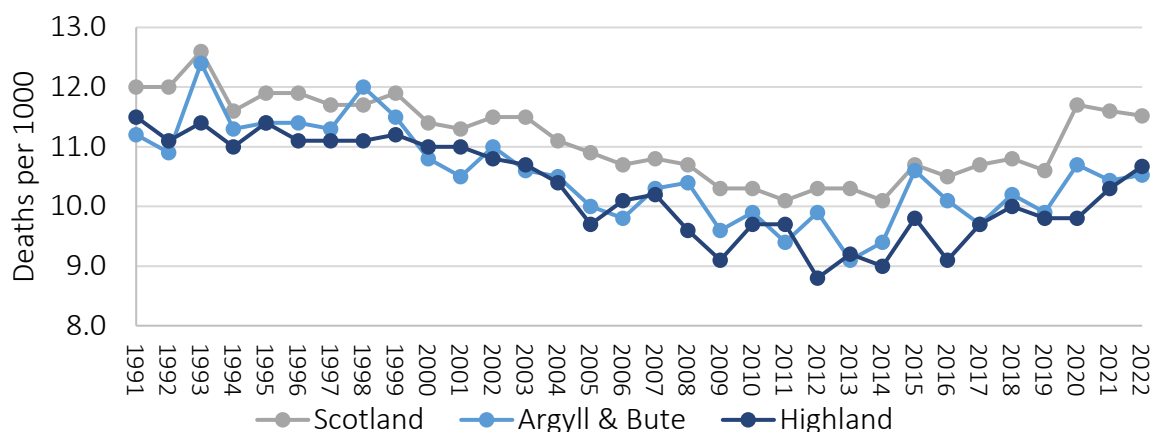
Figure 2: Annual total of deaths in Scotland, Highland, and Argyll & Bute 1991-2021



Source NRS, see appendix 3

When expressed as a rate (adjusted for age and gender), the same general trend down and then recently increase in death rate can be seen for Scotland, Highland, and Argyll and Bute, noting the increase started before the Covid-19 pandemic, although it appears to have been worsened by the pandemic (see Figure 3).

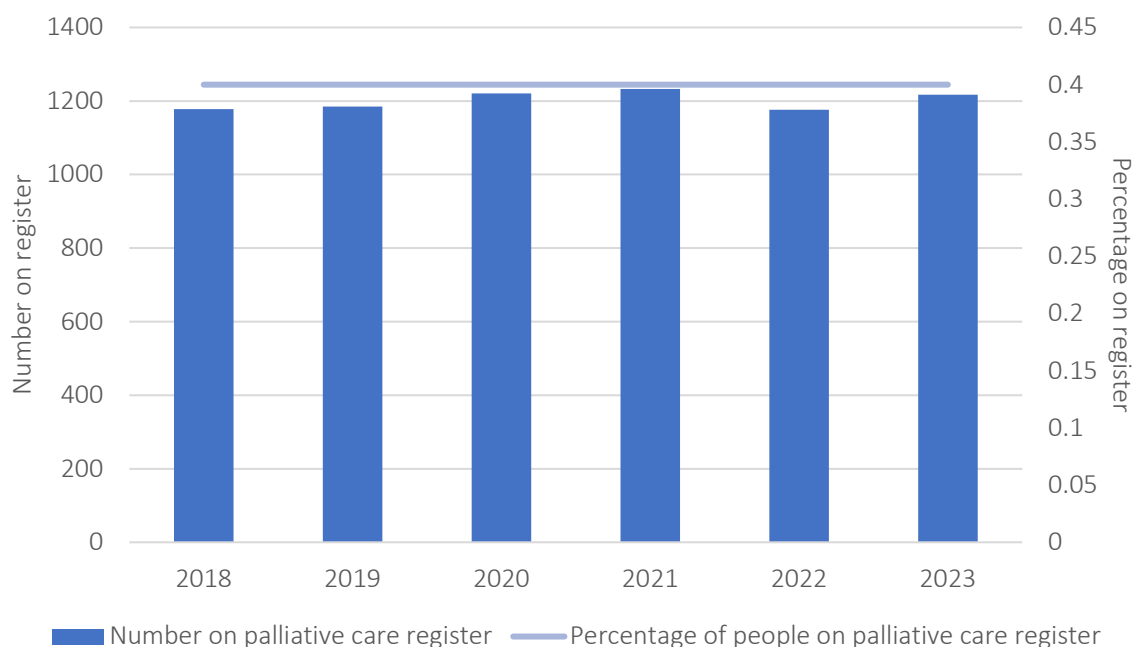
Figure 3: Deaths per 1,000 population - "standardised" using the age/sex-specific rates for Scotland, Highland and Argyll & Bute 1991-2021



Source: NRS, see appendix 3

The number of people on general practice palliative care registers in NHS Highland has stayed relatively stable over the last five years, and the percentage of the population on those registers has remained at 0.4% (see Figure 4).

Figure 4: Number and percentage of people on GP palliative care registers in NHS Highland 2018-2023



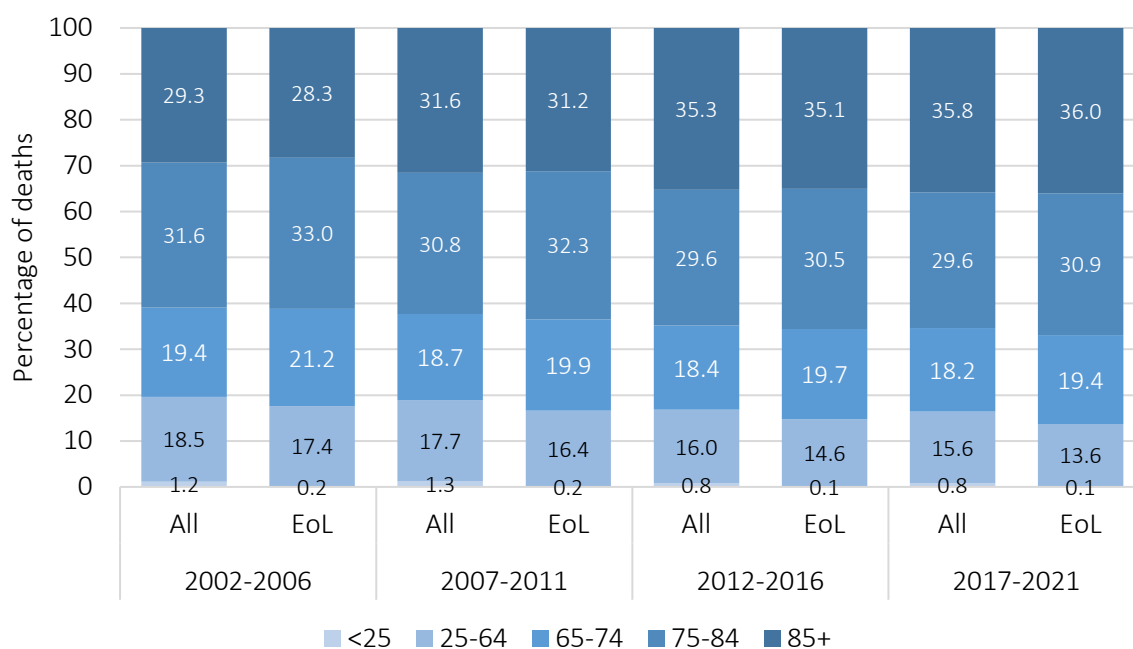
Source: Public Health Scotland (PHS) SPIRE data, see appendix 3

Estimates of the annual average number of deaths that have end-of-life support (palliative care) needs ranges from 2790 to 3520 deaths (or between 0.9 and 1.25 of the total population (see Appendix 2 on how end-of life support needs have been estimated). This is considerably lower than the number of people on GP registers (0.4%), with perhaps 1500 people with end-of-life needs not being recorded.

Over the five-year period from 2017-21, people are dying at an older age in NHS Highland when compared to 2002-06. 35.8% of all deaths in the most recent years are people over 85 compared to 29.3% of all deaths in 2002-2006.<sup>iv</sup> This is even more marked when looking at people who are dying of a condition that would benefit from end-of-life support (as identified using the Finucane methodology), where 36% of those deaths are in people over 85, compared to 28.3% in 2002-06 (see Figure 5).



Figure 5: Comparison in the percentage age composition of five-year death cohorts: causes of deaths that might benefit from End of Life support (EoL) versus deaths from all causes from 2002 to 2021

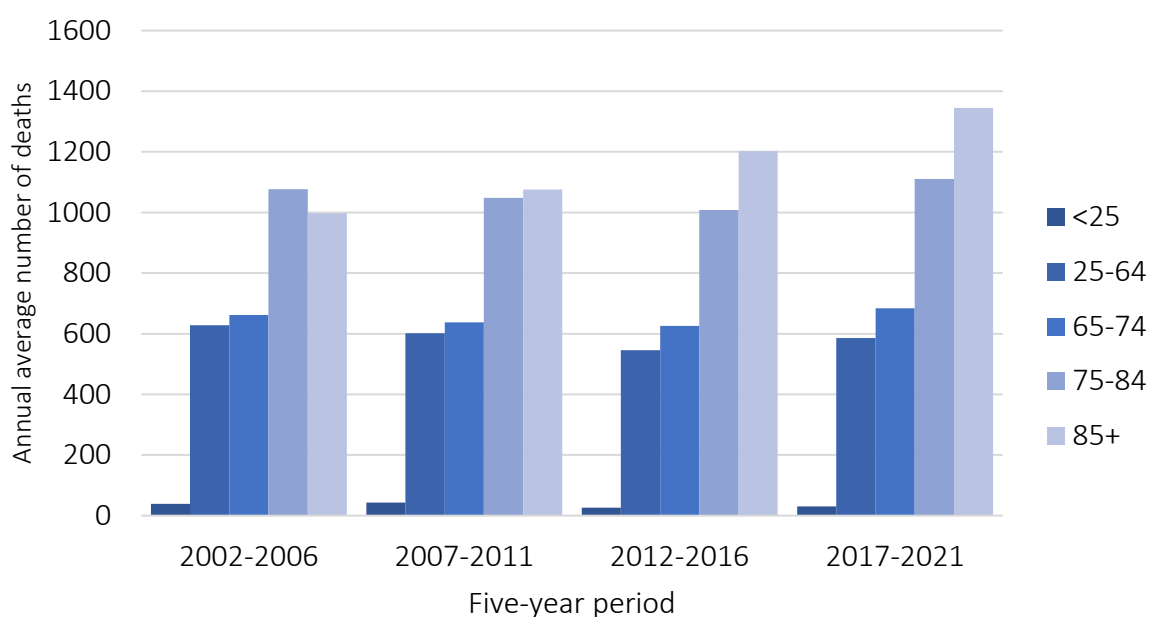


Note: small % of people dying age under 25 shown at base of each bar.

Source: NRS deaths records for NHS Highland, EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

Looking at the absolute numbers of deaths by age, shows the same increase in deaths in people aged over 85 in recent years (see Figure 6).

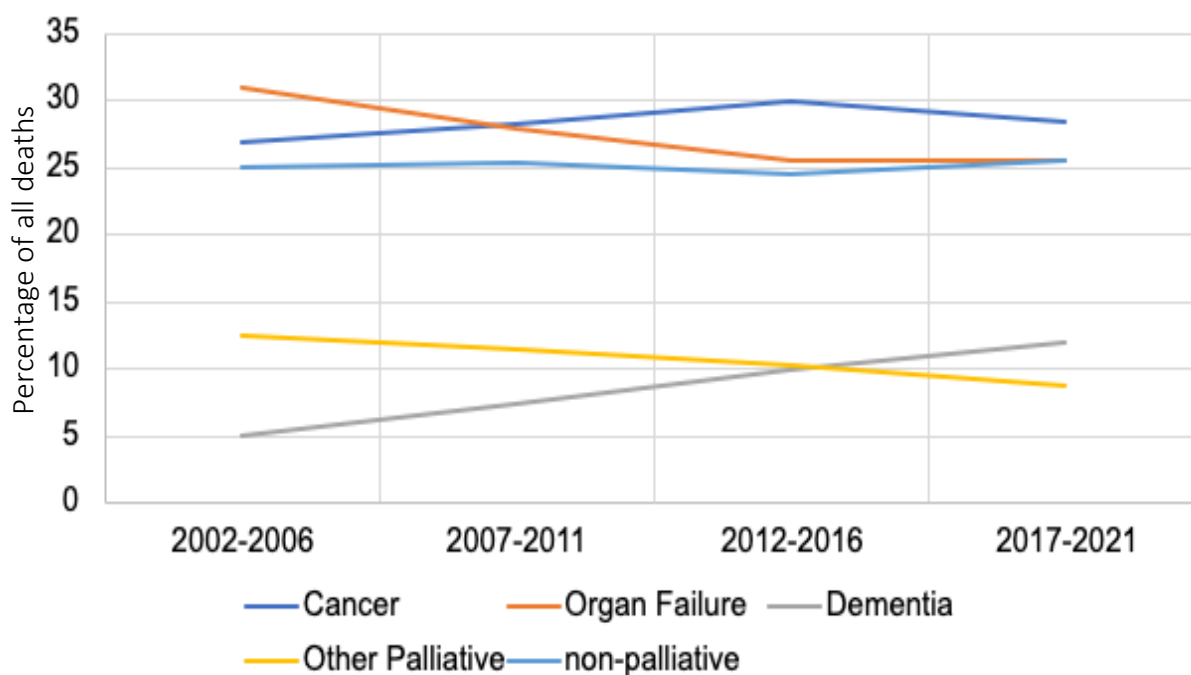
Figure 6: Ages of death of residents of NHS Highland 2002 - 2021



Source: NRS deaths records for NHS Highland, see appendix 3

Longevity and lifestyle changes mean that the causes of death have changed. Using the grouping of conditions used by Finucane and colleagues we can see that in NHS Highland, deaths from conditions classified as organ failure (e.g. heart failure, renal failure, COPD) are falling as a percentage of total deaths, whereas deaths from conditions associated with frailty (including dementia) are increasing as a proportion of all deaths. Deaths from cancer are relatively static as a percentage of all deaths (see Figure 7).

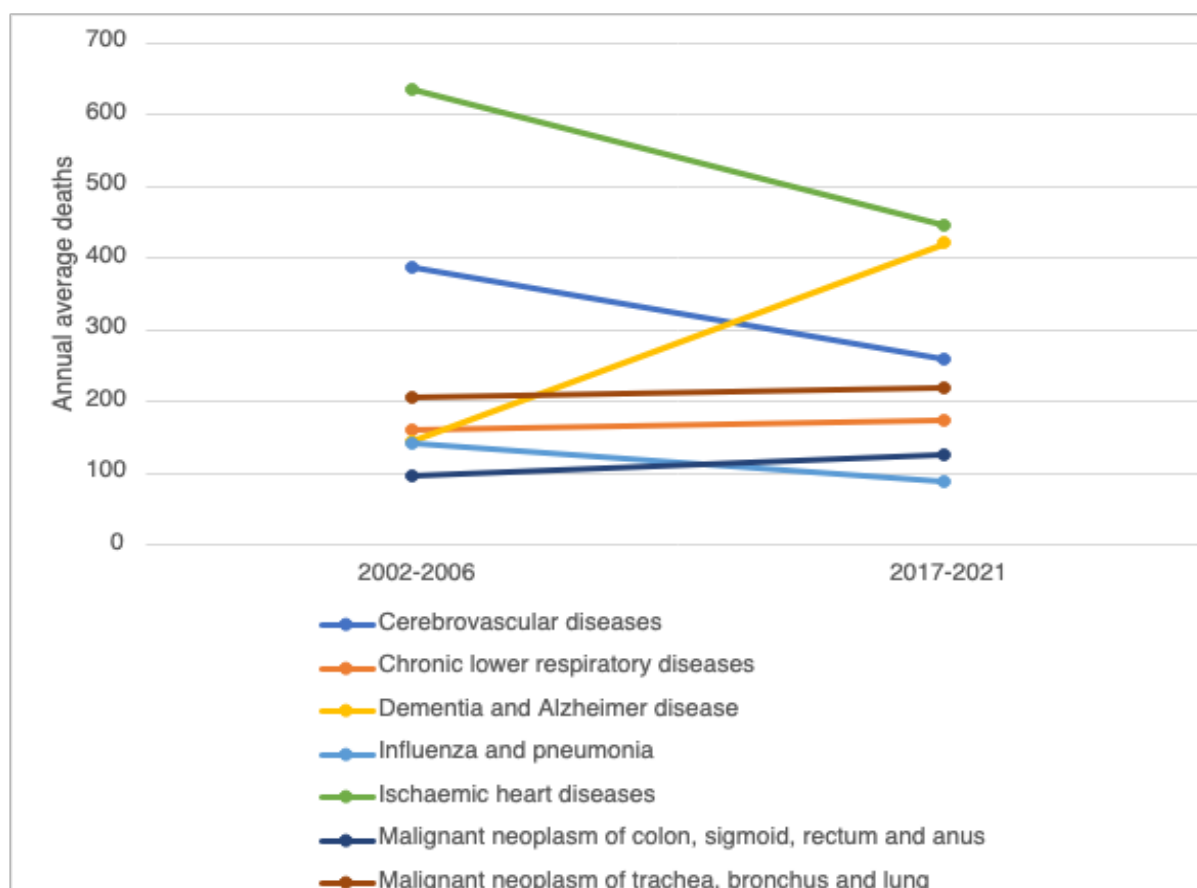
Figure 7: Trends in proportion of deaths of NHS Highland residents by grouping of EoL causes of death 2002-2021



Source: NRS deaths records for NHS Highland, EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

Similarly, looking at traditional disease groupings, when comparing the annual average number of deaths in 2002/06 with 2017/21, we see a large rise in death from dementia, smaller rises in deaths from cancers and lower respiratory diseases, and falls in deaths from ischaemic heart disease and cerebrovascular disease (stroke) (see Figure 8).

