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Public expenditure in the last year of life

Research Report

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Contents

Executive summary

More than 600,000 people die each year in the UK, and the quality of their last year of life is greatly influenced by the care and support they receive from publicly funded services. It is estimated that 90% of these people could benefit from palliative and end of life care, but there is great variation in availability and quality of service provision. The final year of life is also a time of financial hardship for many, due to loss of income and increased costs.

Although we know what good care and support can look like, there is remarkably little evidence of how much public expenditure supports people in their last year of life. This leaves a critical gap in evidence available to decision-makers so they can make the best possible use of public funds and get care and support right.

Marie Curie commissioned Nuffield Trust and the Health Economics Unit to estimate the range of public expenditure that supports the care of people in their last year of life. This includes health care in community and acute settings; hospice care; social care for people in their homes and in institutions; and social security benefits.

Some of this expenditure – such as the State Pension – would be incurred irrespective of whether someone is in their last year of life, but these are all important contributors to quality of life.

Estimates include overall expenditure for each sector and sub-sector, and per person, for the UK, and for each of the four nations in the appendices for this report.

We estimated expenditure using published data on service use and costs, and unpublished data provided from stakeholders.

We engaged with 50 stakeholders in the process of identifying relevant data, reviewing assumptions and validating estimates. A workshop reviewed interim estimates with people with clinical and policy expertise in end of life care or with lived experience, as well as experts in economic analysis, health, social care and social security data.

Data availability specific to the last year of life was limited and variable by sector and nation, so extrapolation from relevant available data was necessary. Sensitivity analyses provide plausible ranges addressing uncertainty in the estimates, and a detailed methodological appendix describes the data and estimation process, including assumptions.

There is only one chance to get care and support right for individuals in their last year of life and their families. The estimates in this report highlight the dominance of hospital care in public expenditure supporting people in their final year (as in other aspects of health care), despite stated policies in each UK nation to shift care from hospital to communities.

The evidence can be used to consider resource decisions to improve care and support across health and social care. Opportunities to improve data collection and availability would further improve evidence-based decision-making to make best use of public monies.

Key findings from the report

1 People at the end of life have significant needs for health, social care and social security. Drawing on a wide range of data sources, we estimate that in 2022 there was at least £22 billion public expenditure for people in the last year of life in the UK. This amounts to £33,960 of public expenditure per person who died. Over half of this total expenditure (almost £12 billion) was on health care, 22% (almost £5 billion) was on social care, and 25% (£5.5 billion) was on social security.

2 Of public funds spent on health care for people in their last year of life, 81% was spent in hospital, and 56% was spent on emergency hospital care. Put another way, for every £5 of health care spend, £4 was spent in hospital with £2.80 of that on emergency hospital care.

3 We estimate that people in the last year of life account for nearly 10% of all hospital costs. However, hospital expenditure may be underestimated, because we could not fully adjust for differences in the cost of care received by people at the end of life who may have more complex needs.

4 The type of care with the largest health care spend for people in the last year of life is hospital inpatient care, accounting for 73% of health expenditure (£8.6 billion).

5 Expenditure on primary and community health care accounted for only 11% (£1.3 billion) of health expenditure for people in the last year of life.

6 Public expenditure on services provided by independent hospices accounted for less than 4% of health expenditure. The public purse funds 44% (£414 million) of the cost of services provided by independent hospices; including voluntary contributions, hospice care would still only account for 8% of health expenditure.

7 Overall, this means that we spend five times as much on supporting people in the final year of life as hospital inpatients, as we do supporting them with primary care, community health and hospice care.

8 For social care expenditure, the largest element is residential and nursing home care, which we estimate accounts for 63% of all social care expenditure on people in the last year of life (£3 billion).

9 For social security expenditure, we estimate that the State Pension comprises almost 90% of expenditure for people in the last year of life (£4.9 billion), for the benefits we were able to identify.

Introduction

How we support dying people is a key marker of a caring society. People at the end of life need not just health and social care to maintain as good a quality of life as possible, but also financial support, to maintain living standards as well as to meet additional everyday costs.

Although there is strong evidence about what good care at the end of life should look like, provision of services is patchy and unequal.[1] Providing care to people at the end of life is a core part of the work of hospitals, GPs, community and social care services, but despite this, there is remarkably limited data about service provision – including how much public expenditure goes towards supporting people in the final year of life.

End of life care has had a limited profile compared with other pressures on the health system and public finances. This has profound implications for how resources are allocated for people at the end of life, as decision-makers cannot measure the consequences of decisions or understand the impact of policy shifts on this group of people.

This research starts to address this gap by setting out what we know about public expenditure on people in the last year of life. We present findings from our research that aimed to understand what data is available about volume and cost of public services for people in the last year of life, and we aimed to use this data to develop the best estimate possible for expenditure in 2022.

In the report, we discuss how data gaps impacted on the estimates and, where possible, indicate a range of plausible estimates. Although we did not undertake an analysis of change over time, we discuss underlying trends that will impact public expenditure.

Our analysis is at a high level and has been undertaken rapidly to inform current debates about end of life care and upcoming decisions on public expenditure. The scope of the work is summarised below and was necessarily limited (See Scope and methods section). Throughout the report, we note gaps in data and assumptions made in producing our estimates.

Scope and methods

Our analysis is intentionally broader than expenditure specifically on palliative and end of life care, and includes all people who died, including sudden deaths. It is estimated that 90% of people who die could benefit from some form of end of life and palliative care (care that offers physical, emotional and practical support to people with a terminal illness).[2]

We included expenditure that would be incurred even if the person was not in the last year of life – such as the State Pension – because this too is expenditure that supports quality of life for dying people. Likewise for health and social care, expenditure is included regardless of whether this was to address needs at the end of life – so, for example, the prescribing costs included are not just for medications to manage symptoms at the end of life.

Within the scope of the research, we did not compare spending with outcomes or quality of care and so do not discuss cost-effectiveness of treatment.