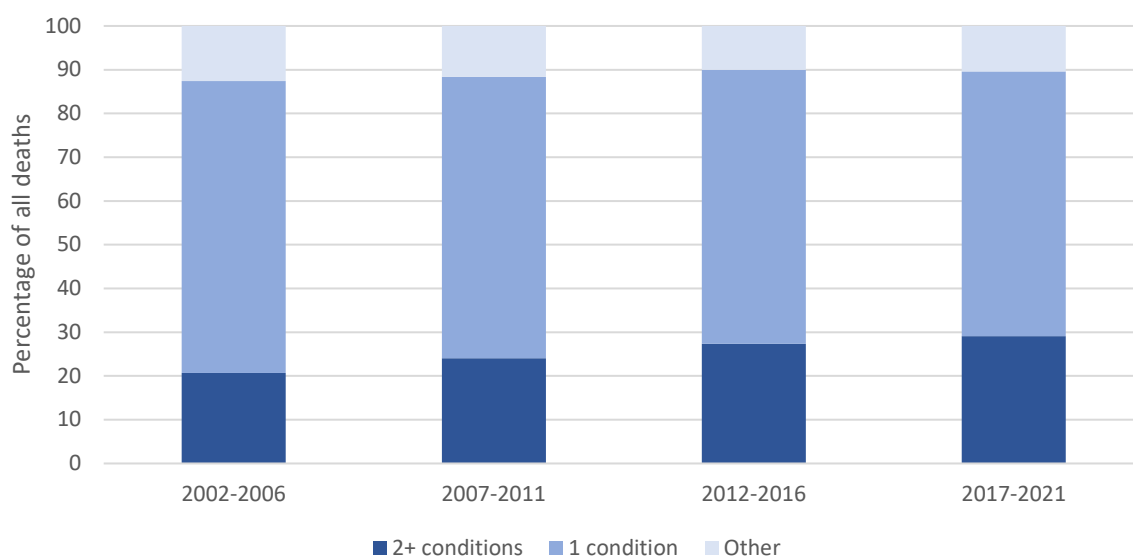
Figure 8: Changes in the leading causes of death, 2002-2021 for NHS Highland residents



Source: NRS deaths records for NHS Highland and adapted Office for National Statistics cause of death grouping

Research in Scotland has shown the increasing rates of multi-morbidity, and complexity, in people at the end-of-life.<sup>v</sup> In NHS Highland, there has been an increase in the number of people dying with multi-morbidity (two or more conditions) (see Figure 9).

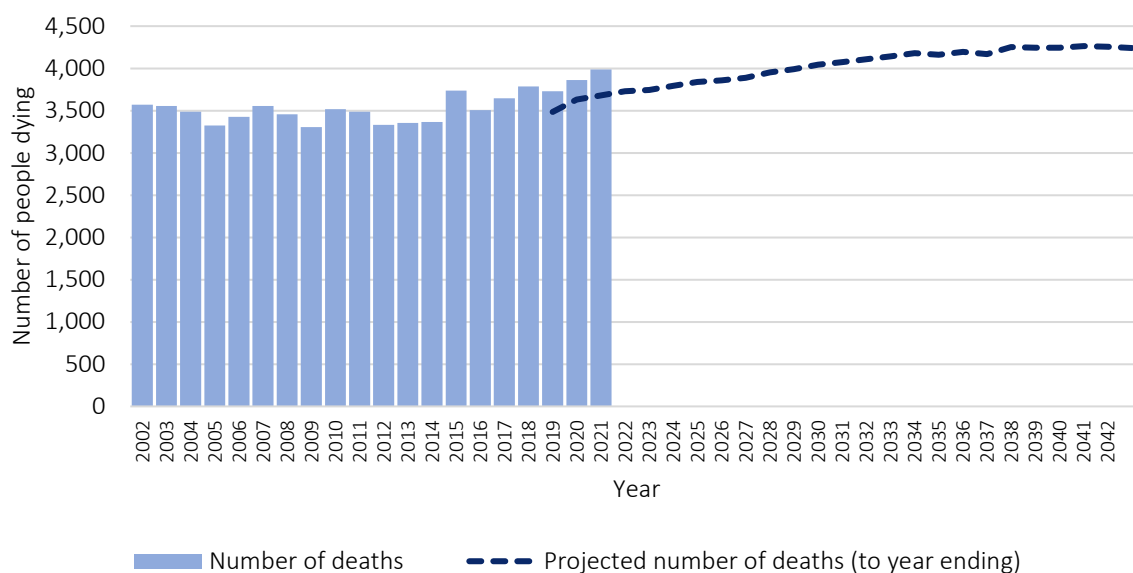
Figure 9: People dying with two or more conditions (multi-morbidity) as a percentage of all deaths 2002-06 to 2017-21



Source: NRS deaths records for NHS Highland, multimorbidity defined using cause of death codes as in Finucane et al. 2021, see appendix 3

Looking ahead, the trends we have seen over the last two decades are predicted to continue. Research has been done looking at the number and causes of deaths across Scotland over the next two decades. On top of the rise in the number of people dying in NHS Highland we have seen over the last ten years, deaths are projected to continue rising, reaching 4242 by the end of 2043, a 6.3% increase from 2021 (see Figure 10).

Figure 10: Predicted number of people dying in the NHS Highland 2002-2043

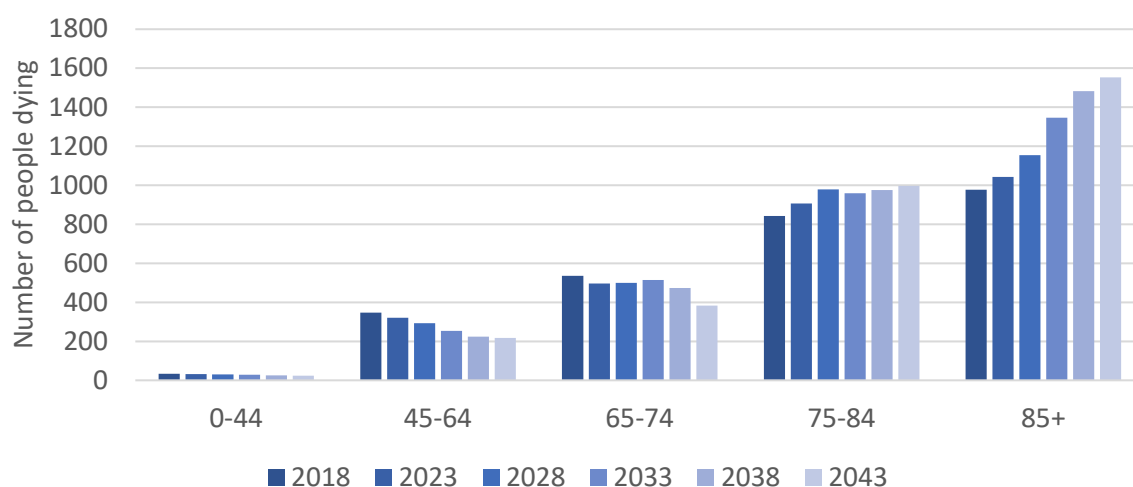


Source: NRS death time series and NRS 2018-based sub-national principal population projections

Just as importantly, the nature of the end of life continues to change.

Figure 11 shows that whilst deaths, and the need for end-of-life support will fall for people aged under 75, it is going to increase in NHS Highland for people dying aged over 75 and especially over 85 years.

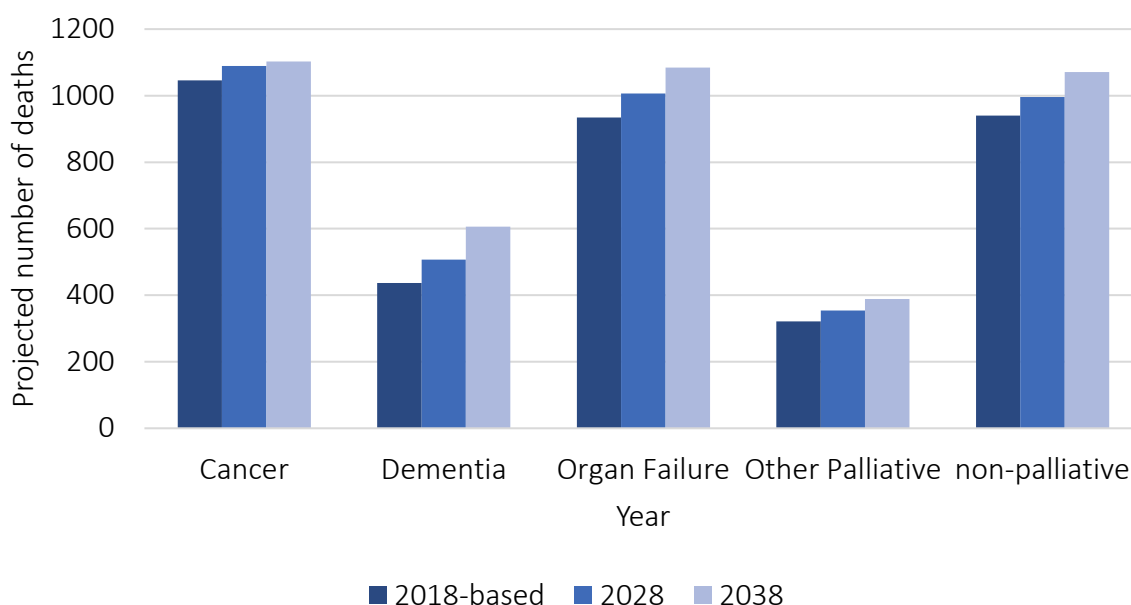
Figure 11: Projected estimates of the number of people dying in NHS Highland with palliative care needs (EoL deaths) by age up to 2043



Source: NRS deaths records for NHS Highland and NRS 2018-based population projections. EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

The number of deaths, and changes in the cause of death is projected to continue in the future in NHS Highland (see Figure 12).

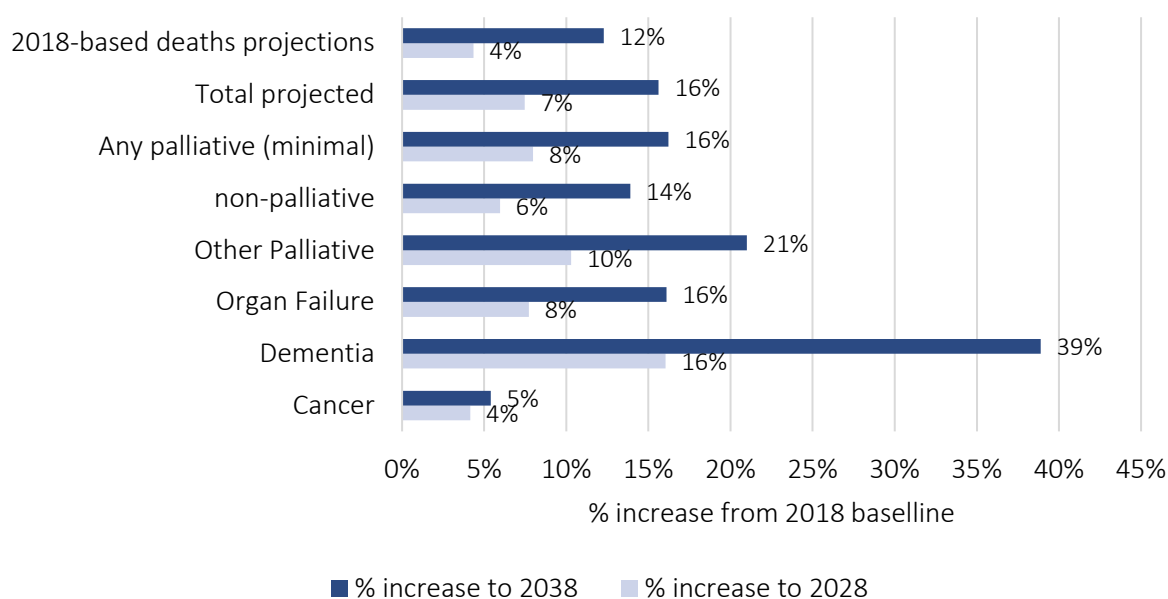
Figure 12: Projected main underlying cause of death in NHS Highland by disease group up to 2038



Source: NRS deaths records for NHS Highland and NRS 2018-based population projections. EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

The biggest percentage increase will be seen in deaths with dementia, especially by 2038 (see Figure 13).

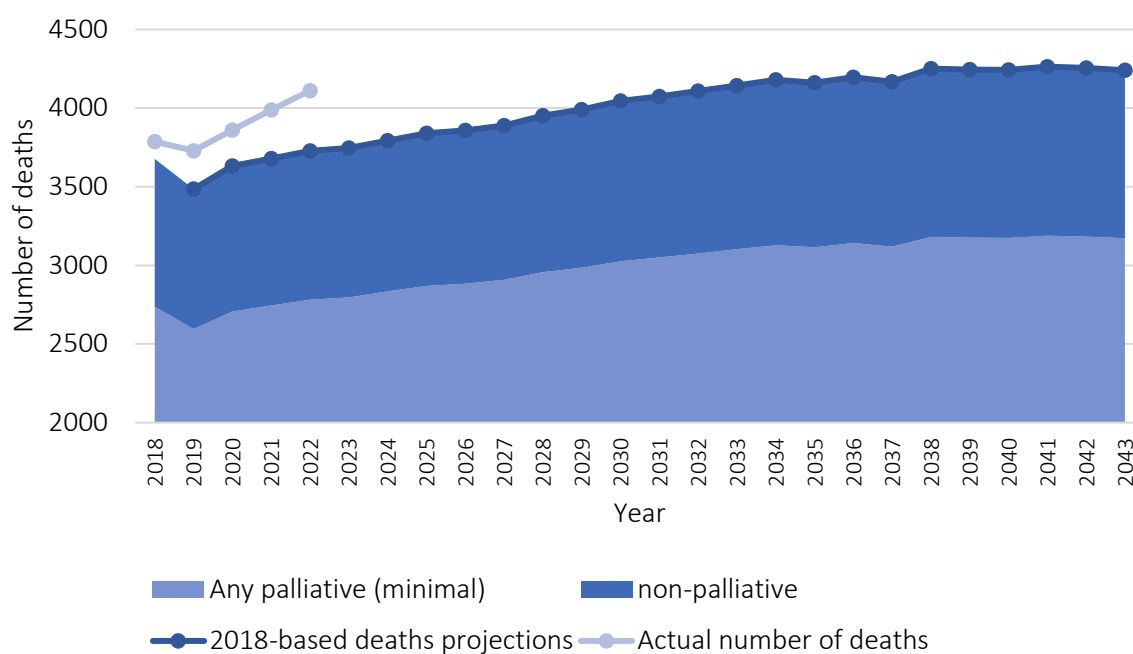
Figure 13: Percentage increase in cause of death by disease group from 2018 baseline



Source: NRS deaths records for NHS Highland and NRS 2018-based population projections. EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

This means that the number of people dying with palliative care needs in the NHS Highland, which has been increasing year on year, is going to continue increase (see Figure 14).

Figure 14: Projected number of people dying in NHS Highland with palliative care needs and no palliative care needs 2018-2043



Source: NRS death time series, NRS deaths records for NHS Highland and NRS 2018-based population projections. EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

It is clear, therefore, that in NHS Highland, we need to prepare for more people dying, more often at an older age, with more palliative care needs, more often dying with dementia and complex multi-morbidity.

# Events or activity people experience in the last year of life

## Summary

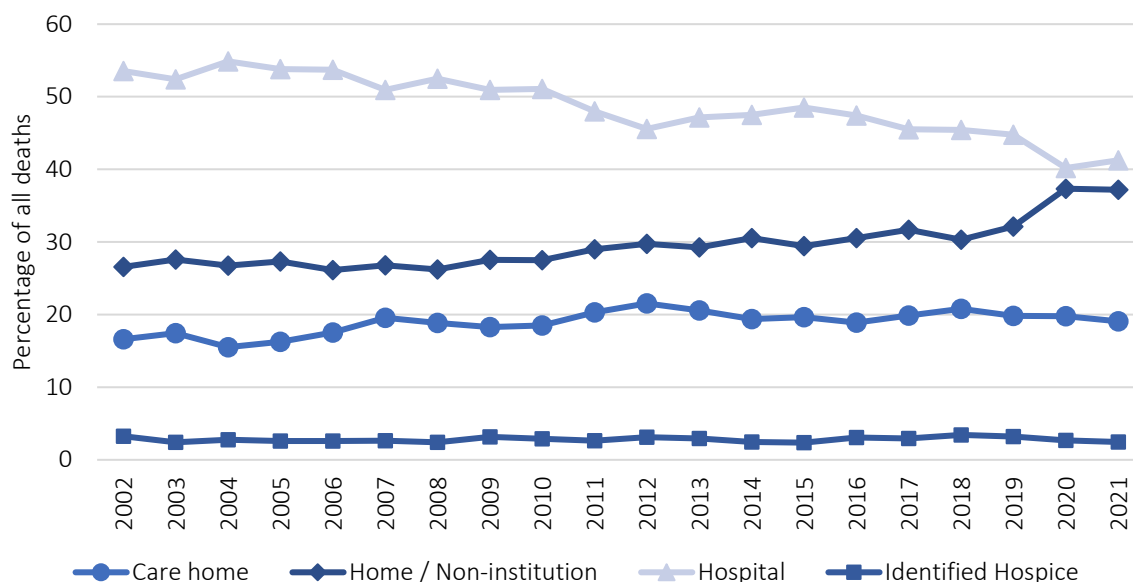
- In Scotland, 61% of people would prefer to die in their usual place of residence. Fewer than 10% wish to die in hospital or a care home.
- Over the last 20 years, the number and proportion of NHS Highland residents dying at home has increased, and the number and proportion of people dying in hospital has decreased.
- In NHS Highland, the place a person dies is highly impacted by the area in which they live, especially the degree of remoteness.
- Older people are much more likely to die in a care home than younger people, this is important given the rise in the number of people dying over the age of 85.
- The cause of death impacts the place where people die. People dying with dementia are more likely to die in a care home and much less likely to die in hospital; those dying of cancer are less likely to die in hospital and more likely to die at home; and those dying of organ failure and other palliative conditions are more likely to die in hospital and less likely to die at home.
- People who reside in more deprived neighbourhoods are less likely to die in a care home- this might be due to a lower life expectancy or fewer care homes being available in more deprived neighbourhoods.
- People who reside in more deprived neighbourhoods are more likely to die in hospital, possibly due to reduced access to alternative out of hospital services.
- Emergency hospital admissions are a significant feature in the last year of life, with only 32% of people not experiencing any emergency admission of any kind.
- The number of emergency admissions increases in the last few months of life.
- In the last month of life, there is a sharp increase in the number of people experiencing an emergency admission, but a fall in the length of stay per admission.
- 72% of people who are admitted as an emergency to a hospital in the last month of life die whilst in hospital.
- Bereavement services have undergone several changes during and after the Covid-19 pandemic. In 2022-23 there 167 referrals and 490 sessions for bereaved people. People living in the south area are more likely to receive bereavement services compared to those living in more remote areas.

The events or activity that leads up to an individual's death give us a picture of how the health and care system is responding to their needs. It also gives us a clue as to the quality of life leading up to the death, although it can only be a proxy; a death at home is no guarantee of a 'good' death. A recent YouGov survey commissioned by Marie Curie found that, in

Scotland, 61% of people said they would prefer to die at home. Less than 10% of people in the survey expressed a preference to die in a care home or a hospital. <sup>vi</sup>

In NHS Highland, the place of death has been changing over the last 35 years. Death in hospitals (acute and community) have fallen, whilst deaths in people’s homes have increased. Deaths in care homes and hospices have remained largely static (see Figure 15).

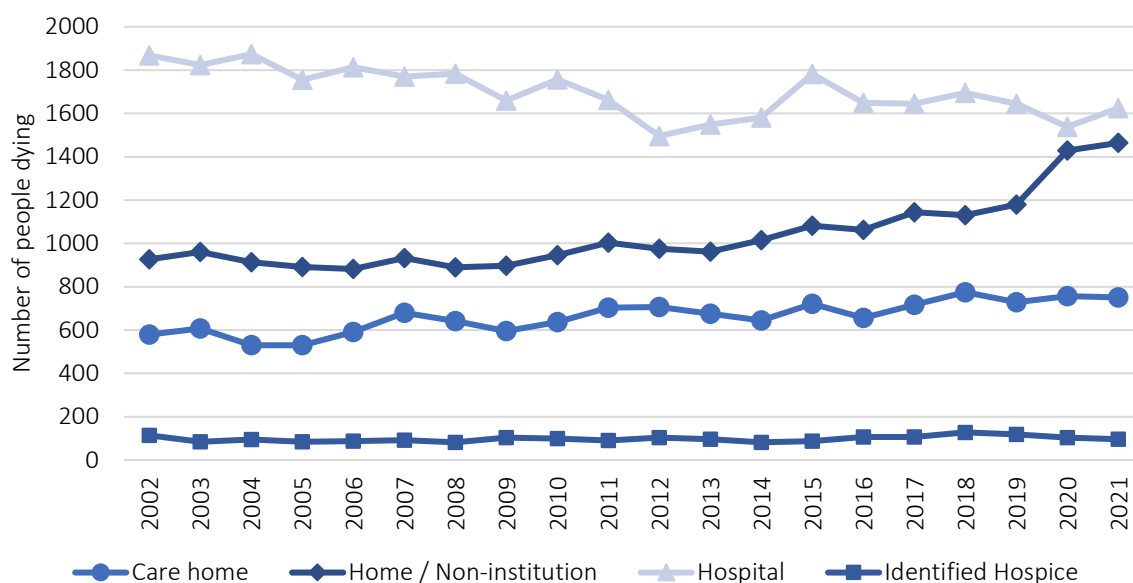
Figure 15: Trends in the place of death as a percentage of total for residents of NHS Highland



Source: NRS deaths records for NHS Highland, see appendix 3

Because the number of deaths has increased, the increase in deaths at home is even more stark, but absolute increases in deaths in care homes can be seen, whilst the number of deaths in hospital has fallen by a modest amount (see Figure 16).

Figure 16: Number of people dying in home, care home, hospital, 2002-21.

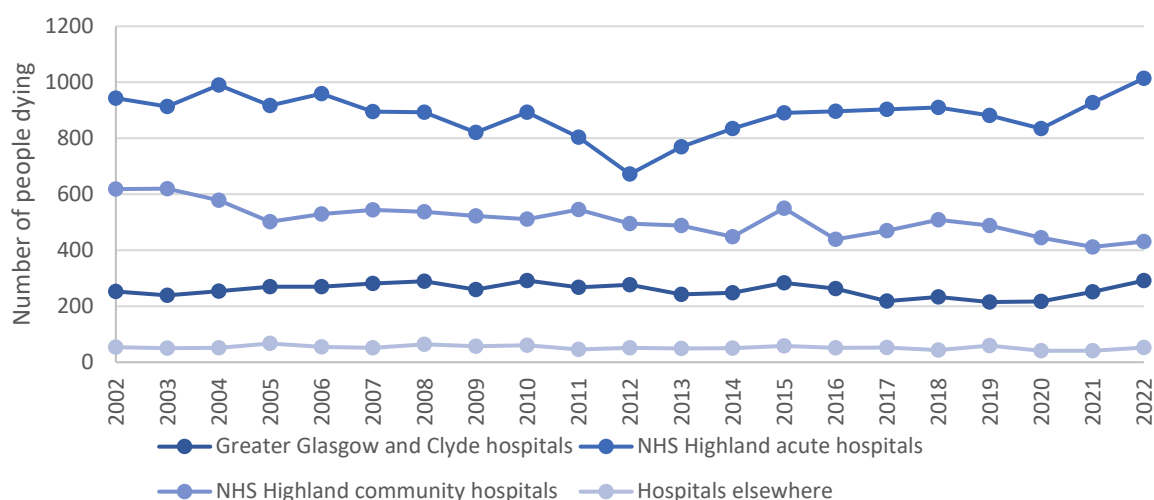


Source: NRS deaths records for NHS Highland, see appendix 3



When looking at hospital type, we can see that in the last ten years there has been a gradual decline in the number of NHS Highland residents dying in community hospitals, and an increase in residents dying in acute hospitals (see Figure 17).

Figure 17: Number of people dying in hospital settings by type of hospital. 2002-2022.

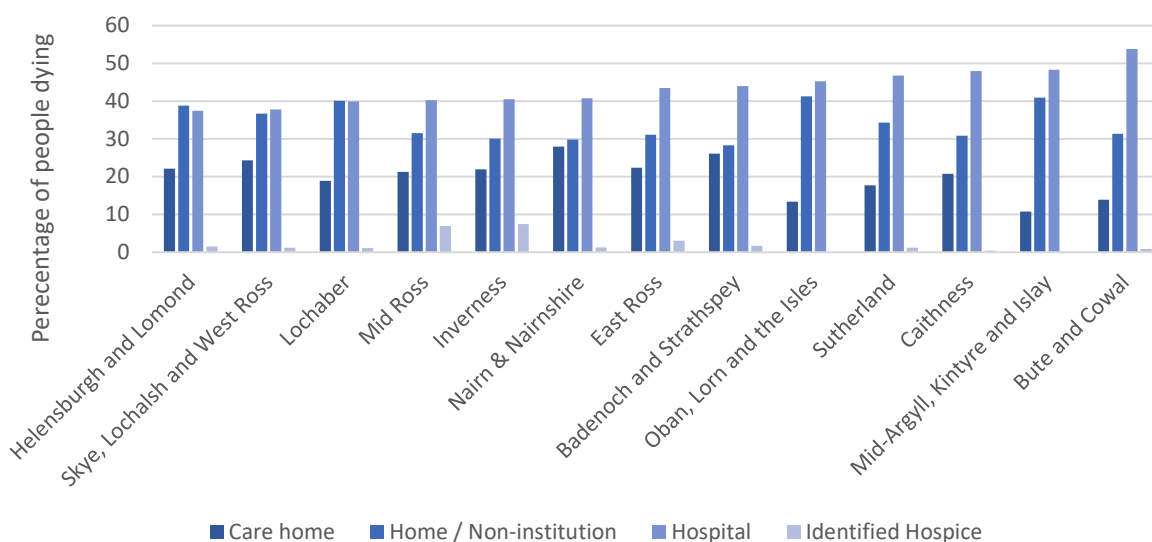


Source: NRS deaths records for NHS Highland, see appendix 3

The place of death is highly dependent upon where you live in NHS Highland (see Figure 18). This is unsurprising considering the geography and distribution of the population in NHS Highland, including on islands without mainland road links. Variation in place of death varies between areas in NHS Highland:

- By 2.5-fold in care homes
- By ten-fold in hospice
- By one third in home and hospital

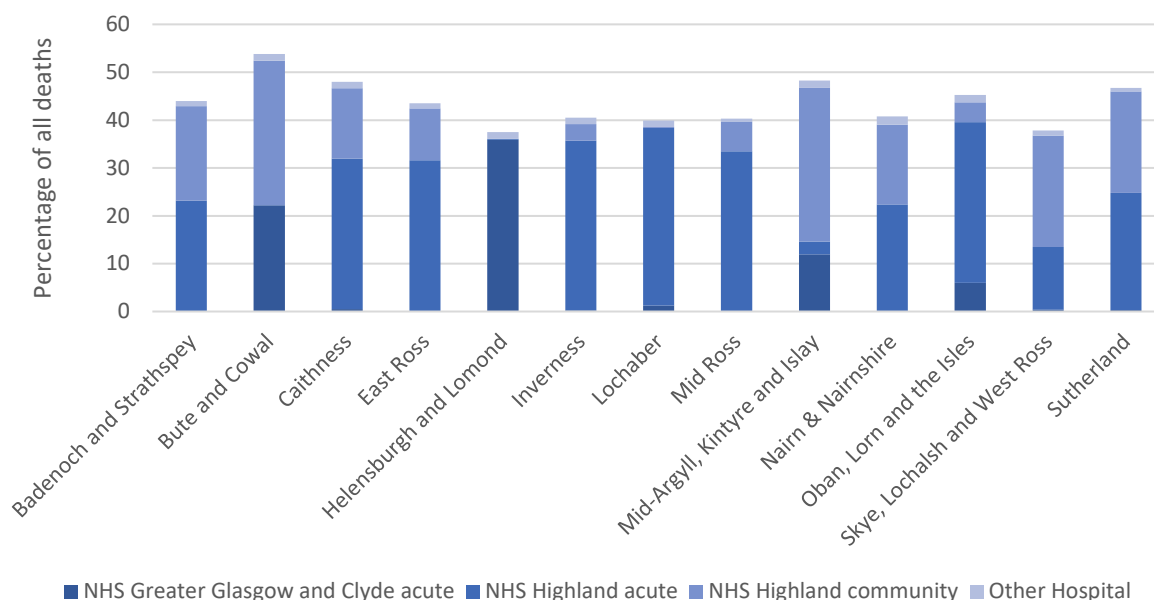
Figure 18: Place of death for residents of NHS Highland shown by locality by percentage, 2017-2021



Source: NRS deaths records for NHS Highland, see appendix 3

Looking at the type of hospital, this demonstrates further variation in the place of death based on area or locality, especially between dying in an acute or community hospital based in NHS Highland or an acute hospital in Greater Glasgow and Clyde area (see Figure 19).

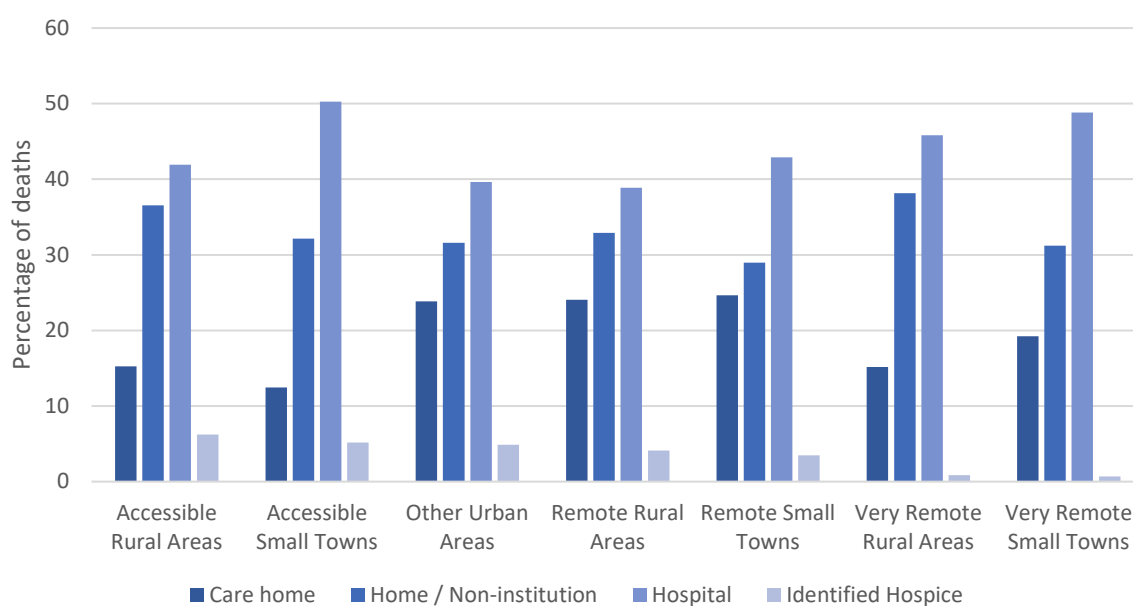
Figure 19: Percentage of people dying in hospital by type of hospital for NHS Highland residents 2017-2021



Source: NRS deaths records for NHS Highland, see appendix 3

This variability is likely driven by geography and the availability of local services, further emphasised when we look at place of death according to classification by type of place. It is notable that living in a very remote rural town or area is associated with a lower likelihood of dying in a hospice or care home, and a higher likelihood of dying in hospital (see Figure 20).

Figure 20: Place of death according to type of place of residence 2017-2021



Source: NRS deaths records for NHS Highland, see appendix 3

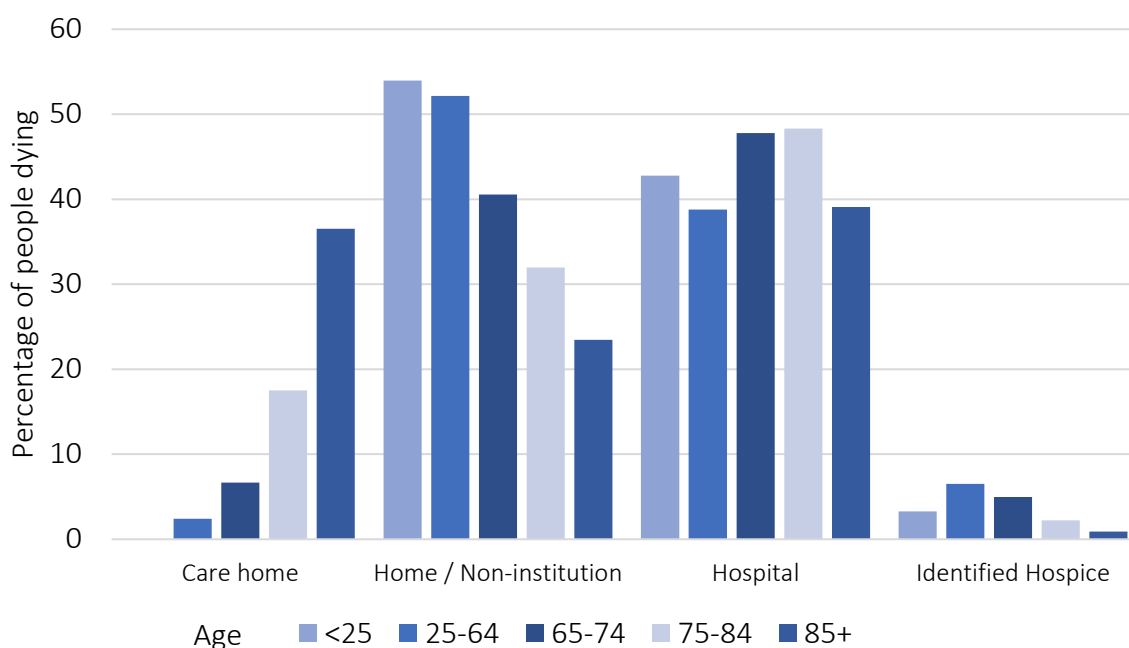
This raises two questions:

- Should the place of death be determined by proximity to services, or is this inevitable?
- More importantly, is there a difference in the outcomes experienced during the last weeks and days of life for people dying in different localities and in different settings?

See the chapter on outcomes, below.

Age is another important factor in regard to the place of death, especially whether the person dies at home or in a care home. Age seems to be less of a factor when looking at the likelihood of someone dying in hospital (see Figure 21).

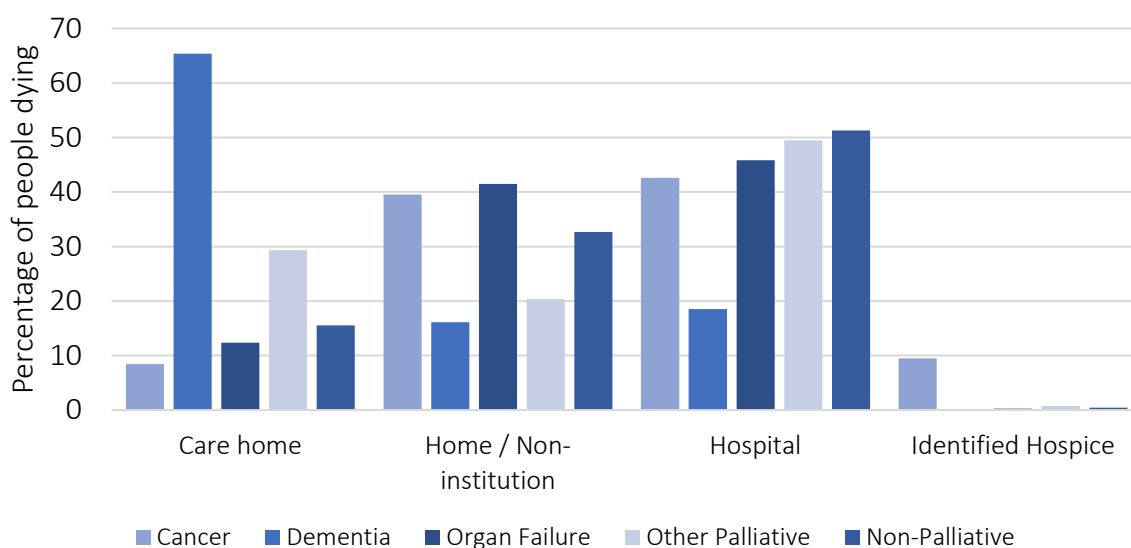
Figure 21: Place of death of NHS Highland residents by age band, 2017-2021



Source: NRS deaths records for NHS Highland, see appendix 3

Cause of death appears to impact the place of death. This is especially true where the cause of death includes dementia or 'other' conditions that would benefit from palliative care (including a proportion of people having had a stroke, neurological conditions, and HIV) where both have a higher number of people dying in care homes. Looking at deaths in hospital, there is a difference between conditions that would benefit from palliative care; there are few people dying from dementia, but people dying from cancer appear to be less likely to die in hospital than people dying of organ failure (including heart or renal failure), or people dying of 'other' conditions responsive to palliative care (see Figure 22).

Figure 22: Place of death of NHS Highland residents by cause of death (using Finucane classification) 2017-2021

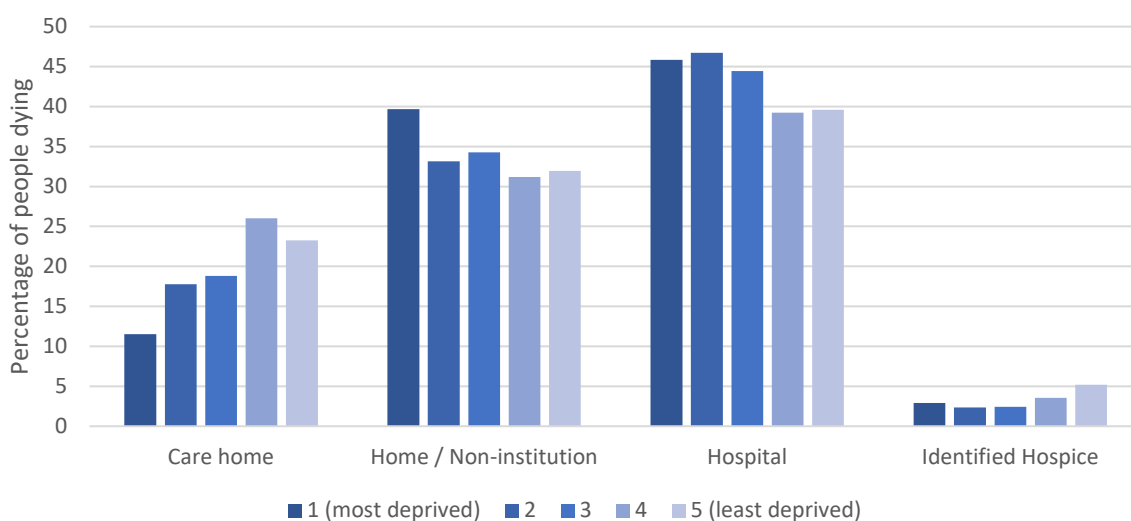


Source: NRS deaths records for NHS Highland. EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

A foundation of the NHS is that care should be equitable (fair), based on need. By looking at the deprivation status of the area in which people who die resided, we can see two associations (see Figure 23):

- First, that death in a care home is less likely if you live in a more deprived neighbourhood than if you live in a less deprived neighbourhood, and
- Second, that if you come from a deprived neighbourhood, you are more likely to die at home or in hospital than if you lived in a less deprived neighbourhood. Second, that if you come from a more deprived neighbourhood, you are more likely to die at home or in hospital than if you lived in a less deprived neighbourhood.