While including social security expenditure provides a more complete

estimate of public spend, our analysis does not encompass wider societal costs borne by individuals and families, or the cost of informal care.[3]

The findings for the UK were estimated from analysis for each of the UK nations. UK findings are presented in the main report and nation estimates in Appendix 1.

There were significant limitations in the data available, with little data available about social care, and numerous gaps in data about health services, particularly data specific to each UK nation. Where nation-specific data was not available, we extrapolated from other UK nations, most often England, for which we were able to find more published sources of data, using information on the number of deaths (Appendix 3).

More detail on inclusions and exclusions are highlighted in the relevant parts of the report, along with the data sources used and implications of data gaps. The analysis used published data and statistics, research evidence and reports and evidence provided by stakeholders, as set out in Appendix 2 and Appendix 4.

For health care and social security, we estimated expenditure for each service area or benefit for each person who died by estimating the proportion of people who used the service, the average level of activity and the cost for each activity.

Total expenditure for each UK nation was estimated by multiplying spend per person with the number of people who have died. This approach was taken to enable analysis of spending on different types of services. However, this approach was not possible for social care, for which the estimate was based on proportion of all social care expenditure.

The findings are presented for the calendar year 2022, which was the most recent year for which data was available for a wide range of services, and likely to be more representative of activity since the Covid-19 pandemic. Where estimates of cost and activity were not available for this year, adjustments have been made, or alternative approaches used, as outlined in the methods.

In some cases, the data refers to expenditure during 2022, and in other cases the data relates to expenditure on people who died in 2022, and for some sources the closest financial year available was used.

While every effort was made to plug the gaps in the data in the time available to complete the analysis, the methods applied will inevitably impact the certainty of our estimates. We undertook a sensitivity analysis to provide an idea of the range of plausible estimates (Appendix 5).

We held a workshop to discuss interim findings with stakeholders, including people and organisations with clinical and policy expertise on end of life care, people with lived experience and experts in economic analysis and health, social care and public expenditure data. Throughout the project we drew on expertise from a wide range of people to identify sources and to validate and sense-check our findings (see Appendix 2).

What is the estimate of public expenditure on people in the last year of life across the UK?

Our analysis estimates UK annual public expenditure on health care, social care and social security to be in the region of £22 billion in 2022, for people aged 18 or older in the last year of life. This equates to an average of £33,960 of public expenditure per person in the year before death, for each of the 652,000 people aged 18 and over who died in the four nations in 2022. Over half of this expenditure (almost £12 billion) was on health care, 22% (almost £5 billion) was on social care and 25% (£5.5 billion) was on social security (see Table 1).

When we modelled the impact of uncertainty in a probabilistic analysis, the mean estimate was £22.2 billion with a 95% credible interval ranging from £22.0 billion to £22.3 billion.

One-way sensitivity analyses demonstrated that the most influential parameters were emergency admissions, State Pension, residential and nursing home costs and elective admissions in England, followed by emergency admissions in Scotland.

Our findings were developed based on estimates for each nation, which are discussed in Appendix 1.

It was not possible to use UK-wide data on total public expenditure (for all people, not just those who died) to put these numbers in a wider context, because data is not published at a sufficiently granular level to enable comparison with our findings.

For health care, we were able to use estimates of England's total spend data for care sectors to determine that around 10% of hospital and ambulance costs were for people in the last year of life, and 2% of costs were for primary care and 4% were for community services. For social care, we estimated 12% of total expenditure of local-authority-funded social care was on people in the last year of life (again, this was calculated for England: see Appendix 6). For social security, we were able to use the total expenditure data for England, Scotland and Wales, and found that up to 3% may have been spent on people in the last year of life.

Table 1. Estimated spend on people in the last year of life by sector, UK, 2022

Sector	Spend per person, £	£millions	%
Health care	18,020	11,749	53
Social care	7,440	4,851	22
Social security	8,500	5,540	25
All sectors	33,960	22,140	

Note: There were 652,000 deaths of people 18 and over in the UK in 2022.

What are the components of health care expenditure for people in the last year of life?

We estimate that, in 2022, the UK governments spent £11.7 billion providing health care to people in the final year of life. This is 53% of total public expenditure on people at the end of life.

Hospital care constitutes the largest share (£9.6 billion, 81%) of health care spending: inpatient care alone accounts for 73% (£8.6 billion) of expenditure, which consists of emergency and elective admissions, accounting, respectively, for 54% (£6.3 billion) and 19% (£2.3 billion) of total health care expenditure (see Figure 1 and Table 2).

A&E attendances and emergency admissions account for 3% (£307 million) and 54% (£6.3 billion) respectively, so taken together, over half of all health spending is on urgent hospital care.

Unplanned out-of-hospital care contributes around 4% to spend in the last year of life (£454 million) – which includes NHS 111/NHS 24 and ambulance services.

Primary and community care account for a relatively smaller share of health spending. General practice expenditure (7%) is split between GP practice contacts, including out of hours (£287 million) and community prescribing (£528 million). An estimated £495 million (4%) is spent on contracts with community health care services, such as district nursing. However, our estimates do not include public expenditure on dentistry or optometry.

Independent hospices account for less than 4% (£414 million) of public health care expenditure on people in the last year of life.

The public purse pays for 44% of the costs of services provided by hospices across the UK. The remaining 56% (£526 million) of the cost of hospice services is met from charitable support (Appendix 4: Hospice care). Some specialist palliative care services are provided within the NHS, but there is no separate data available about these: expenditure on these services will be included, however, within the NHS hospital, community and other health care services.

Overall, this means that we spend five times as much on supporting people in the final year of life as hospital inpatients, than we do supporting them with primary care, community health and hospice care (excluding NHS hospice care).