Figure 23: Place of death according to deprivation quintile of place of residence 2017-21



Source: NRS deaths records for NHS Highland, see appendix 3

Emergency admissions might be a good thing in the last year of life, responding to the preferences and needs of the individual, their family and carers, thus improving the quality of their last phase of life. But as we get nearer the time of death, emergency admissions could also be associated with poorer outcomes including over-medicalisation, potentially ‘futile’ care, albeit provided with the best of intentions (this was raised by focus groups in the NHS Highland- see chapter on outcomes). So, it is noteworthy that emergency admissions become more likely as you approach death in NHS Highland. In the five-year time period 2017-2021, there were nine times more emergency admissions for people in the last month of life (8172), compared to people in the first month of their last year of life (937) (see Table 1 and Figure 24). Many of these were people experiencing multiple admissions, with a 13-fold increase in multiple emergency admissions between the first months of the last year of life (65 people) and the last month (818 people - see Table 1).

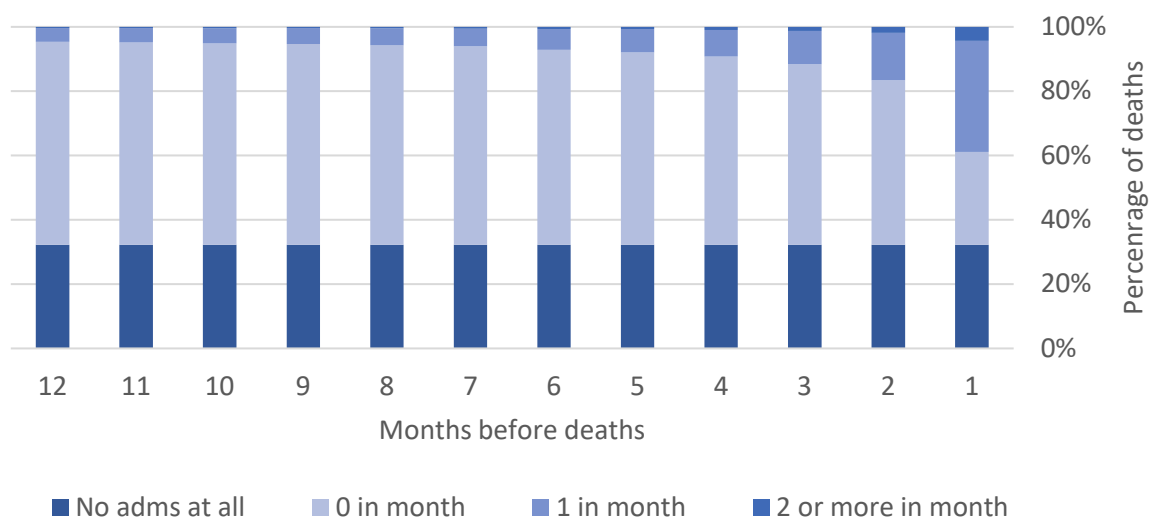
*Table 1: NHS Highland resident emergency hospital admissions by month prior to death, 2017-2021.*

Months prior to death	Number of admissions	Zero admissions that month	1 adm that month	2+ adm that month	Any admission that month
1	8172	5406	6458	818	7276
2	3486	9578	2754	350	3104
3	2428	10505	1950	227	2177
4	1929	10957	1545	180	1725
5	1634	11205	1345	132	1477
6	1459	11353	1213	116	1329
7	1240	11559	1019	104	1123
8	1169	11612	982	88	1070
9	1072	11689	925	68	993
10	1064	11718	879	85	964
11	982	11784	821	77	898
12	937	11816	801	65	866

*Source: PHS linked dataset (deaths and SMR01 admissions), based on Continuous Inpatient Stays, EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3*

Only 32% of people avoid any emergency hospital admission in the last year of life, showing what a significant feature emergency hospital care has become during the time leading up to death. As people approach death, the likelihood of an emergency hospital admission rises dramatically, with many experiencing two or more in a month. In the last month of life 40% of people will experience an emergency hospital admission (see Figure 24).

Figure 24: Percentage of people in NHS Highland experiencing emergency hospital admissions in the twelve months leading up to their death, 2017-2021

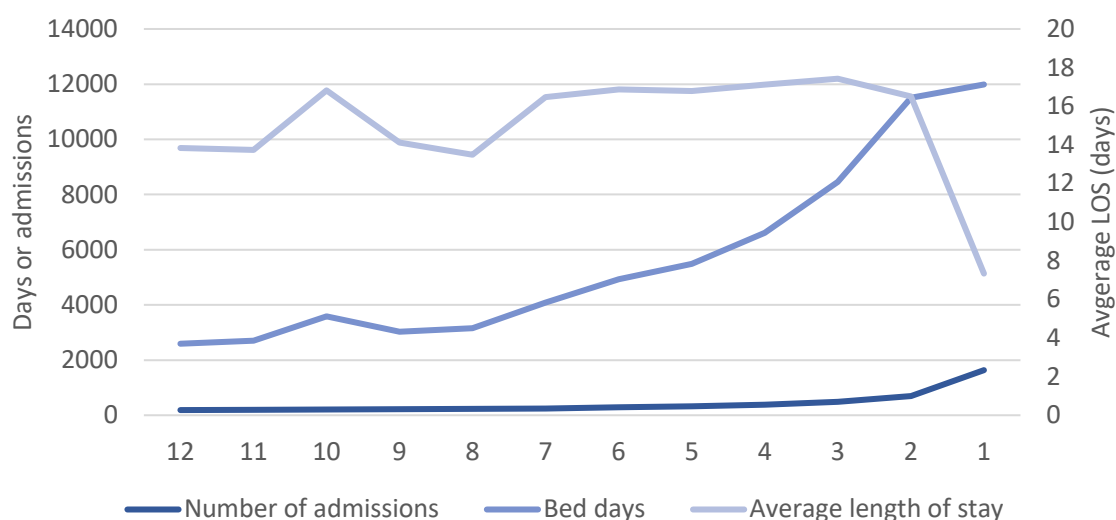


Source: PHS linked dataset (deaths and SMR01 admissions), based on Continuous Inpatient Stays, EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

Research looking at multi-morbidity and the impact it has on people dying in Scotland shows that it is highly associated with emergency hospital admissions at the end of life, albeit with fewer, but longer admissions. <sup>v</sup>

As the number of emergency admissions rise, dramatically in the last few months of life, so does the number of occupied bed days. However, the average length of stay falls dramatically in the last month of life (see Figure 25).

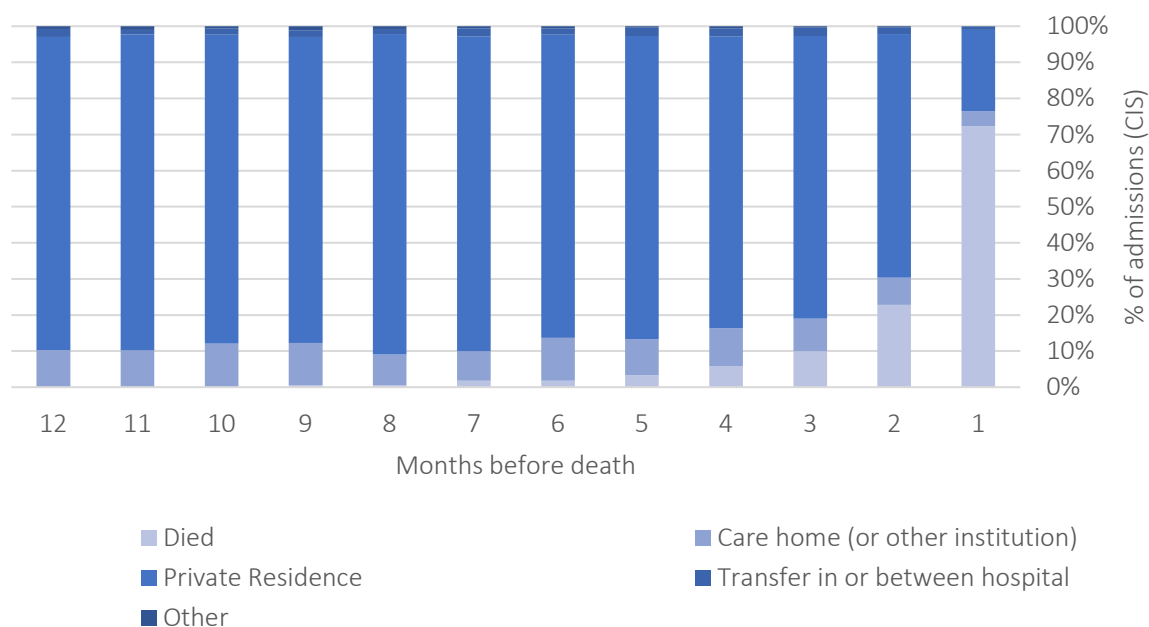
Figure 25: Occupied bed days, length of stay and number of admissions for NHS Highland usual residents in last 12 months of life by month of admission, 2017-2021



Source: PHS linked dataset (deaths and SMR01 admissions), based on Continuous Inpatient Stays, EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

The fall in length of stay could be because people are being rapidly discharged to die in their usual place of care, or because they die soon after admission. Indeed, 72% of people who have an emergency hospital admission in the last month of life die in hospital supporting the latter hypothesis (see Figure 26).

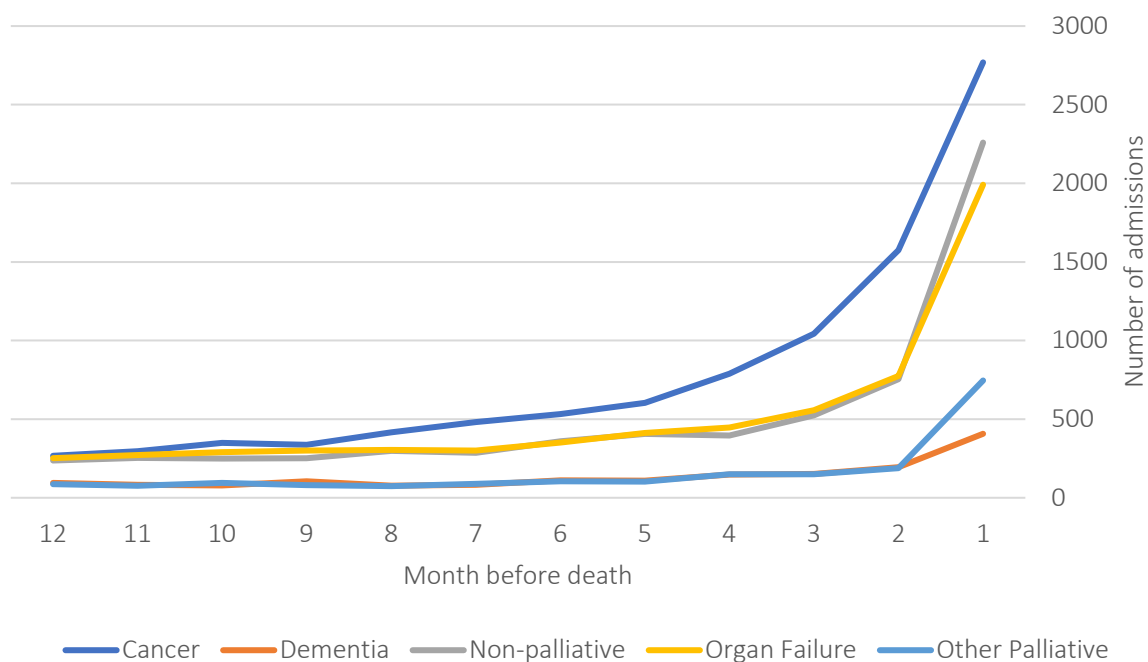
Figure 26: Outcome after emergency hospital admission for NHS Highland residents in the last year of life, 2017-2021.



Source: PHS linked dataset (deaths and SMRO1 admissions), based on Continuous Inpatient Stays, see appendix 3

When we start to look at emergency admissions by cause of death (using the Finucane grouping), we see that people dying with cancer start to have more emergency admissions from around 8 months prior to death, with a steep rise in the last 4 months before death. Note, however, that people dying of cancer are less likely to die in hospital (see Figure 22, above) supporting a discharge to die at home hypothesis. A similar pattern is seen with organ failure (e.g. heart failure) and, surprisingly, people who die from non-palliative care amenable conditions. People who die from dementia or other palliative care conditions (including neurological conditions, stroke and HIV), have a steep rise in the last month of life (see Figure 27).

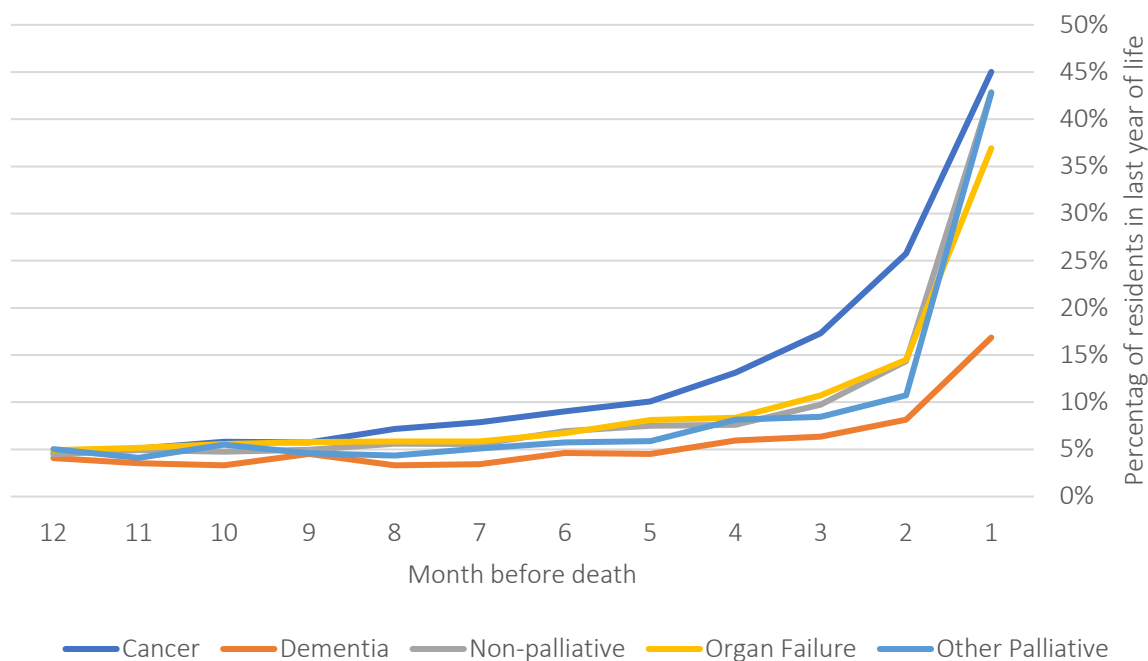
Figure 27: Number of emergency hospital admission for NHS Highland residents in the last year of life by cause of death, 2017-2021



Source: PHS linked dataset (deaths and SMR01 admissions), based on Continuous Inpatient Stays, EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

A similar pattern is seen when looking at the number of admissions as a percentage of deaths (see Figure 28).

Figure 28: Percentage of NHS Highland residents in the last year of life who experience any emergency hospital admission in the months leading to death by cause of death 2017-2021

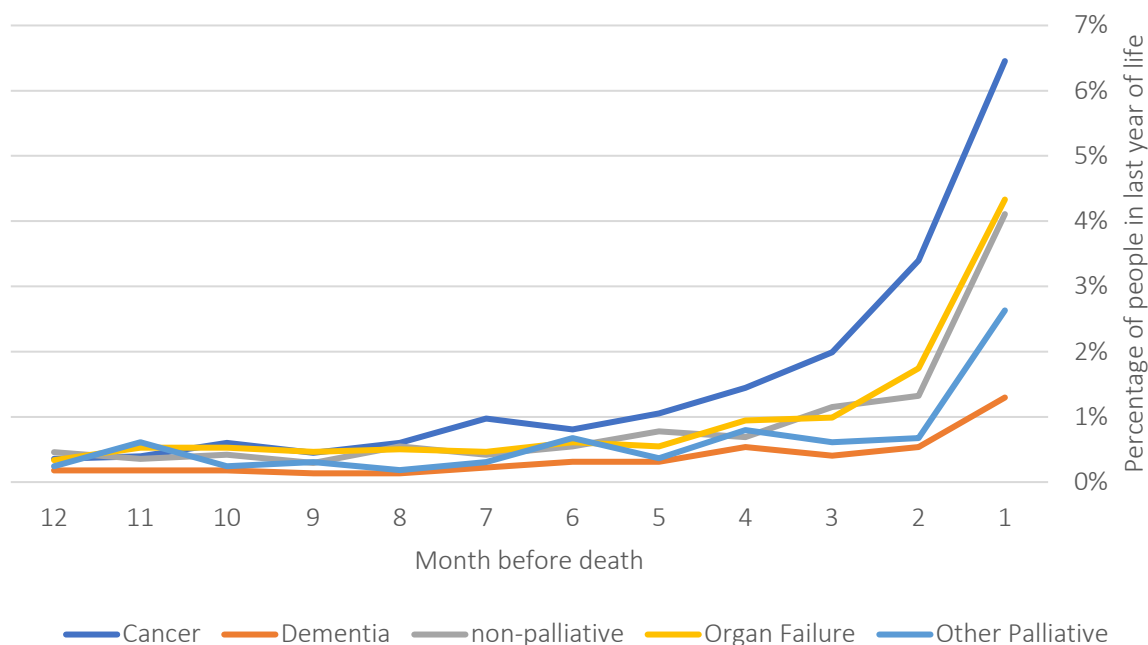


Source: PHS linked dataset (deaths and SMR01 admissions), based on Continuous Inpatient Stays, EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3



People dying with cancer in the NHS Highland have a higher chance of experiencing two or more emergency hospital admissions, followed organ failure or non-palliative care amenable conditions (see Figure 29).