Figure 1. Distribution of health expenditure by service type

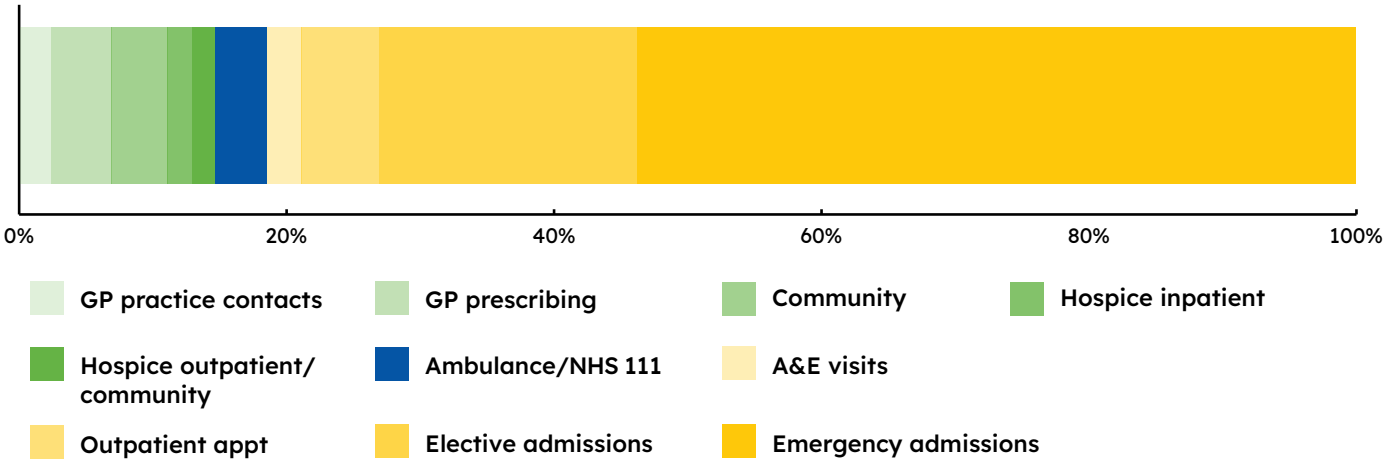


Table 2. Estimated spend on health care in the last year of life by health care services in the UK, 2022

Setting	Subtype	UK £millions	%
GP practice	Contacts	287	2.4
	Prescribing	528	4.5
	Subtotal	815	
Community	**Subtotal**	495	4.2
Hospice care*	Inpatient	217	1.8
	Outpatient and community	197	1.7
	Sub total	414	
Unplanned care out of hospital	Ambulance	425	3.6
	NHS111	29	0.2
	Subtotal	454	
Unplanned care in hospital	A&E visits	307	2.6
	Emergency admissions	6,314	53.7
	Subtotal	6,621	
Planned care in hospital	Elective admissions	2,267	19.3
	Outpatient appointments	683	5.8
	Subtotal	2,950	
Hospital care (all unplanned and planned care in hospital)	**Subtotal**	**9,571**	
Health care	**Total**	**11,749**	

Note: *NHS hospices and specialist services included in relevant sub-sector spend; service spend may not add up to sub-totals due to rounding.

Health care data and evidence

Table 3 provides a summary of the types of activity included in the analysis, and main limitations. The evidence sources used varied between nations, and nation-specific differences are noted in the relevant appendices.

Table 3. Summary of health care service use data used in the analysis and main limitations

Setting	Main data used for activity estimate	Main limitations
Primary care	General practice contacts Out of hours primary care service contacts	Dentistry and optometry not included
Prescribing	Items prescribed in general practice	Estimated based on age-specific data and research evidence specific to end of life care High-cost drugs in hospital assumed to be within overall hospital costs
Community care	Community care contacts	Estimated from referral data and survey responses
Hospice care	Hospice UK information collated from data returns provided by independent hospices	NHS hospices or specialist services not identified separately, but will be included in relevant NHS spend Split of inpatient and other hospice costs based on estimating inpatient costs; not directly costing activity due to limited data
Unplanned – out of hospital care	NHS 111 or NHS 24 contacts Ambulance contacts	Urgent care provided by community teams, e.g. rapid response not identified separately
Unplanned – hospital care	Non-elective admissions Emergency department visits	Uncertainty in estimating cost for end of life stays, which are likely to be longer and more complex than other admissions
Planned – hospital care	Elective admissions Outpatient attendances	Uncertainty in estimating cost of end of life stays
Mental health services		Not included, although services provided by community services and hospices likely to be within expenditure for those services

Estimates for the UK will be influenced most strongly by estimates for England, because of its much larger population, accounting for 82% of deaths in the UK in 2022 (Appendix 3).

In addition, we were able to find more data on service use specific to people at the end of life for England than for Scotland, Wales or Northern Ireland. For these reasons, we used data for England as a starting point for producing UK estimates.

In cases where activity data for a specific nation was unavailable, we used data from another nation as a proxy (based on availability of data). When applying estimates from one nation to another, we attempted to account for differences in population demographics wherever possible. However, we acknowledge that service provision and health care usage patterns differ between UK nations, as discussed in Appendix 1.

Estimating the costs of service use also posed a challenge because there is no dedicated source of unit costs (the average cost for each unit of activity) specifically for end of life care. End of life care often involves supporting individuals with more complex needs and intensive treatment – which is more expensive than the costs of care provided to the general population.

We have used nation-specific data on unit costs for England, Scotland and Northern Ireland, as outlined in the methods (Appendix 4: Hospital care). In discussion with stakeholders and where data allowed, we applied an adjustment to adjust unit costs using additional data sources (e.g. unit costs for admissions were adjusted to take account of longer lengths of stay for people at the end of life). However, our analysis may underestimate actual expenditure, as we have not been able to take full account of differences in complexity of need.

Further detail on costs and activity for each health care service and how they have been estimated can be found in Appendix 4.

What are the components of social care expenditure for people in the last year of life?

We estimate that in, 2022, UK authorities and trusts spent almost £5 billion providing social care services to people in the final year of life (see Table 4). This is 22% of total public expenditure on people at the end of life.