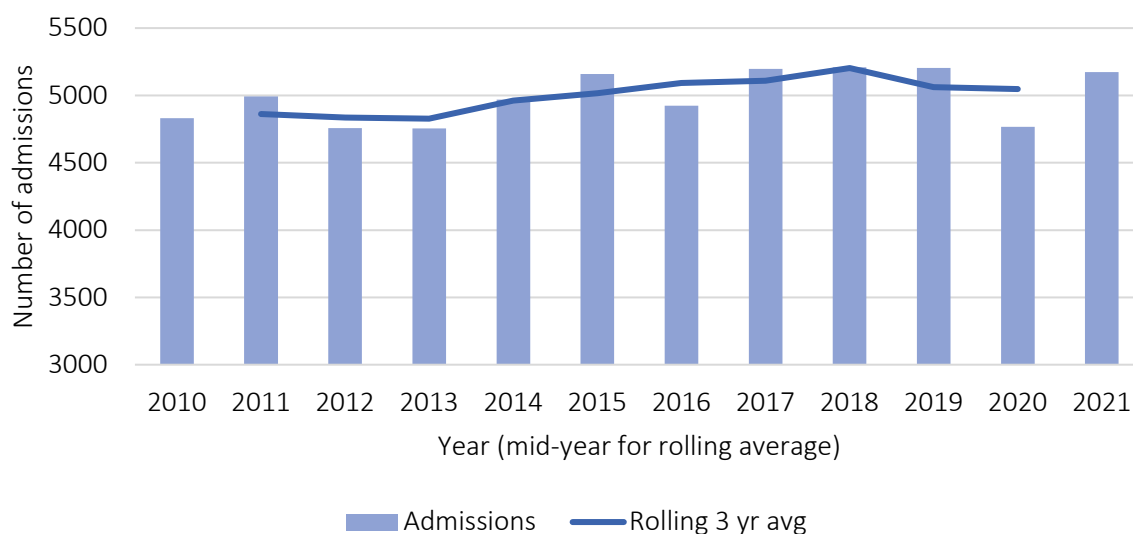
Figure 29: Percentage of NHS residents in the last year of life experiencing two or more emergency hospital admissions by cause of death 2017-2021



Source: PHS linked dataset (deaths and SMRO1 admissions), based on Continuous Inpatient Stays, EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

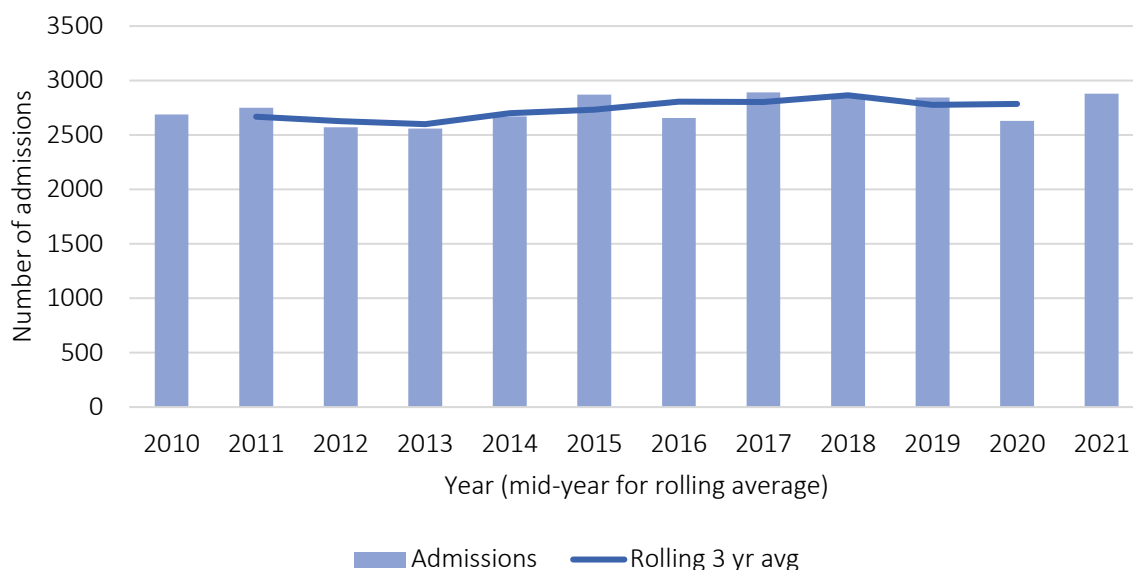
The number of emergency admissions for people in the last 12 months (see Figure 30) and the last 3 months of life (see Figure 31) have remained relatively stable between 2010 and 2021.

Figure 30: Number of emergency admissions (continuous inpatient episodes) for NHS Highland residents in the last year of life 2010-2021



Source: PHS linked dataset (deaths and SMRO1 admissions), based on Continuous Inpatient Stays, see appendix 3

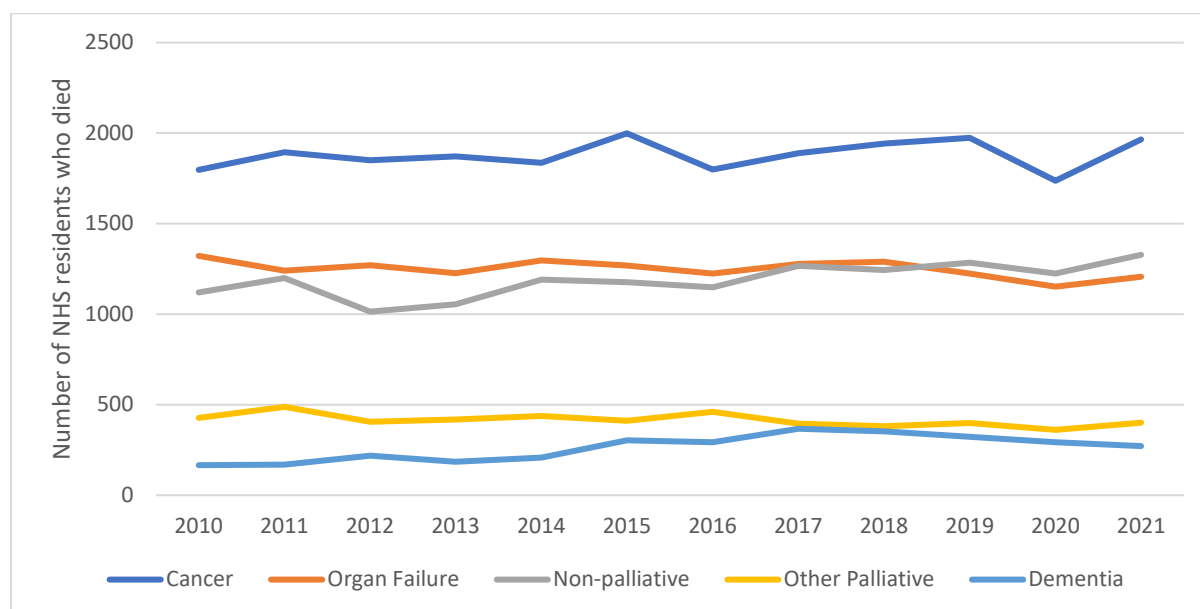
Figure 31: Number of emergency admissions for NHS Highland residents in the last three months of life 2010-2021



Source: PHS linked dataset (deaths and SMR01 admissions), based on Continuous Inpatient Stays, see appendix 3

When using the Finucane et al’s methodology to identify people dying with different palliative care needs, the same relatively stable number of emergency admissions between 2010 and 2021 is seen (see Figure 32).

Figure 32: Number of emergency admissions for NHS Highland residents in the last year of life, split using Finucane palliative care needs categories; 2010-2021

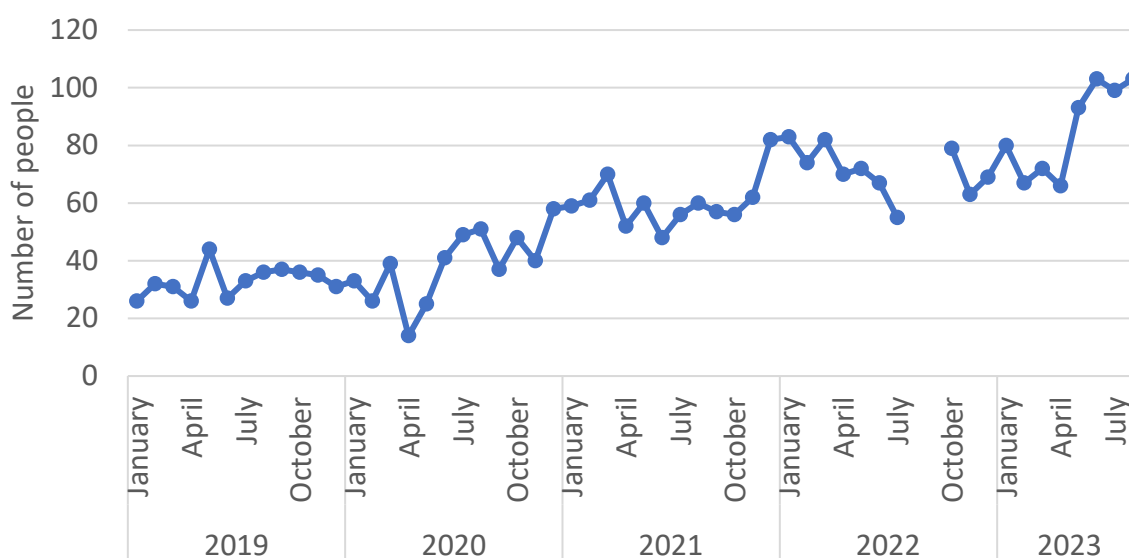


Source: PHS linked dataset (deaths and SMR01 admissions), based on Continuous Inpatient Stays, EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

## Palliative care helpline

The Palliative Care Helpline is a service for people at the end of life, family and carers (before and after the death of their loved one) and by care professionals. Between 2019 and 2023, there has been an upward trend in the use of the Palliative Care Helpline (see Figure 33).

Figure 33: Number of people who called the Palliative Care Helpline January 2019 to August 2023.



Source: NHS Highland Adatastra system. Notes: service expanded to in hours provision in May 2023 and two months data missing towards the end of 2023. See appendix 3.

## Services to support people who are bereaved.

Highland Hospice Adult Bereavement Services supports adults who have lost someone close to them. Services provided include support via phone/email/mail/text, group sessions and individual counselling which can be face-to-face, online or by phone. In 2022-23, 154 clients were supported, with 167 referrals received during the year.

Annual numbers of referrals were lower in 2020/21 and 2021/22 but have increased in 2022/23 (see Table 2)

Table 2: Number of referrals to Highland Hospice Bereavement Service, 2019/20 - 2022/23

Year	2019/20	2020/21	2021/22	2022/23
Number of referrals	124	75	79	167

Source: Highland Hospice

There are many reasons for changes in numbers of referrals. These include:

- The adult service has been gradually opened to any cause of death
- Increased awareness raising activities.
- The impact of COVID-19, and lack of face-to-face work during this time.
- The introduction of a new recording system in 2021/2022.

The number of counselling sessions provided is returning to pre pandemic levels, although the number of counsellors available in 2019/20 were higher than today (see Table 3). The service has reported an increase in the complexity of referrals and increased awareness and impact on mental health of change/loss/bereavement.

*Table 3: The number of counselling sessions provided 2019/20 - 2022/23*

Year	2019/20	2020/21	2021/22	2022/23
Number of sessions	552	335	352	490

*Source: Highland Hospice*

Most referrals to the bereavement service are from people who die and are resident in the South area of NHS Highland (59% in 2022/23), although they only account for 44% deaths. Note that numbers are relatively small and there is considerable variation from year to year in the proportion of referrals by area, particular from areas more remote from South (in the North and West, see Table 4).

*Table 4: Number and percentage of referrals by area 2022/23*

Areas	Number	Percent of all referrals	Percent of all deaths
South (Inverness, Nairn & Nairnshire, Badenoch & Strathspey)	98	59%	43%
Mid (East Ross and Mid Ross)	31	19%	21%
North (Caithness and Sutherland)	20	12%	19%
West (Skye, Lochalsh, West Ross and Lochaber)	9	5%	17%
Missing	9	5%	
<b>Total</b>	<b>167</b>	<b>100%</b>	

*Source: Highland Hospice and NRS deaths records for NHS Highland (2017-2021), see appendix 3*

# Resources used for people at the end of life

## Summary

- Many aspects of spending on the last year of life are unknown, including informal care from family and carers, social services, community nursing and core general practice.
- Of the spend we do know about, the amount spent on people who died in the financial year in question in NHS Highland has remained much the same over the period 2017-18 to 2019-20, with £44 million being spent in 2019/20.
- 68% of people experience an emergency admission in the last year of life, making it a significant feature of dying in NHS Highland.
- 71% (£31 million) of that £44 million is spent on emergency admissions.
- Bed occupancy related to emergency admissions for people at the end of life has increased from 25.2% of all emergency beds in January 2016 to 29.7% in July 2022.
- Spending on GP out of hours services for people in the last year of life increased by 18%
- Hospice charitable service spending has increased by 27% over the period 2017-18 to 2019-20 (in line with 23% increase of inpatient activity, and 124% increase in outpatient hospice activity).
- A large number of people in Highland Council receive social care support (at home or in a care home) at the time of their death.

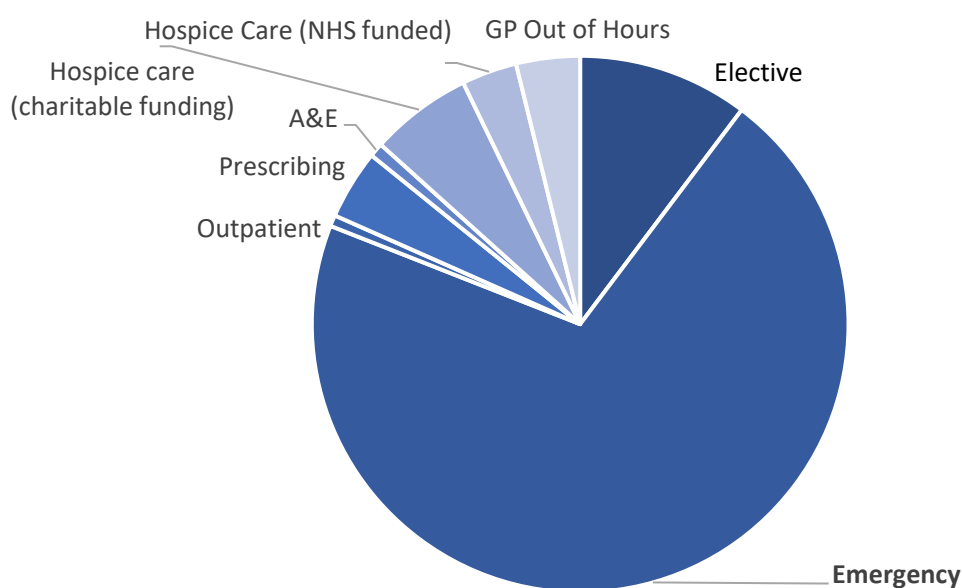
Calculating how financial resources were used is complex, chiefly because for large parts of the health service in NHS Highland (and elsewhere) it is difficult to calculate the resources deployed on people in the last year of life (in general practice for instance). Most costing effort occurs in acute hospitals where most of the NHS spend is. Although even then it is not always classified by population group. In community and primary care settings, where 90% of NHS activity occurs, costing activity is generally rudimentary.

Decisions whether it is cheaper (and possibly better value) for someone to die out of hospital are not so simple. First, we do not have data relating to the outcome that matter for people dying and for their families and carers allowing us to compare the quality of the end of life in different settings. Second, in 2018-19 the reported costs of a general hospital, such as Caithness General is £2,238 per inpatient case treated, whereas the largest community hospital, Mid-Argyll, costs £11,457 per case (note this is the average costs for all cases, not just end of life and includes a large mental health ward- source PHS). There may be many good clinical reasons for this such as the provision of long-term rehabilitation. However, it

should not be assumed that dying out of a larger general hospital is always ‘cheaper’ because costing data is largely institution based, rather than based on condition or problem making it easier to understand productivity than efficiency. <sup>1</sup>

In 2019-2020, the total spend on people who died in that financial year (FY) was at least £44,380,798.<sup>2</sup> Note that this does not include spend on informal care (e.g. from family and carers), social care packages nor on daytime general practice care but does include out of hours general practice care. Of the costs we do know about, they can be further broken down as shown in Figure 34.

Figure 34: Split of £44.4 million spent on NHS Highland residents who died in 2019-20



Source: PHS and Highland Hospice. Note many costs are not included, e.g. core general practice, community nursing, social care, informal care.<sup>3</sup> .See appendix 3

These patterns of spending have stayed roughly the same for NHS funded hospice services over recent years (the exception is GP out of hours where there has been an 18% increase in

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<sup>1</sup> Source: ISD Scotland - Public Health Scotland <https://www.isdscotland.org/Health-Topics/Finance/Costs/Detailed-Tables/index.asp#Hospital-Sector>

<sup>2</sup> Highland Hospice data based on activity in the year specified. Public Health Scotland data based on service use in that year by NHS Highland residents who died in the specified year. See Appendix 3 for further details of calculations of costs.

2019/20 compared to 2017/18)<sup>3</sup>, and the spend on charitably funded hospice services has increased by 27% (see Table 5).