Spending by local authorities (or integrated health and social care trusts in Northern Ireland) made up the greatest portion of this expenditure (78%). This included residential and nursing care (£3 billion, 63% of all social care expenditure), home care (£557 million, 11%), and other services (e.g. provision of equipment and home adaptations, £170 million, 4%).

We also include Continuing Healthcare (CHC), which are packages of care funded by the NHS.[4] These services made up 22% (£1 billion) of estimated social care expenditure for people in the last year of life.

Our estimates only include public spend and not the considerable proportion of expenditure by individuals and families. For example, it is estimated that more than a third of residential care in England is self-funded.[5]

For local authority expenditure, we were unable to identify data sources on use of social care that were specific to people at the end of life, so our estimates are largely based on the proportion of expenditure on social care, as outlined in more detail below.

Table 4. Estimated total spend on social care in the final year of life, 2022/23

Social care	Social care service type	UK £millions	%
Local authority funded*	Residential and nursing care	3,077	63.4%
	Home care	557	11.5%
	Other (including equipment and adaptations)	170	3.5%
	Subtotal	3,804	
Continuing Healthcare	**Subtotal**	1,047	21.6%
Social care	**Total**	**4,851**	

*Integrated health and social care trusts in Northern Ireland; service spend may not add up to sub-totals due to rounding.

Social care data and evidence

Local authority spending

Our analysis of social care expenditure in the final year of life is derived using prior Nuffield Trust work that used linked person-level social care and mortality data from seven English local authority (LA) areas[6] to outline people's use of care services at the end of life.

Revisiting the data from this study, we calculated that the cost of services in the final year as a proportion of all LA expenditure on adult social care is 11.8%. Breakdowns were included for residential and nursing care, home care and other services.

We applied this proportion to recent years' estimates of total annual adult social care expenditure for Scotland, Wales and Northern Ireland, as well as for England. We also took account of higher rates of deaths in these nations: after adjusting for age, death rates are 19%, 9% and 4% higher than England in Scotland, Wales and Northern Ireland respectively (see Appendix 3).

Continuing Healthcare spending

In the second part of our analysis, we developed cost estimates of NHS Continuing Healthcare (CHC). CHC are packages of care arranged and funded by the NHS.

We have limited information about the type of people who are eligible for such services, and so our estimates are less reliable than our other findings. They are based on annual England expenditure figures received via a Freedom of Information (FOI) request to NHS England. Three categories of services were recorded in the English FOI data.

For the basis of calculating final year of life costs, we treated two of these categories as no different to LA-funded social care services (and so used 11.8% and equivalent proportions as outlined above for LA spending); the third, fast-track, was considered by stakeholders to be substantially – but not wholly – relevant to individuals near the end of life. To account for this, we took the bulk of these costs (four-fifths) as relevant to individuals' final year.

No CHC data was available for Wales and Northern Ireland. Instead, we first calculated the ratio of England CHC estimates to England LA-funded expenditure estimates. We then applied this to LA-funded expenditure estimates for Wales and Northern Ireland. Scotland replaced CHC in 2015 with a different kind of funding called Hospital Based Complex Clinical Care (HBCCC). HBCCC has limited use – only for people who need care in hospitals and, as such, we did not include any CHC-equivalent expenditure as part of Scotland's social care costs.

See Appendix 4 (Social care) for more detail.

What are the components of social security expenditure for people in the last year of life?

We estimate that, in 2022, UK authorities spent almost £6 billion on social security for people in the final year of life (see Table 5). This is 25% of total public expenditure on people at the end of life.

The State Pension forms the largest portion of overall public spending on social security and benefits for people in the last year of life, accounting for an estimated 89% of the total. This is because most people receive this, regardless of income or end of life status, and most deaths occur among people above State Pension age. Benefits linked to ill health, including Personal Independence Payments (PIP) and Attendance Allowance, are significantly lower still in comparison (£430 million, 8% of total social security expenditure in the final year of life). Means-tested benefits are lower still (£187 million, 3%).

Special rules for the end of life (SREL) are applicable to some benefits (Table 5).[7] People meeting the eligibility criteria receive the highest level of benefit (also available to people who are seriously ill or disabled) and have claims processed more quickly.[7]

The eligibility criteria for all benefits are the same across all four UK nations, except for the equivalent of PIP and Attendance Allowance in Scotland (the Adult Disability Payment and Pension Age Disability Payment).

Receipt of PIP and Attendance Allowance under SREL is likely to be an underestimate of the number of people who are receiving benefits in the last 12 months of life. There will be people already receiving these benefits due to a previously existing medical condition that impacts their daily living. It is unlikely these people will re-apply under SREL if they are already receiving the highest amount.

Additionally, we also understand from stakeholders that the uptake of benefits at the end of life is low, with people finding it difficult to access and navigate the system.[8] There will be a high number of people in the last year of life who will not be receiving benefits to support ill health. For carers, we include an estimate of expenditure on Carers Allowance; the carers element of Universal Credit is not included.

Means-tested benefits, including Universal Credit and Pension Credit, represent the smallest amount of public expenditure on social security and benefits in the last 12 months of life. These are important from an equity perspective, since expenditure on these benefits is concentrated on those with the lowest levels of income.

Table 5. Estimated spend on social security benefits in the last year of life by beneficiary, UK, 2022

Benefit type	Social security benefit	UK £millions	%
Working age	Attendance Allowance	179	3.2%
	Personal Independence Payment	251	4.5%
	Universal Credit ill health	64	1.2%
	Carers Allowance	44	0.8%
	Housing benefit	32	0.6%
Pensionable age	State Pension	4,923	88.9%
	Pension Credit	47	0.8%
Total estimated spend		**5,540**	

Note: service spend may not add up to sub-totals due to rounding.

Social security data and evidence

We used Department for Work and Pensions (DWP) benefit data, accessed using Stat-Xplore. For each benefit, the data was broken down by nation and age. For Northern Ireland, we used published data from the Department for Communities. For the most part, eligibility for benefits is the same across all UK nations (see Appendix 4: Social security).

Different approaches were taken to determine the number of people claiming under SREL for each benefit, based on advice from stakeholders and availability of data. Personal Independence Payment (PIP) is the only benefit where available data allows us to see the number of people claiming under SREL.

Further detail is provided in Appendix 4.

Trends that may influence public expenditure on people in the last year of life

Has health and social care spend on end of life care changed over time?

It has not been possible to replicate the analysis of spending for earlier time periods, because there are too many gaps in the data, such that the confidence in estimates for earlier time periods would be low.

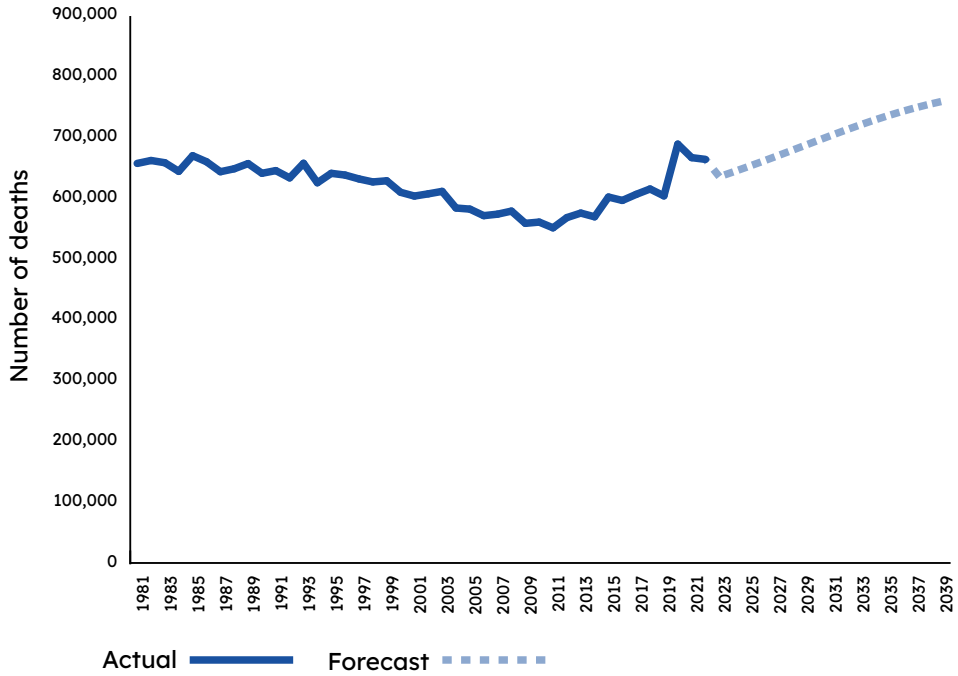
However, our analysis highlights the main drivers on expenditure on people in the last year of life. We summarise here how these factors have changed over time, considering three main elements:

- The number of people who die each year
- Changes in how services are provided
- Expenditure on care.

The number of deaths each year in the UK is increasing

The number of deaths each year in the UK was declining until 2011, but has increased since then, as people born in the high birth rate years after the second world war now reach older ages.[9] By 2035, there are expected to be an additional 79,000 more deaths than in 2022, an increase of 12% over this period.[10] This is expected to result in total expenditure on people in the last year of life also increasing, unless there is a balancing reduction in spend per person who dies, which seems implausible.

Figure 2. Number of deaths per year (all ages), UK, 1980-2040



Source: ONS vital statistics[9]; ONS population forecasts[10]

Shifts in health and social care activity will reflect wider trends in how care is delivered

Trends in activity and use of resources by people in the last year of life will be impacted by several factors, but the combined impact of these on trends in service provision is complex.

One factor is that health care activity tends to increase over time,[11] in both the UK and elsewhere, in part reflecting the development of new treatments, which are more complex and costly than existing care, along with other changes in services – for example, greater use of diagnostic tests.

Alongside this, the average age of death is increasing, and more people have multiple long-term conditions and more complex care needs. The balance of health and social care needs at the end of life varies by cause of death: for example, the increase in the number of people dying with dementia is expected to increase the need for social care.[12] Also, older people are more willing to undertake surgical and other interventions, which will also increase planned treatment for people at the end of life.[13]

On the other hand, there has been a decline in the number of people dying in hospital in the past 20 years. People who die in hospital are more likely to have been admitted to hospital in the last months of life, and will have had more emergency admissions, which as shown earlier is a considerable driver of expenditure.[14]

Expenditure on health and social care reflects choices and priorities of government

The amount spent on health and care also reflects choices and priorities of governments. In response to the financial crisis of 2008, there was a general squeeze on public expenditure across the UK. Health and social care expenditure are both devolved, with funding based on a standard formula, such that changes in funding for England are reflected in broad terms in Scotland, Wales and Northern Ireland. Each nation may then decide how to use this funding and whether to use additional locally raised revenue to meet nation-specific priorities.

While health care services were more protected than other sectors during this period, there was limited growth in spending on health care. In England, real terms expenditure (adjusted for inflation) remained broadly static between 2008/9 and 2019/20, once population growth and increased needs of an older population are accounted for.[15] Health expenditure has increased since 2019/20, although growth has largely been within the acute hospital sector.[16] Expenditure across the UK nations has broadly followed the same pattern.[17]

Trends in social care spend

Public expenditure on social care has been more constrained than for health care, because of reductions in real terms funding for local government. Real terms expenditure fell in England between 2011/12 and 2019/20, and remained broadly static in Scotland and Wales, but increased in Northern Ireland.[18] Spend in England continues to be lower per head of population than in Scotland, Wales and Northern Ireland.[19]

How has social security spending changed over time?

Social security spending on people in the last year of life will be influenced by the same demographic trends as health and care. More people dying each year and the proportion of older people in the population increasing will increase expenditure on people in the last year of life.