*Table 5: Costs of providing care to NHS Highland residents who died in 2017-18, 2019-20 and share of costs as a percentage of total.*

Service area	2017/18		2018/19		2019/20	
Elective	£4,517,072	10%	£4,497,326	11%	£4,564,138	10%
Emergency	£31,630,391	72%	£30,096,125	71%	£31,369,168	71%
Outpatient	£299,961	1%	£277,841	1%	£298,314	1%
Prescribing	£1,968,584	4%	£1,871,649	4%	£1,858,716	4%
A&E	£362,685	1%	£343,930	1%	£374,453	1%
Hospice care (charitable funded)	£2,156,390	5%	£2,433,793	6%	£2,730,041	6%
Hospice Care (NHS funded)	£1,430,700	3%	£1,436,420	3%	£1,479,513	3%
GP Out of Hours <sup>3</sup>	£1,447,330	3%	£1,392,715	3%	£1,706,455	4%
<b>Total estimated spend</b>	<b>£43,813,114</b>	<b>100%</b>	<b>£42,349,799</b>	<b>100%</b>	<b>£44,380,798</b>	<b>100%</b>

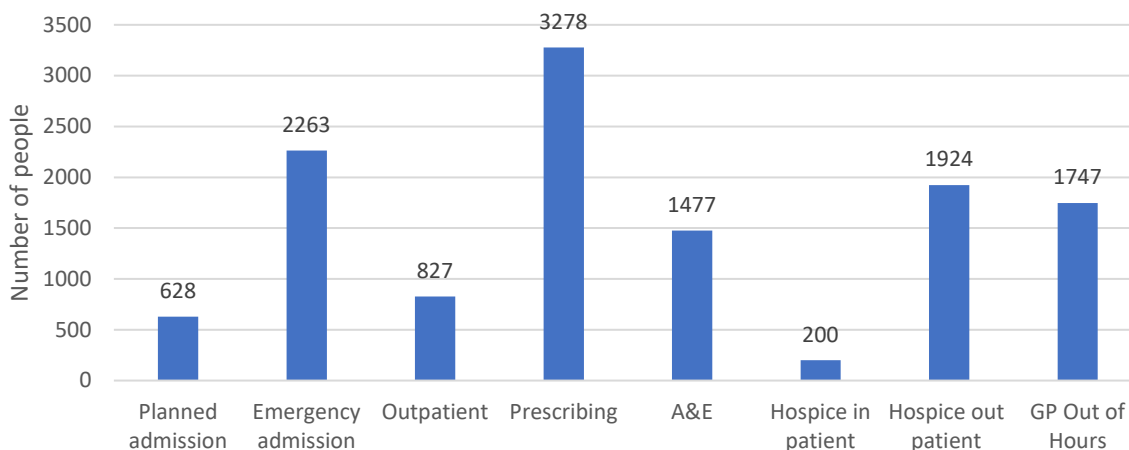
*Source: PHS and Highland Hospice, see appendix 3\* See footnote 3.*

Looking at NHS Highland residents who died in 2019-20 in, we can see which services they accessed (see Figure 35).

*Figure 35: Number of NHS Highland residents who died and accessed end of life services in 2019-20*

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<sup>3</sup> PHS caution that their data on GP out of hours are based on rough estimates and this apparent increase may not represent a real increase in cost



Source: PHS and Highland Hospice, see appendix 3

The pattern of service usage for people at the end of life has not changed for NHS services in recent years. But there has been a large increase in use of hospice services accounting for the increase in charitable hospice spending (23% increase in inpatient admissions and 124% increase in outpatient attendances – see Table 6).

Table 6: Use of services by people in the last year of life 2017-20

Service area	2017/18	2018/19	2019/20
Planned admission	615	613	628
Emergency admission	2235	2203	2263
Outpatient	844	766	827
Prescribing	3248	3147	3278
A&E	1482	1405	1477
Hospice inpatient	163	196	200
Hospice outpatient	857	1238	1924
GP Out of Hours	1864	1689	1747

Source: PHS and Highland Hospice, see appendix 3

Almost all NHS Highland residents who died in the FY in question received a prescription. What is apparent is the relative dominance of emergency admissions as a resource used in the last year of life. 68% of NHS residents who died in 2020-21 experience at least one emergency admission<sup>4</sup>, and the cost of emergency admissions, as a proportion of the total

<sup>4</sup> Source: PHS linked dataset (deaths and SMR01 admissions), based on Continuous Inpatient Stays, EoL causes of death defined using underlying cause of death codes as in Finucane et al. 2021, see appendix 3

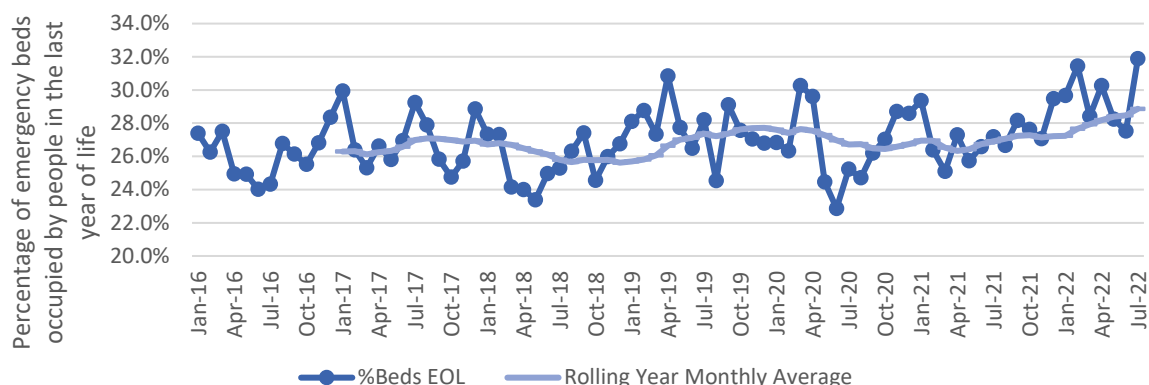


cost of care in the last year of life is 71% (£31.4 million out of £44.4 million). This should be compared to:

- >55% of people accessing hospice services for 9.5% of the total spend.
- 51% of NHS Highland residents accessing GP out of hours services who died in 2019-20, accounting for 4% of the total spend.

This high proportion of resources used on emergency admissions of people in the last year of life means that they use a large proportion of emergency beds in NHS Highland acute hospitals. This proportion has increased slightly from 27.4% of all emergency beds in January 2016 to 31.9% in July 2022 (or an increase in the 12-month rolling average from 26.3% to 28.9% of all emergency beds occupied by people in the last year of life – see Figure 36).

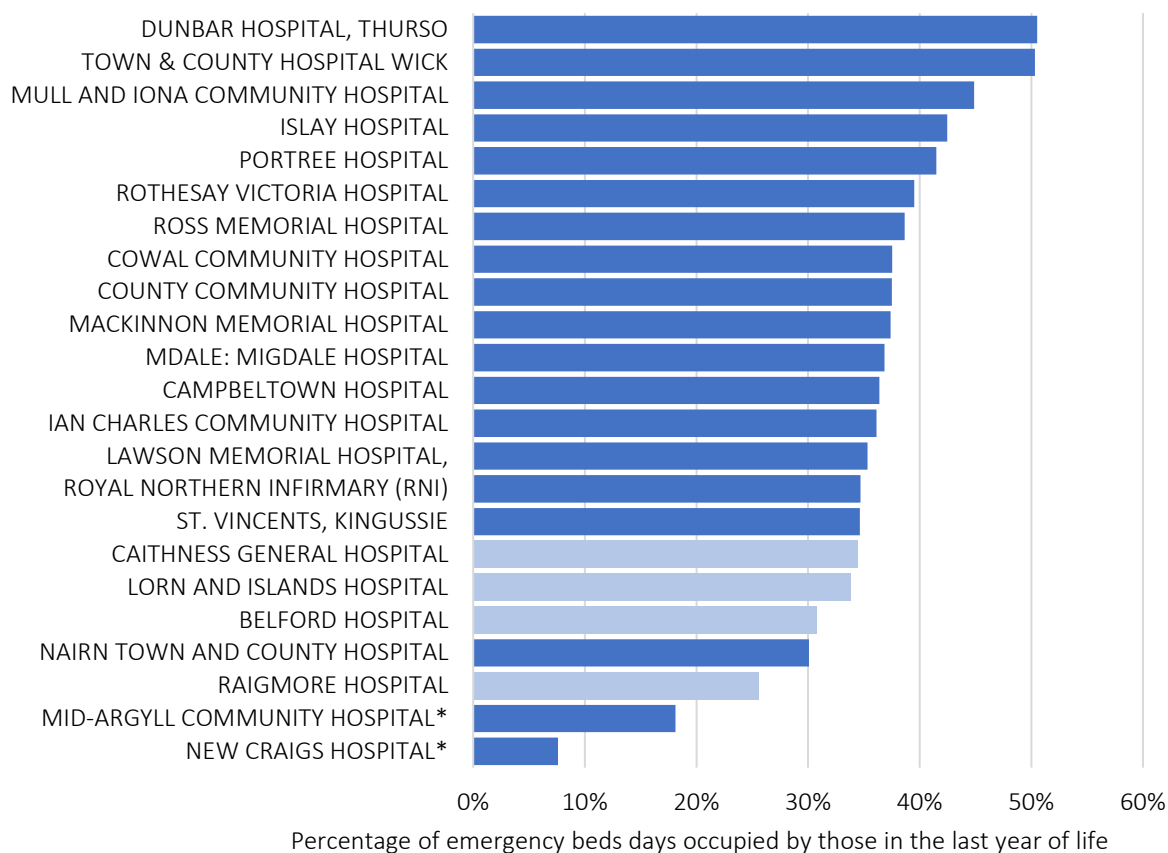
Figure 36: Acute NHS Highland Hospitals % Emergency Beds Occupied by Patients in the Last Year of Life Jan-16 to Jul-22



Source: NHS Highland hospital data and PHS deaths data, see appendix 3. Note that y-axis starts from 20%.

When we look at the emergency bed occupancy for acute and community hospitals in NHS Highland, the large proportion of people at the end of life is clear, but the large variation in emergency bed use for people at the end of life between community hospitals is also evident (from 30-51%, if we compare similar community hospitals – see Figure 37).

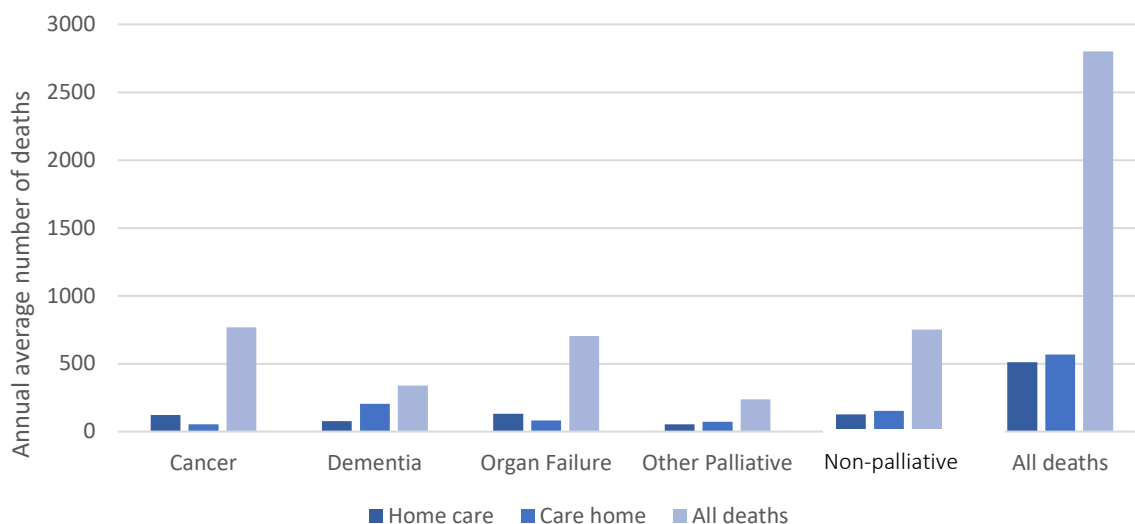
Figure 37: Average monthly percentage of emergency beds occupied by people in the last 12 months of life, 2019-2021



Source: NHS Highland hospital data and PHS deaths data, see appendix 3. \*These two hospitals have mental health specialities and this likely results in a higher proportion of emergency bed use by those not in the last year of life. Acute hospitals are shown in lighter blue.

We do not have cost or spend data for social care but do know that a large number of Highland Council residents at the end of life receive social care support such as home care of assisted care home placements (see Figure 38).

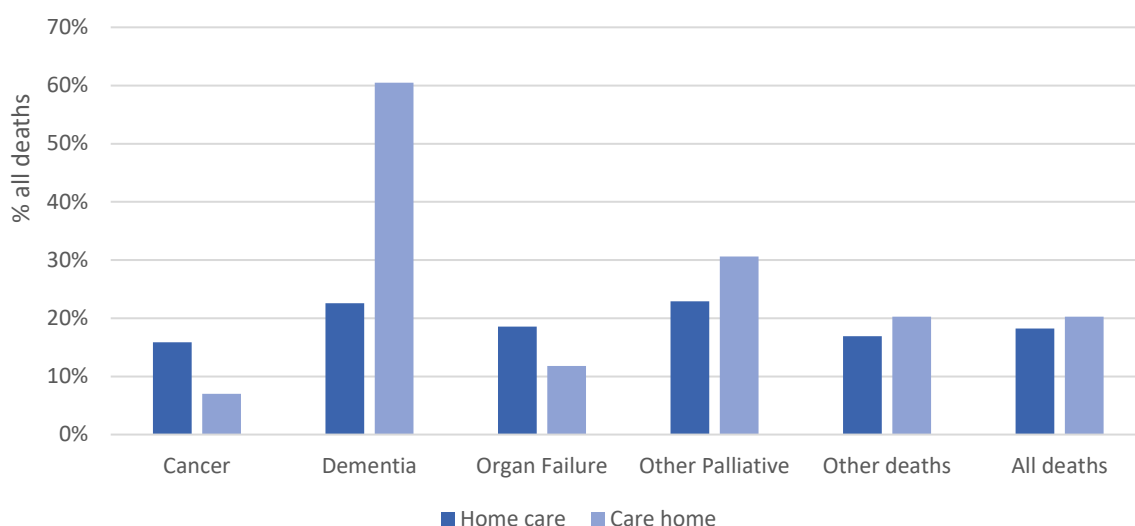
Figure 38: Number of people resident in Highland Council receiving social care support at the time of death, 2020/21-2022/23



Source: NHS Highland Social Care data and NRS deaths records for NHS Highland, see appendix 3

As a percentage of all deaths of Highland Council residents, people dying with dementia are most likely to receive social care support, possibly because they start to receive social care support before entering a terminal phase (see Figure 39).

Figure 39: Percentage of Highland Council residents dying of different conditions who are receiving social care support at the time of death, 2020/21-2022/23



Source: NHS Highland Social Care data and NRS deaths records for NHS Highland, see appendix 3

## Outcomes for people at end of life

In recent years, there has been a strong emphasis on putting in place processes likely to improve outcomes, including supporting people to die out of hospital, advanced care planning and anticipatory prescribing. But none of these guarantee a high-quality end of life. Indeed, the significant role of emergency admissions in the last year of life should raise concerns. Routine data on the quality of people's death is found wanting; at present we are not measuring what matters, but we have plans for that to change.

Focus groups were conducted with representatives of the Highland Senior Citizen's Network, Highland Hospice Women's Group and Connecting Carers.

Positive activities that these groups believed improved outcomes at the end of life included:

- Peer to peer support was invaluable for many people at the end of life.
- Having information that is particular to the individual, especially if it helped to make choices.
- Continuing to live life freely because the clinician respected the importance of what mattered to me.
- Being respected, heard and consulted.
- Being communicated with sympathetically, empathetically, and honestly.
- Knowing how to access support.
- Connecting Carers, Advocacy Service and Marie Curie gave great support.

Activities that could be improved to gain better end of life outcomes included:

- Communication: this was seen as a major issue for all the groups consulted. Professionals were not felt to be raising the topic of someone being at the end of life. More honest conversations were wanted.
- Over-treatment: some groups felt that treatment was continued beyond the point it was providing benefit to the quality of life of someone at the end of life.
- Lack of respect: an assumption that the professional knows best.
- Support for families: there were many ways in which families could experience a better outcome if they received more support. From the practical elements like power of attorney and making a will, through to support in navigating services and getting support (especially out of hours). The burden on families is not sufficiently recognised.

Whilst some of these activities might be considered outcomes (e.g. being respected), not all of these activities can be considered as outcomes. Many are an expression of the processes that underlies the outcomes that matter to people at the end of life, and the families and carers.

To that end, and informed by work in North East Essex, the End of Life Together oversight board has agreed to adopt a set of outcomes that matter. These will drive all the efforts we make, including how resources are used, to maximise value at the end of life (see Table 7: Ten outcomes that matter for people at the end of life (and the families and carers) in NHS Highland).

*Table 7: Ten outcomes that matter for people at the end of life (and the families and carers) in NHS Highland*

Planning
1. That it was recognised that I was in the last year of life in a timely manner
2. I was informed that I was in the last year of my life in a sensitive and honest manner
3. My preferences for where I wish to be cared for towards and at end of life were discussed and recorded
4. My care preferences are written into care plans that are accessible to everyone involved in the delivery of my care
Delivery
5. My care plan preferences were respected and considered during the last year of my life
6. That my family member, or person I was supporting at end of life was treated with compassion, dignity and empathy
7. That my family member, or person I was supporting at end of life had their pain and symptoms addressed controlled and managed
8. That I was only given medical treatment or admitted to hospital where necessary and for shortest duration possible
9. I/ my family /carer receive access to palliative care services where required during the day and at night
10. As a family member or carer supporting an individual during and after their end of life I felt supported by the services involved

The degree to which we are achieving these outcomes will be captured in a dashboard derived from a set of measures that inform us how the outcomes are achieved. The full set of measures, associated actions and narrative are shown in appendix 1. Many outcomes can only be measured by directly asking the individual, their families or carers, although technology can be used to facilitate this process. It should be noted that other measures are

often only proxies for the outcomes and as such need to be interpreted in context, often alongside other sources of knowledge (see Figure 40, page 50).

Combining this dashboard alongside measures of resource used (notably spend) will allow the End of Life Together team to measure progress in improving value.

## Conclusions

Whilst this report contains many lessons for us to improve the support we provide to people at the end of life, there are some conclusions that seemed to stand out to us in the End of Life Together Board.

### **People who die in NHS Highland possibly experience inequities, especially from the impact of rurality and accessibility.**

There are differences in the care people receive, where they die, or whether they experience an emergency admission. These differences are found when we look at age of death, the level of deprivation of where the individual live and what they die from. But perhaps the starkest are the differences seen between neighbourhoods with different levels of rurality and accessibility. There is a limit to what that can be done to create structural equity in a rural health board (that is provide the same facilities in all areas); this in turn means there are limited opportunities to mitigate differences in the processes of end-of-life care support (e.g. where you die) although some processes, such as helplines, should be geographically agnostic.

### **We are not systematically identifying NHS Highland residents at the end of their life, nor are we capturing or sharing their preferences in order to be able to fulfil them**

We know from our focus groups that NHS Highland residents in general seeking lower cost activities to provide them with better outcomes. Indeed, they explicitly do not want intensive medical input. But there is gap between the number of people who die from conditions that would benefit from end-of-life support, and the number that is identified and their preferences documented. Worse still, when we do identify them, we are not sharing those preferences, making fulfilling them unduly difficult.

### **We do not know the outcomes people in NHS Highland experience at the end-of-life**

This is chiefly because we do not have a set of agreed outcomes that are important to people at the end of life, and hence we are not measuring them. This is important for many reasons, including the ability to know if changes we make are leading to improved outcomes and because, given we have limited ability to change structural and process aspects of end-of-life support, we should at the very least strive for equity in outcomes at the end of life.

### **The number of people who would benefit from end-of-life support is increasing, and the causes and the age of death are changing**

The number of people in NHS Highland who would benefit from end-of-life support is predicted to increase, and they are more likely to die at an older age with complex co-morbidities, including dementia. This increase in need is likely to outstrip resources, so we need to take action to provide high value pro-active end of life care, so as to avoid the system being over-whelmed by demand for reactive care.