Social security spending is also driven by changes in eligibility criteria and the value of specific benefits for people at the end of life and health and disability-related benefits.

Time series data from 2019 to the most recent data point in 2024 suggests that uptake of special rules at the end of life (SREL) has been gradually increasing across England, Scotland and Wales (there is no data for SREL for Northern Ireland). In particular, there had been a significant increase in Universal Credit caseload.

Although Scotland's Universal Credit caseload under SREL has remained steady since mid-2022, Wales and England's have continued to rise, potentially due to the shift of people onto Universal Credit from legacy benefits.

In addition, Personal Independence Payment (PIP) and Attendance Allowance have seen a sharper rise in caseload under SREL since mid-2023, likely a reflection of change in SREL policy from six to 12 months left to live.

The number of people receiving the State Pension dipped during the pandemic, reflecting high mortality in older age groups, but has been steadily increasing since and has now returned to pre-pandemic levels.

Conversely, the number of people receiving Pension Credit has been declining since the start of the pandemic. Research suggests this is likely due to people assuming they are not eligible to receive Pension Credit.[20] Both trends are reflected across all four UK nations.

For both State Pension and Pension Credit, the average weekly amount received has increased by approximately 30% since 2019. This increase is primarily due to the application of the State Pension triple lock, meaning that pension payments have increased more than other benefits.

For PIP and Attendance Allowance, the monthly amount received has increased by slightly less – approximately 25% since 2019. The standard allowance and ill-health elements of Universal Credit have also increased over this time, although this is not guaranteed in legislation, and subject to a decision by the government each year, usually delivered in the Autumn Statement.

Discussion

This analysis provides high-level estimates for public expenditure on people in the last year of life. The research was undertaken rapidly to inform current debates on public spending and end of life care, and draws on previous analysis and routine data sources. By identifying where resources are used, there is scope to enable public funding to be better targeted for the benefit of people and their families, but also for the benefit of the wider system – to make services more effective and more sustainable.

Main findings

Our analysis was intentionally broad, and included expenditure for all people who died, including sudden deaths. We included expenditure that would be incurred even if the person was not in the last year of life – such as the State Pension – because this too is expenditure that supports quality of life for dying people.

We estimate that UK public expenditure on health care, social care and social security for people aged 18 or older in the final year of life, in 2022, to be in the region of £22.1 billion (95% credible interval ranging from £22.0 billion to £22.3 billion). This is equivalent to £33,960 per person for the 652,000 adults who died.

Over half (53%) was spent on health care (£11.7 billion). An additional 22% covered social care (£4.8 billion), and 25% went to social security payments (£5.5 billion).

These amounts make up a significant proportion of total NHS and social care spend: for example, we estimate that at least 10% of hospital and ambulance expenditure is on people in the last year of life.

Hospital and care homes are the biggest elements of health and social care spending at the end of life, comprising 43% and 14% of public expenditure respectively. Health care services provided in the community – combining general practice, urgent care outside hospital and community services – accounts for only 8% of expenditure. Greater investment in primary and community services for end of life care might reduce expensive use of hospital services,[21] and there is now a growing evidence base of reductions in time in hospital due to palliative and end of life care interventions.[22]

Independent hospices account for less than 4% of health expenditure from the public purse on people at the end of life. Just under half of expenditure on services provided by hospices is publicly funded, but even if all hospice services were funded, it would still only be around 8% of total health care spend.

For social security, pensions are the biggest element of expenditure: most people over pensionable age are eligible. In contrast, uptake of payments under special rules for people at the end of life is limited, and recent and ongoing research[8, 23] indicates that many people who are eligible do not take up benefits.

Limitations

We experienced significant challenges in undertaking this work, due to gaps in data and evidence available within the timescale for the project.

Routine data on service use for people at the end of life is generally not available, so we drew on research studies, published and unpublished activity data, and estimates based on the number of people who died.

Data gaps limited our ability to examine differences across the UK, or to examine trends over time. For social care and community services, there is limited data available about important areas of service provision, even without trying to identify data relevant to people who died.

There are known differences in service use between groups of patients based on cause and place of death. However, we were limited in the extent to which we could analyse data in a consistent way, particularly within the timescale of the project. Future research using linked datasets would be the most promising approach to develop more granular estimates of expenditure for sub-groups of people who died, for example, based on cause or place of death. In particular, there are stark variations between more and less socioeconomically deprived populations in place of death and services used at the end of life.[24]

There were also limitations to data on appropriate unit costs of care. In particular, the length of stay in hospital and type of care provided to people at the end of life are likely to be different to other groups of patients. We assessed several approaches to develop estimates of cost of care, to take account of differences in case mix. NHS unit costs are published for England, Scotland and Northern Ireland, but there are differences in the types of activity covered.

The time period used overlaps with the Covid-19 pandemic, which had an impact on all health and social care services, including those for people at the end of life. Our previous research identified changes that occurred at the start of the pandemic, notably more people dying at home and increases in recording of contacts with the GP practice team. Further Nuffield Trust research has established that patterns of care from the start of the pandemic broadly continued.[25] As a result, our estimates of expenditure for 2022 are likely to be reflective of the current state of health care for people at the end of life.

Future research

We identified opportunities to improve data on end of life care, as well as developments already underway that would enable more granular analysis in the future. Each area we included in the analysis also merits dedicated research to refine and improve on the estimates we produced. Stakeholders identified several potential refinements that might be possible, given more time.

Across health care, there is growing momentum around the use of linked datasets.[26] Linking mortality to routine health datasets would allow care provision at the end of life to be analysed and reported consistently. However, gaps in underlying data, such as for community services, would also need to be addressed. We were not able to undertake new analysis using linked data within the timescale for the project, but platforms such as the SAIL databank in Wales could be used to undertake new analysis of service use at the end of life.[27] Aggregate-level data from the Wales end of life dashboard was provided for the study.[28]

For social care, a client level data collection is being rolled out for adults in England. This could dramatically improve our ability to understand the provision of social care, particularly if also linked to mortality data.[29]

Stakeholders we spoke to during the project identified developments in progress. For example, in Northern Ireland, the Encompass programme[30] is developing a shared record for health and social care that in time may include functionality to capture comprehensive information on end of life care provision.

There is ongoing work across the UK nations to harmonise health statistics,[31] but considerably more progress is needed to enable consistent data analysis.

The developments noted here will all bring improvements to the data available about end of life care. However, greater benefit could be obtained by taking a strategic approach to identifying gaps in data, and how these could be addressed systematically. For example, routine linkage of health, social care and benefits data to mortality data would enable data on service use at the end of life to be published regularly.

Implications for public expenditure

Our analysis demonstrates the considerable public expenditure in the last year of life and highlights the potential to consider different resource decisions and how these could improve support for people at the end of life. There is only one chance to get end of life care right. In addition, the quality of support at the end of life has long-lasting impacts on bereaved families and friends.

Nationally, all UK governments have had health policies that aim to shift care from hospital to communities.[18] In England, this forms a key part of the government's strategy to make the NHS in England more sustainable, as it is, for example, for the Scottish Government and NHS Scotland.

The level of hospital spending in care in the last year of life overshadows all other spending, despite long-standing policy goals to improve provision of end of life care in community settings and reduce deaths in hospital. The structural factors that have prevented a significant shift in services to community settings need to be better understood and addressed.

Understanding the reasons for the higher proportion of people from the most deprived areas who die in hospital will be important for improving equity in provision of end of life care, and enabling a shift from hospital to community services. Access to social care for people at the end of life is likely to be an important factor in place of care and place of death. So too is the impact of poverty on whether individuals and their families have the resources to enable people to stay at home at the end of life.[32]

At a local level, we hope this analysis will enable health bodies responsible for commissioning and planning end of life care services to consider how services in their health system are designed, and to identify opportunities for improvement in end of life care.

Appendix 1

UK nations data

This section summarises the data for each UK nation separately.

The estimates provide a useful picture of spend in each nation, based on the best evidence we could identify. However, we urge caution if comparing expenditure between the four nations. There are differences in health and social care systems and demographic factors. In addition, the results are influenced by the underlying data, which may not always be specific to the nation context. It is therefore important to consider estimates for each nation alongside the bullet point notes on nation context, data limitations and differences. The sensitivity of results to these data limitations has been explored through sensitivity analysis.

The structure of social security benefits is broadly similar across the UK, but differences in each nation are noted.

England

Nation context

- Health and social care in England are the responsibility of the Department of Health and Social Care, and social security is the responsibility of the Department for Work and Pensions.
- Integrated Care Boards in England have a duty to plan end of life care services, but there are known to be wide variations in provision, and end of life care has often not been a priority relative to targets such as reducing elective waiting times.[33]
- England has the largest population to the extent that the estimates of expenditure per person for the UK are close to the estimates for England.
- However, it is important to recognise that there are widespread differences by region within England in age structure, deprivation and access to services.

Data notes and caveats

- The majority of research studies we identified were from England. Therefore, in most cases, we were able to use activity data specific to England, although the caveats and challenges discussed in Appendix 4 still apply.

Overall findings

Our analysis estimates that public expenditure on health care, social care and social security in England for people aged 18 or older, in 2022, was in the region of £18 billion – or £33,460 per person who died. When we modelled the impact of uncertainty on the results in a probabilistic sensitivity analysis, the probabilistic estimate was £17.8 billion with a 95% credible interval of £17.7 billion to £18.0 billion. One-way sensitivity analyses highlighted that the most influential parameters were emergency admissions, State Pension, residential and nursing home costs, elective admissions and outpatient appointments.

Table A1.1. Estimated spend on people in the last year of life by sector, England, 2022

Sector	Spend per person, £	£millions	%
Health care	17,630	9,463	53
Social care	7,290	3,911	22
Social security	8,550	4,588	26
All sectors	33,460	**17,961**	

Note: There were 536,700 deaths of people 18 and over in England in 2022; service spend may not add up due to rounding.

Health care

Total expenditure and expenditure per person on health care is summarised below, along with the activity estimates used.

Table A1.2. Estimated spend on health care in the last year of life by health care service, England, 2022

Setting	Subtype	Mean activity/ event per person who died	Spend per adult who died (£)	Total spend (£millions)
GP practice	Contacts	20.2	440	237
	Prescribing	--	780	418
	Subtotal	--	1,220	655
Community	**Subtotal**	10.0	800	432
Hospice care*	Inpatient	--	340	185
	Community and outpatient	--	310	165
	Subtotal	--	650	350
Unplanned care out of hospital	Ambulance	1.9	680	365
	NHS 111	1.2	45	24
	Subtotal	--	720	389
Unplanned care in hospital	ED visits	1.9	500	268
	Emergency admissions	1.7	9,360	5,024
	Subtotal	--	9,860	5,292
Planned care in hospital	Elective admissions	1.3	3,340	1,791
	Outpatient appointments	4.6	1,030	555
	Subtotal	--	4,370	2,346
Hospital care (all unplanned and planned care in hospital)	**Subtotal**	--	14,230	7,637
Health care	**Total**	--	17,630	9,463

Note: *NHS hospices and specialist services included in relevant sub-sector spend; service spend may not add up to sub-totals due to rounding.

Social care

Total expenditure and expenditure per person on social care is summarised below.

Table A1.3. Estimated total spend of social care in the final year of life, England, 2022/23

Social care	Social care service type	Spend per adult who died (£)	Total spend (£millions)
Local authority funded	Residential and nursing care	4,490	2,410
	Home care	810	436
	Other (including equipment and adaptations)	250	133
	Subtotal	5,550	2,980
CHC	Total	1,730	931
Social care	Total	7,290	3,911

Note: service spend may not add up to sub-totals due to rounding.

Social security

Total expenditure and expenditure per person on social security is summarised below.