## **Emergency hospital admissions are a major feature as people in NHS Highland approach death- reflected in the way resources are used**

It is notable how many people in NHS Highland experience one or more emergency hospital admissions as they approach death. Whilst many emergency hospital admissions lead to a better outcome for the individual, many may not, and it is likely that many could be avoided altogether. However, we have a system that does not ration “lower value” reactive care, and yet rations “higher value” proactive support for end-of life care. As an End-of-Life Care Together Board, and system, we need to find ways to reverse that tendency and shift the investment to higher value, often lower cost, care, leading to better outcomes.



## Value opportunities – key actions

As outlined in the introduction, value is subjective, so value improvement is likewise subjective. So, our aims for people at the end-of-life in NHS Highland, and their family and carers, is based on those developed by the EU and adopted by the G20 group of nations<sup>2</sup>:

- To increase the equity or fairness of outcomes from end-of-life support in NHS Highland, based on need (allocative value),
- To improve the experience at the end of life for the dying individual in NHS Highland and the family and carers by meeting their goals (personal value),
- To use the resources that we have available for end-of-life support in NHS Highland as efficiently as possible (technical value)
- And in doing so, benefiting society in Highland, Argyll and Bute.

As the Chief Medical Officer, Professor Sir Gregor Smith, says in his action plan for Value Based Health and Care:

*“Working collaboratively across traditional health and social care boundaries, utilising the skills and expertise of multidisciplinary professional groups will help us to deliver Value Based Health and Care centred on what matters to the people in our care.”<sup>i</sup>*

Arguably, this exhortation is nowhere more important than when providing support for people at the end-of-life. One challenge, which we will find the means to overcome, is how can we move resources across those health and social care boundaries, so they are used in higher value end of life support, as opposed to staying within institutional budgets, possibly on lower value (often higher cost) activities?

With that challenge in mind, there are four key actions that we, as the End-of-Life Together Board want to take:

- Build a movement for change by communicating the findings of this report, in an appropriate format, within the NHS and wider, including with the public.
- Identify people at the end-of-life, listen to them and share their preferences so we can fulfil them.
- Take our agreed outcomes, measure them, and reflect and act on them on a regular basis to enable us to track improvements in value.
- Trial a rolling series of projects to impact the number of emergency hospital admissions, whilst better fulfilling people’s end of life preferences, reducing possible inequities of outcomes and better use resources.

### **Build a movement for change**

To better prepare ourselves for the growing need for support at the end of life for NHS Highland residents, and address many of the issues we already have (like possible inequity

and an over reliance on reactive care), it is important that we start to build a movement for change. This should be in appropriate formats, and shared across the NHS, the care sector and with the public (notably those at the end of life and their family and carers). It is important for us to build a common understanding of the issues and actions that people at the end-of-life face in NHS Highland.

**Identify people at the end-of-life, listen to them and share their preferences so we can fulfil them.**

We should improve the identification of NHS Highland residents who are at the end-of-life. This will require awareness training and skills development, alongside feedback and sharing of successful practice between care providers. It is likely this will need to focus on general practice and care homes but might also include those in secondary care likely to see people at the end of life, especially treating conditions where we might suspect identification is lower than expected (e.g. cardiology, respiratory, neurology, care of the elderly).

**Use our agreed outcomes that matter and measure them on a regular basis to support value improvement activities.**

It is important that we know if we are improving value for people at the end of life, because whilst all improvements are a change, not all changes are an improvement. We can only do by starting to measure our agreed set of outcomes that matter at the end-of-life.

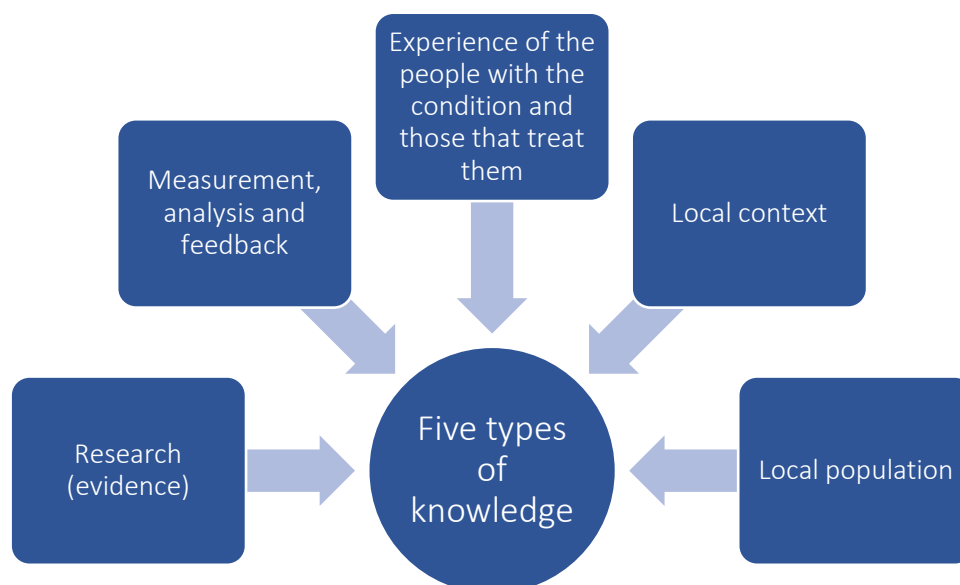
Within the measures, we need to include our use of resources, the combination of a measuring outcomes and resources providing a value-based health and care dashboard. We should also improve our use of data from sectors that are under-represented in this report, such as general practice, social care and community data.

**Trial a rolling series of projects to impact the number of emergency hospital admissions, whilst better fulfilling people's end of life preferences and reducing possible inequities of outcomes.**

Combining the dashboard with four additional aspects of knowledge (research evidence; local user and carer experience; understanding of the population; and understanding of the local circumstances) we should undertake a series of improvement cycles to systematically improve our use of resources to improve outcomes.

What we will do will be informed by all five types of knowledge (see figure 40) - it is possible that what is done in one community, such as Inverness, might differ from what is done in another, such as Bute, in order to improve the equity of outcomes. As with all continuous improvement approaches, a rapid review of a sample of recent emergency admissions, combined with the experience of people at the end of life (and their family and carers) and frontline care givers, will provide sufficiently robust hypotheses for testing regarding the cause of, and mitigating actions to reduce, emergency hospital admissions at the end of life.

Figure 40: Five types of knowledge needed for value improvement.



Source: Gray, M., Airoidi, M., Bevan, G., & McCulloch, P. (2017). *Deriving optimal value from each system.vii*

Initially, to free resources, these improvement cycles, continuous value improvement (CVI), should focus on ways to reduce emergency hospital admissions. It is highly likely, from what we learnt in our focus groups that the means to reduce admissions will be low cost and high value. As the early identification, recoding, sharing, and fulfilling of preferences is likely to be a key aspect of reducing emergency admissions, the improvement cycles might also test the best way to improve this action. As with all improvement cycles, it will be key to:

- Maximise learning between different projects seeking to improve the same outcomes
- Amend, or ultimately stop, projects that are ineffective (or less effective than they might have been)
- Roll out approaches that have been shown to make an improvement and are likely to be appropriate in different settings.

Whilst these improvement cycles might require some limited seed funding to get started, as they succeed, they will increase our confidence that they will indeed reduce admissions, freeing resources. At this point we need to find a system answer to moving resources between our institutions. Experience has shown that withdrawing resources from institutions is almost impossible, especially if they are already doing more activity than their budget allows (i.e. overspent). Some systems have successfully negotiated a means by which, in return for desired changes in activity, institutions providing reactive care receive a smaller amount of growth monies than they might have expected, whereas institutions providing proactive care receive more growth monies. This requires agreement on a baseline, trends and what to do in the case of unexpected events (e.g. pandemics). Over time these small adjustments in funding will compound to make large shifts in resource use.

## Appendix 1 - Outcomes that matter, actions, measures and narrative

This is the full table containing the outcomes that matter and associated actions and means of measuring the outcomes. It has been approved by the End of Life Together oversight board. The intention is to turn this table into a dashboard to enable NHS Highland end of life support team to improve these outcomes.

Outcomes that matter	Action	Measures	Narrative
1. That it was recognised that I was in the last year of life in a timely manner	To identify and recognise people in the last 12 months of life	Stage 1 % of practice populations on General Practice (pre) palliative care register N. people recorded as being palliative after death by GP practice who may have benefited from earlier identification	Individual / Family Carer-Survey / Focus group Did people feel they were identified as being in the last phase of life soon enough were there any earlier triggers or points of health care
		Stage 2 % of people with a Highland electronic Anticipatory Care Plan (eACP) (N.) (%) people recorded as being palliative after death by GP practice who may have benefited from identification	contact that this could have been ascertained (Individual/Family/Carer

Outcomes that matter	Action	Measures	Narrative
<p>2. I was informed that I was in the last year of my life in a sensitive and honest manner</p>	<p>To inform people thought to be in their last year of life and their families the likelihood of death within the next 12 months sensitively and honestly</p>		<p>GP Identification of specific groups that are being identified retrospectively and who have not been on palliative care registers</p> <p>Individual / Family Carer-Survey / Focus group were conversations sensitive and honest (individual / Family / carer</p> <p>Reporting of feedback from 3rd sector partners</p>
<p>3. My preferences for where I wish to be cared for towards and at end of life were discussed and recorded</p>	<p>To elicit and record people's preferences for care and place of death during the last 12 months of life</p>	<p>Stage1</p> <p>% of people at death with a Key Information Summary (KIS) with preferred place of care recorded</p> <p>% of people at death with a KIS with preferred place of death recorded</p> <p>Report on numbers of those without these preferences recorded</p>	<p>Individual / Family Carer-Survey / Focus group</p> <p>Were care preferences discussed and did people feel that the information they were provided was clear enough to help them make these preferences in an</p>

Outcomes that matter	Action	Measures	Narrative
		<ul style="list-style-type: none"> <li>- GP Data</li> <li>- Coordination / Enhanced</li> <li>- Enhanced Palliative Care Helpline (EPCH)</li> </ul> <hr/> <p>Stage 2</p> <ul style="list-style-type: none"> <li>% of people at death with a Highland eACP stating preferred place of care</li> <li>% of people at death with a Highland eACP stating preferred place of death</li> <li>Report on numbers of those without these preferences recorded</li> <li>- GP Data</li> <li>- Coordination / EPCH -</li> <li>% of people who have a 'What matters to me' completed on Highland eACP</li> </ul>	informed manner
4. My care preferences are written into care plans that are accessible to everyone involved in the delivery of my	To ensure people's preferences for care and place of death are accessible to all parts of	<p>Stage 1</p> <ul style="list-style-type: none"> <li>% of practices signed up to End of Life Care Together</li> <li>% of patients with a KIS with 4-6 criteria met</li> </ul>	Individual / Family Carer-Survey / Focus group were all professionals involved in care delivery able to access a

Outcomes that matter	Action	Measures	Narrative
care	the health and social care system/end-of-life-care system and that people can record or view their own preferences	<p>Stage 2</p> <ul style="list-style-type: none"> <li>% of people on Highland ACP</li> <li>% of Care Homes with access to Highland eACP</li> <li>Number of organisations across health and social care with access to Highland eACP</li> <li>% of people with digital access to their own care plans</li> <li>% of carers with access to digital care plans of the individual with terminal illness and of their own individual care plan</li> <li>Number of times staff from different organisations access the eACP</li> </ul>	common care plan without the need to repeat this information
5. My care plan preferences where respected and considered during the last year of my life	To respect people's preferences for care during the last 12 months of their life	<p>Stage1</p> <ul style="list-style-type: none"> <li>% of people at death with a KIS stating preference for care that achieve this preference</li> <li>% of people at death with a KIS stating preference for place of death that achieve this</li> </ul>	Individual / Family Carer-Survey / Focus group were preferences met and if not can they express why not

Outcomes that matter	Action	Measures	Narrative
		<p>preference</p> <p>% of KIS updated in the last 3 months</p> <p>(N.) (%) people recorded as being palliative after death by GP practice who may have benefited from identification care planning</p>	
		<p>Stage 2</p> <p>% of people at death with a Highland ACP stating preferred place of care that achieve this preference</p> <p>% of people at death with a Highland ACP stating preferred place of death</p> <p>% of Highland ACP updated in the last 3 months</p> <p>(N.) (%) people recorded as being palliative after death by GP practice who may have benefited from identification</p>	
<p>6. That my family member, or person I was supporting at end of life was treated with compassion, dignity and empathy</p>	<p>To treat people at end of life as individuals, with dignity, compassion and empathy</p>		<p>Individual / Family Carer-Survey</p> <p>Did the family or carer feel that their loved one or person they were supporting were</p>



Outcomes that matter	Action	Measures	Narrative
			<p>treated with dignity, compassion and empathy</p> <p>Work with 3rd sector partners to identify delivery of this through their members</p>
<p>7. That my family member, or person I was supporting at end of life had their pain and symptoms addressed controlled and managed</p>	<p>To control pain and manage symptoms for people during the last 12 months of life</p>	<p>Attributed calls resolved through Coordination and ePCH service coded as symptom management</p> <p>Numbers of people on palliative care registers (ST1) or with Highland Anticipatory Care Plan (ST2) with electronic anticipatory prescribing in place at end of life</p> <p>Contacts with coordination service / EPCH logged as symptom control</p> <p>(N.) (%) of people with anticipatory medications contacting Coordination or EPCH</p>	<p>Individual / Family Carer-Survey</p> <p>Did the family or carer feel that concerns around pain and other symptoms were considered addressed and controlled if not why</p>
<p>8. That I was only given medical treatment or admitted to hospital where necessary and for shortest</p>	<p>To minimise inappropriate, unnecessary and futile medical intervention</p>	<p>Reduction in the % of beds days in Highland in the last 6 / 3 / 1 months of life (mindful of COVID effect)</p>	<p>Individual / Family Carer-Survey</p> <p>Was it felt that medical</p>

Outcomes that matter	Action	Measures	Narrative
duration possible	during the last 12 months of people's life	<p>Reduction in the % of unscheduled admissions in the last 6 /3 / 1 months of life (mindful of COVID)</p> <p>% of Deaths that Occur in Hospital / % of people that have hospital as their preferred place of care / death</p> <p>N. Delayed discharges logged through acute hospital for those identified as being in last year of life</p> <p>Median admissions / length of stay in last year of life</p> <p>% of people admitted in last 6/3/1 month of life</p> <p>% of people with &gt;3 admissions in last 3 months of life</p> <p>Readmission rates</p> <p>% of people referred to coordination hub for at home care who are unable to receive this care</p> <p>% of people who then go on to have a hospital admission within 7 days of this request</p>	interventions or admission may have been futile or unnecessary in the last year of life if so why was this the case
9. I/ my family/ carer receive access to palliative care	To ensure that people at end of life have access	% of people in institutional care due to lack of access to care whether through admission or	Case study feedback on access to services

Outcomes that matter	Action	Measures	Narrative
services where required during the day and at night	to flexible 24/7 end-of-life care services irrespective of the place of care or the organisation/s providing care	delay in discharge through a) GP feedback b) Coordination Service Coding c) Marie Curie d) Discharge Teams  % change from baseline in those receiving supported Social at EoL  % of people referred to coordination hub for at home care who are unable to receive this care  % of people who then go on to have a hospital admission within 7 days of this request  (N.) (%) Applications to Highland End Of Life funding that are unsuccessful in obtaining additional resource coded  Unscheduled care activity  N. Delayed discharges logged through acute hospital for those identified as being in last year of life	Individual / Family Carer-Survey  Did you feel that you were able access to supportive services that have enabled your family member / person you supported at end of life to meet there preferences for care and at end of life. If not please can further information to be provided  Review of complaints at EoL
10. As a family member or	To provide support to	Percentage of carers with an adult carers support	Qualitative feedback from

Outcomes that matter	Action	Measures	Narrative
<p>carer supporting an individual during and after their end of life I felt supported by the services involved</p>	<p>the families and other carers during and after their loved one's end of life</p>	<p>plan for those caring for someone with a terminal illness (Carers Act 2016)</p> <p>Numbers of referrals to local bereavement services through coordination service</p> <p>Number with / Median length of time of Social care package in place</p> <p>Number with community Marie Curie / Highland hospice supports</p> <p>Number with voluntary sector support</p>	<p>representative 3rd sector organisations</p> <p>Family Carer-Survey – Did family members and carers feel supported during both at end of life and after death by the services they interacted with. If not why was this.</p> <p>Review of EoL Complaints</p> <ul style="list-style-type: none"> <li>- NHS</li> <li>- Hospice</li> <li>- Care Home</li> </ul>

## Appendix 2 - Estimating the need for end-of-life support (palliative care)

Gomez-Baptiste *et al.* (2012)<sup>viii</sup> estimated that 75% of deaths could have palliative care needs based on the prevalence of long-term health conditions. More recent publications have used the ICD-10 classification of underlying cause of death, or the cause of death in any position included in the death certification, to estimate the number of deaths that could have a palliative phase (Murtagh *et al.* 2014<sup>ix</sup>, Etkind *et al.* (2017)<sup>x</sup>, Finucane *et al.* (2021), and Mason *et al.* (2020)<sup>xi</sup>). Estimates based on underlying cause of death, applied to NHS Highland deaths in 2017-2021, identify close to 75% of deaths, whereas using all death codes identifies around 90% of deaths (see Table 8). Mason *et al.* (2020) classifies all ICD-10 codes for those aged 18+, with some causes split differently across categories depending on age at death. Applying this method to NHS Highland deaths identifies 91% of deaths for those 18+, equivalent to 90% of all deaths. Finucane *et al.* (2021) group codes into Cancer, Organ Failure, Dementia and Other palliative, as well as non-palliative deaths and, applied to underlying cause of deaths, provides a minimal estimate of deaths with palliative care needs. Estimates of the annual average number of deaths that have palliative care needs ranges from 2790 to 3520 deaths.

The method based on underlying cause of death using a definition by Finucane *et al.* (2021) was used for the estimates of the number of deaths with palliative care needs (EoL deaths). This was chosen because it was recently used to estimate palliative care needs in Scotland and due to its simplicity of implementation. Note that it forms a minimal estimate of the number deaths with palliative care needs (Table 8).

Table 8: Different estimates of the number of people who die who would benefit from palliative care (EoL deaths)

Source	Method	% deaths	% population (2017-2021)
Gomez-Baptiste et. Al. 2012	Based on percentage of people dying from chronic progressive diseases in high-income countries.	75%	0.9%
Exclude certain non-palliative causes (in-house)	Excludes deaths associated with pregnancy, childbirth injury, poisoning, external causes, unknown causes and sudden cardiac death without and circulatory contributory causes.	94%	1.1%

Source	Method	% deaths	% population (2017-2021)
Murtagh et al. 2014 (underlying cause)	Malignant neoplasm, heart disease, including cerebrovascular disease, Renal disease, Liver disease, Respiratory disease, Neurodegenerative disease, Alzheimer's, dementia and senility, HIV/AIDS	78%	0.9%
Murtagh et al. 2014 (any position)	As above but includes all contributory causes.	92%	1.1%
Finucane et al. 2021 (underlying cause)	Similar to Murtagh but excludes acute respiratory infections, pneumonia and influenza. Assigns 4 palliative groups: cancer, organ failure, dementia, other.	74%	0.9%
Finucane et al. 2021 (any position)	As above but includes all contributory causes.	90%	1.0%
Mason et al. 2020 (those 18+)	Assigns 5 groups, depends on age-band: Clear terminal phase (Cancer), Intermittent (Organ failure), Gradually dwindling (Frailty, Progressive neurological condition), Various and External. First three are palliative. COVID-19 was added by inclusion in the same groups as flu and pneumonia.	91% (of 18+) 90% (of all)	1.1%
Total	All deaths (2017-2021) based on NRS deaths file removing residents from outside Scotland.	100%	1.2%

Source: NRS deaths records for NHS Highland, see appendix 3

### Appendix 3 - Data sources

Figures	Figure 1
Data	Life Expectancy at birth by gender, age and Council area
Original source	National Records of Scotland
Accessed via	Statistics.gov.scot
Link	<a href="https://statistics.gov.scot/resource?uri=http%3A%2F%2Fstatistics.gov.scot%2Fdata%2FLife-Expectancy">https://statistics.gov.scot/resource?uri=http%3A%2F%2Fstatistics.gov.scot%2Fdata%2FLife-Expectancy</a> <a href="https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/life-expectancy/life-expectancy-at-scotland-level">https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/life-expectancy/life-expectancy-at-scotland-level</a>
Date accessed	11/01/2023

Figures	Figure 2, Figure 3, Figure 10 (actual deaths only),
Data	Number and standardised number of deaths by area
Original source	National Records of Scotland
Accessed via	National Records of Scotland

Link	<a href="https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/deaths/deaths-time-series-data">https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/deaths/deaths-time-series-data</a>
Date accessed	12/09/2023

Figures	Figure 4
Name	Number and percentage of people on palliative care register
Original source	Public Health Scotland
Accessed via	Public Health Scotland
Link	<a href="https://www.publichealthscotland.scot/publications/general-practice-disease-prevalence-data-visualisation/general-practice-disease-prevalence-visualisation-27-june-2023/">https://www.publichealthscotland.scot/publications/general-practice-disease-prevalence-data-visualisation/general-practice-disease-prevalence-visualisation-27-june-2023/</a>
Notes	Data includes different number of practices in different years. 83/92 practices were included in 2022/2023 data. See online metadata for more information.

Figures	Figure 10
Name	2018-based principal population projections
Original Source	National Records of Scotland



Accessed via	National Records of Scotland
Link	<a href="https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/sub-national-population-projections/2018-based">https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/sub-national-population-projections/2018-based</a>
Notes	Annual number of deaths are counted between two mid-year timepoints, with year on the x-axis relating to the last year.

### Number of deaths and estimated and projected numbers of deaths with palliative care needs

Figures	Figure 5, Figure 6, Figure 7, Figure 8, Figure 9, Figure 11, Figure 12, Figure 13, Figure 14, Figure 15, Figure 16, Figure 17, Figure 18, Figure 19, Figure 20, Figure 21, Figure 22, Figure 23, Table 4, Table 8
Source	NHS Highland local extract of deaths received from National Records of Scotland.
Open data	The following were accessed from <a href="https://www.opendata.nhs.scot">https://www.opendata.nhs.scot</a> : Data Zone (2011) Population Estimates (National Records of Scotland) Geography Codes and Labels: Data Zone 2011, Health Board 2014 – Health Board 2019 Scottish Index of Multiple Deprivation (Population Weighted), 2020v2, (Scottish Government) Data Zone (2011) Urban Rural Classification 2020 (Scottish Government) Sub Health and Social Care Partnership Areas Datazone to Locality Lookup Health board projections (Population projections)

	<p>2018-based projected number of deaths between mid-year points was downloaded from National Records of Scotland:  <a href="https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/sub-national-population-projections/2018-based">https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/sub-national-population-projections/2018-based</a></p>
Numbers of deaths	<p>Deaths with Residential codes outside Scotland were excluded.</p> <p>Deaths were filtered to only include those where the Council area of residence was Argyll and Bute (04) or Highland (18).</p> <p>Deaths records were checked for duplicates with the same surname, forename, date of death and date of death registration and the most recently provided record was kept for any duplicates in the dataset.</p> <p>SIMD, Scottish Government Urban-Rural classification and HSCP localities were joined to death records via the 2011 datazone provided by NRS.</p> <p>For data presented by age band or using age bands in the methods, death records with missing data on age at death were first excluded.</p>
Estimating number of deaths with palliative care needs (EoL deaths and EoL cause of death groupings)	<p>Number of deaths that may have palliative care needed was estimated in different ways, using methods from other sources:</p> <p><i>Exclude certain non-palliative causes (in-house):</i></p> <p>This method was based on the ICD-10 code (<a href="#">ICD-10 Version:2010 (who.int)</a>) of the underlying cause of death. Deaths considered to potentially have palliative needs were defined by excluding deaths associated with pregnancy, childbirth injury, poisoning, external causes, unknown causes (ICD-10 chapters O, S, T, V, W, X and Y and ICD-10 codes R95-R99 as underlying cause of death) and sudden cardiac death without and circulatory contributory causes (I461 as underlying cause of death without any of I21, I22, I44 and I45 as any cause of death).</p> <p><i>Gomez-Baptiste et al. 2012</i></p>

This method was based on an estimate made by Baptiste et al. 2012, based on percentage of people dying from chronic progressive diseases in high-income countries, and was defined as 75% of all deaths.

*Murtagh et al. 2014 (underlying cause)*

This method was based on an estimate from Murtagh et al. 2014 who used an expert panel to identify ICD-10 coding of cause of death that are likely to be associated with need for palliative care. These were Malignant neoplasm (ICD-10 chapter C, excluding I12 and I13), Heart disease, including cerebrovascular disease (I0-I6), Renal disease (N17, N18, N28, I12, I13), Liver disease (K7), Respiratory disease (J06-J09, J1, J20-J22, J4, J96), Neurodegenerative disease (G10, G20, G35, G122, G904, G231), Alzheimer's, dementia and senility (F01, F03, G30, R54) and HIV/AIDS (B20-B24). The estimate was based on the underlying cause of death only.

*Murtagh et al. 2014 (any cause)*

This used the same method as that above but included the presence of the identified conditions in any coding of cause of death, not solely the underlying cause.

*Finucane et al. 2021 (underlying cause)*

This method used the same method as Etkind et al. 2017 and was very similar to that used by Murtagh et al, 2014, but it excluded acute respiratory infections, pneumonia and influenza (J09-J18). Five grouping are described: Cancer, Organ failure (cardiovascular, respiratory, renal, liver), Dementia (Dementia, Alzheimer's disease, senility), Other palliative deaths (Huntingdon's disease, motor neuron disease, Parkinson's disease, progressive supranuclear palsy, multiple sclerosis, multi system atrophy, stroke, HIV) and a final group where the death was not considered to have palliative needs. The estimate was based on the underlying cause of death only.

*Finucane et al. 2021 (any cause)*

This used the same method as that above but included the presence of the identified conditions in any coding of cause of

	<p>death, not solely the underlying cause.</p> <p><i>Mason et al. 2020</i></p> <p>This method also used ICD-10 coding and was based on the underlying cause of death only. Mason et al. assigned five groups, depending on age-band, allowing a proportion of deaths from certain conditions e.g. influenza and pneumonia, to be considered in different groups. They refer to a Delphi method to come to a consensus on the groups. These were: Clear terminal phase (Cancer), Intermittent (Organ failure), Gradually dwindling (Frailty, Progressive neurological condition), Various causes and External causes. The first three were considered to have palliative care needs. For this work, COVID-19 was added to the definition of the groupings by inclusion in the same groups as flu and pneumonia. All causes of death were included in one of the five groupings.</p>
Leading causes of death	<p>Leading causes of death were based on a grouping of underlying causes described by the Office for National Statistics. This was, in turn, based from a list compiled by WHO. The groupings were further adapted to include codes related to COVID-19 (U071, U072, U109) as a new grouping.</p> <p><a href="https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2021#leading-causes-of-death">https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2021#leading-causes-of-death</a></p> <p><a href="https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/methodologies/userguidetomortalitystatistics/leadingcausesofdeathinenglandandwalesrevised2016">https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/methodologies/userguidetomortalitystatistics/leadingcausesofdeathinenglandandwalesrevised2016</a></p> <p>The highest causes of death from the years 2016 to 2019 were chosen for display, as prior to COVID-19.</p>
Multi-morbidity	<p>Multimorbidity was defined, as in Finucane <i>et al.</i> 2021, as the presence of more than one of the 4 broad palliative groupings of cause of death (Cancer, Organ failure, Frailty, Other palliative causes), found within any cause of death coding.</p>
Projections of	<p>Estimated EoL (palliative) deaths occurring in 2017-2021 were used to produce rates that were then applied to projected</p>

<p>deaths with palliative care needs</p>	<p>population sizes.</p> <p>Rates of deaths by each of the 5 groupings of cause of deaths, as defined in Finucane <i>et al.</i> 2021 and Etkind <i>et. Al</i> 2017, were calculated for each five-year age band and sex. National Records of Scotland population estimates were used as a base. Five year age bands finished at age 90 with all those aged 90 and over grouped into a single age band. Rates of deaths were then multiples by the National Records of Scotland 2018-based principal population projections, by 5-year age band and sex to produce a projected number of deaths.</p> <p>The total projected deaths were higher than those published by National Records of Scotland and, unlike when population projections are made, there was no decrease in the population due to this higher number of deaths. Therefore, the projected deaths were scaled to match the total projected number of deaths published by National Records of Scotland, using a factor derived from the ratio between the National Records of Scotland population projections and the total projected deaths using the method described here.</p>
<p>Place of death</p>	<p>Hospices were identified by the word ‘Hospice’ in the location name.</p> <p>Those locations not identified as hospices were then categorised using coding of death location as follows:</p> <p>Last letter “H” – Hospital</p> <p>Last letter “N” – Home / Non-institution</p> <p>Last letter “J”, “K”, “R”, “S”, “T”, “U” or “V” – Care home</p> <p>Other codes – Other institution</p> <p>Further information regarding location codes is available from Public Health Scotland:</p> <p><a href="https://www.isdscotland.org/products-and-services/data-definitions-and-references/national-reference-files/">https://www.isdscotland.org/products-and-services/data-definitions-and-references/national-reference-files/</a></p>

	<p>Hospital codes were further broken down as follows:</p> <p>Acute NHS Highland hospital  “C121H”, “H202H”, “H103H” or “H212H” –</p> <p>These are:</p> <p>Lorn &amp; Islands Hospital, Oban  Raigmore hospital, Inverness  Caithness General hospital  Wick and Belford Hospital, Fort William</p> <p>Other NHS Highland hospitals  Starting letter “H” or one of:  “C101H”, “C106H”, “C108H”, “C113H”, “C114H”, “C122H”, “C110H”, “C119H” or “C207H”)</p> <p>NHS Greater Glasgow and Clyde acute hospitals and national treatment centre  “C313H”, “C206H”, “C418H”, “G405H”, “G516H”, “G107H”, “G504H”, “C416H” or “G513H”</p> <p>All other hospitals were classified as “Other”.</p>
Notes	<p>Note that NRS bases residential location on ‘usual residence’. More information about this can be found here: <a href="https://www.nrscotland.gov.uk/basis-of-vital-events-statistics">Geographical basis of Vital Events statistics (nrscotland.gov.uk)</a></p> <p>2018-based population projections are the most recent available projections for health board areas in Scotland. They are subject to assumptions based on trends in fertility, mortality and migration. British exit from the EU, the COVID-19 pandemic</p>

	<p>and changes to mortality are likely to have affected these trends. Further information can be found here on the National Records of Scotland website.</p> <p><a href="https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/uses-and-limitations-of-population-projections">https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/uses-and-limitations-of-population-projections</a></p>
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### Emergency bed occupancy

Figures	Figure 36, Figure 37
Source	<p>NHS Highland e-Health Adms/Dischs View of hospital activity</p> <p>Public Health Scotland deaths for NHS Highland residents, or deaths occurring in NHS Highland obtained from the ACaDMe datamart</p>
Method	<p>Over the period, for each and every day, a list of all emergency patients occupying a bed at midnight was created. Alongside each record, a 'death flag' field (yes/no) highlights whether or not the patient dies (anywhere, not just in hospital) over the next 365 days. This was achieved by linking [Date of Death] to hospital records via CHI number. Analysis of hospital activity was truncated by one year from the data that was available in order to allow a full year to progress to determine whether the patient dies or not.</p> <p>This allows the calculation, for each day of: (i) the total number of emergency patients occupying a bed and (ii) the total number of emergency patients occupying a bed within their last year of life. On any given day, the proportion of beds occupied by emergency patients within their last year of life is simply the ratio of (ii)/(i). The monthly figures are simply the average of the corresponding daily ratios.</p>

Notes	Deaths data for 2023 is provisional.
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### Hospital admissions within the last year of life

Figures	Table 1, Figure 24, Figure 25, Figure 26, Figure 27, Figure 28, Figure 29, Figure 30, Figure 31, Figure 32
Source	NHS Highland local extract of linked SMR01 data and of deaths data, received from Public Health Scotland.
Method	<p>Details on SMR01 data can be found here:  <a href="#">SMR Datasets   ISD Scotland   Data Dictionary</a></p> <p>SMR01 returns include inpatient and day case admissions to all NHS hospitals and contract beds in non-NHS hospitals in Scotland, for care under General/ Acute specialties. It does not include care under mental health or maternity specialties.</p> <p>SMR01 returns with no CHI number were excluded.</p> <p>New SMR01 episodes occur when patients change speciality or hospital. SMR01 episodes may be linked together to form a continuous inpatient stay (CIS).</p> <p>The first episode in a CIS for each CHI number was identified as the earliest admission day. If more than one episode in the same CIS had the same admission day, the lowest coding of 'Admission/Transfer from' was taken. This prioritised admission from private residences, institutions e.g. care homes and temporary residences above transfers.</p> <p>First episodes in a CIS were filtered to only include those that were inpatient admissions though 'Management of patient' code "A", "1", "3", "5" or "7". Therefore some day cases that went on to become inpatient stays were excluded.</p>



The last episode in an CIS was identified as the latest admission day. If more than one episode in the same CIS had the same last admission day, the lowest coding of 'Discharge/Transfer to' was taken. This prioritised episodes that ended with death of the patient.

Deaths were filtered to exclude non-Scottish residents and those with no CHI number.

Deaths were filtered by year of interest.

Deaths were further filtered to deaths of NHS Highland board residents.

Underlying cause of death was classified into five groups (four of which with palliative care needs) according to the method used by Etkind *et al.* (2017) and Finucane *et al.* (2021). This method was described above for estimated number of deaths with palliative care needs.

The number of days between the admission of the first episode in the CIS and the discharge of the last episode was calculated. This was referred to as the 'length of stay' or number of bed days i.e. CIS with admission and discharge on the same day would have a length of stay of zero bed days.

All CIS associated with an NHS Highland resident who died were joined to the death data using the CHI number.

For each CIS, the number of days between the CIS admission and death was calculated.

Each CIS associated with a death was then categorised according to the number of months before death than the admission occurred. For simplicity, months were defined as a period of 30 days.

CIS more than 12 months before death were excluded from further analysis.

The proportion of people who died (defined by unique CHI numbers) with admissions was calculated, for each of the 12 months before death.

Discharge locations for the last episode in a CIS in the last 12 months of life were grouped according to the main groupings as

	outlined in the SMR data dictionary. These were then further grouped to place 'Temporary' and any other values <5 into an 'Other' category.
Notes	Note that some hospices (including Highland Hospice) submit an SMR01 return for their inpatients.

### Palliative Care Helpline

Figures	Figure 33
Source	NHS Highland Aداstra
Method	<p>Palliative care helpline use was identified as:</p> <p>Any calls with final location 'palliative care helpline'</p> <p>New (not system generated) calls marked case type 'Palliative care call – untriaged'</p> <p>Monthly counts of people were based on unique CHI numbers, excluding any missing CHI numbers.</p>
Notes	Calls may be made by professionals and/or unpaid carers.

### Costings

Figures	Figure 34, Figure 35, Table 5, Table 6
Name	Spend on people in the last year of life

Source	<p>Hospital, GP out of ours and prescribing spend is estimated by Public Health Scotland and provided in a restricted access format.</p> <p>Highland Hospice costs were provided directly by Highland Hospice.</p>
Methods	<p>Full methods are provided by PHS but salient points are provided here.</p> <p>Hospital costs are estimated using PLICS methodology.</p> <p><a href="https://www.isdscotland.org/Tableau/IRF-Mapping-Summary-of-PLICS-costing-methodology.pdf">https://www.isdscotland.org/Tableau/IRF-Mapping-Summary-of-PLICS-costing-methodology.pdf</a></p> <p>The latest costs are for 2019/20 due to the impact of COVID-19 on hospital used. The PLICS method also changed for 2019/20 to account for changes in 2020 due to COVID-19.</p> <p>Prescribing costs are from the Prescribing datamart.</p> <p>Cost for GP out of hours is estimated from the total expenditure in the cost book and total contacts across Scotland, which is then applied to board level activity reported to PHS. It is cautioned to a rough estimate and does not take into account costs of providing this service in different areas.</p> <p>District nursing spend was not included due to known data quality issues resulting in high variation in spend data from year to year.</p> <p>The end of life cohort for the cost data from Public Health Scotland is for people aged 18+ who died in that year. It excludes people who have died due to an accident, as defined by any occurrence of ICD-10 codes V01 to Y84, excluding falls (W00 to W19).</p>
Notes	<p>People living in Argyll and Bute council are not likely to access Highland Hospice inpatient services, or other Highland Hospice services based in Highland council area.</p>

### Social care service use

Figures	Figure 38, Figure 39
Source	NHS Highland local extract of deaths data received from Public Health Scotland Social care use data was provided by NHS Highland Strategy & Transformation Intelligence
Method	Deaths were filtered to exclude non-Scottish residents, those aged 18+ and those with no CHI number. Deaths were filtered to include deaths of Highland council area residents only. Underlying cause of death was classified into five groups (four of which with palliative care needs) according to the method used by Etkind <i>et al.</i> (2017) and Finucane <i>et al.</i> (2021), as previously described. Social care use data included care home and care at home use from 2019/20 to 2022/23, with start and end dates. It included residential and nursing care home use, both long and intermediate stay. It included care at home as mainstream, reablement or pre-reablement. Deaths in 2020/21 and 2022/23 were joined by CHI with this social care service use data. For each death, whether there was any care home or care at home service use within the 12 months (12x30 days) before death was derived.
Notes	Deaths in the 2023 calendar year were provisional

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