Table A1.4. Estimated spend on social security in the last year of life by benefit type, England, 2022

Benefit	Social security benefit	Spend per adult who died (£)	Total spend (£millions)
Working age	Attendance Allowance	280	152
	Personal Independence Payment	380	202
	Universal Credit ill health	100	53
	Carers Allowance	70	37
	Housing benefit	50	28
Pensionable age	State Pension	7,600	4,079
	Pension credit	70	38
Total estimated spend		8,550	4,588

Note: service spend may not add up due to rounding.

Scotland

Nation context

- Health and social care is the responsibility of the Scottish Government. The Scottish Government has responsibility for some benefits, and the UK Department of Work and Pensions delivers Universal Credit, pensions and some other benefits on behalf of the Scottish Government.

- The Scottish Government's stated ambition is that "everyone who needs it can access well-coordinated, timely and high-quality palliative care, care around dying and bereavement support based on what matters to them", contained within their draft strategy 'Palliative Care matters for all', which will be finalised and published early in 2025.[34]

- Scotland has higher age-standardised mortality than other UK nations (see Appendix 3).

- Stakeholders highlighted that health and care services vary considerably across the country between urban areas and rural and island communities, so average rates and unit costs will not be applicable in all areas.

- In Scotland, personal care and nursing elements of social care are free at the point of use, although there is variation in how eligibility criteria are applied. For care home residents, a flat rate payment is paid for personal care and nursing fees.

Data notes and caveats

- For health care, we were not able to identify Scotland-specific research papers, except for a research study that related to people who died in 2016 and included activity for urgent and emergency care (UEC) – both in and out of hospital.[35] We were also unable to identify routine published health service statistics specifically for people at the end of life, which could have informed the analysis.

- To address gaps in Scotland-specific data, we used English estimates, or the average of English and Welsh estimates instead. English and Welsh activity estimates were similar for almost all health care activity types, and so we expect them to be broadly applicable to Scotland.

- Scottish unit costs were applied where available.[36] For hospital care, these were substantially higher than English unit costs, which may be the result of a number of factors, including differences in funding models, costing methodology and population.

- We used unit costs that exclude 'long stay' hospital activity: this is activity for people in hospital for six months or more, without a discharge date primarily in mental health and learning disability units, so not comparable to general admissions as used elsewhere in the analysis.

- All prescriptions are free in Scotland.

- Continuing Healthcare (CHC) in Scotland was replaced in 2015 with a different kind of funding called Hospital Based Complex Clinical Care (HBCCC).[37] HBCCC is used only for people who need care in hospitals and, as such, we decided to not include any CHC-equivalent expenditure as part of Scotland's social care costs.

- Special rules relating to end of life in place for the equivalents of Personal Independence Payment (PIP) and Attendance Allowance in Scotland (the Adult Disability Payment and Pension Age Disability Payment) do not include a timeframe as for other UK nations. Expenditure on PIP will likely be a slight underestimate for Scotland due to the introduction and subsequent shift towards Adult Disability Payment.

Overall findings

Our analysis estimates that public expenditure on health care, social care and social security in Scotland for people aged 18 or older, in 2022, to be in the region of £2 billion – or £36,590 per person who died. When we modelled the impact of uncertainty on the results in a probabilistic sensitivity analysis, the probabilistic estimate was £2.3 billion with a 95% credible interval of £2.2 billion to £2.3 billion.

One-way sensitivity analyses highlighted that the most influential parameters were emergency admissions, State Pension, residential and nursing home costs, elective admissions, outpatient appointments and prescribing costs.

Table A1.5. Estimated spend on people in the last year of life by sector, Scotland, 2022

Sector	Spend per person, £	£millions	%
Health care	21,170	1,327	58
Social care	7,240	454	20
Social security	8,180	512	22
All sectors	36,590	**2,293**	

Note: There were 62,700 deaths of people 18 and over in Scotland in 2022.

Health care

Total expenditure and expenditure per person on health care is summarised below, along with the activity estimates which were used.

Table A1.6. Estimated spend on health care in the last year of life by health care service, Scotland, 2022

Setting	Subtype	Mean activity/ event per person who died	Spend per adult who died (£)	Total spend (£millions)
GP practice	Contacts	20.2	440	28
	Prescribing	--	950	60
	Subtotal	--	1,390	87
Community	**Subtotal**	10.0	470	30
Hospice care*	Inpatient	--	320	20
	Community and outpatient	--	300	19
	Subtotal	--	620	39
Unplanned care out of hospital	Ambulance	1.7	620	39
	NHS 24	1.7	60	4
	Subtotal	--	680	43
Unplanned care in hospital	ED visits	1.4	330	20
	Emergency admissions	1.6	12,220	766
	Subtotal	--	12,550	787
Planned care in hospital	Elective admissions	1.3	4,400	276
	Outpatient appointments	4.6	1,060	66
	Subtotal	--	5,460	342
Hospital care (all unplanned and planned care in hospital)	**Subtotal**	--	18,010	1,129
Health care	**Total**	--	21,170	1,327

Note: *NHS hospices and specialist services included in relevant sub-sector spend; service spend may not add up to sub-totals due to rounding.

Social care

Total expenditure and expenditure per person on social care in Scotland is summarised below.

Table A1.7. Estimated total spend of social care in the final year of life, Scotland, 2022/23

Social care	Social care service type	Spend per adult who died (£)	Total spend (£millions)
Local authority funded	Residential and nursing care	5,860	367
	Home care	1,060	66
	Other (including equipment and adaptations)	320	20
Social care	Total	7,240	454

Note: service spend may not add up to sub-totals due to rounding

Social security

Total expenditure and expenditure per person on social security is summarised below.

Table A1.8. Estimated spend on social security in the last year of life by benefit type, Scotland, 2022

Benefit	Social security benefit	Spend per adult who died (£)	Total spend (£millions)
Working age	Attendance Allowance	240	15
	Personal Independence Payment	390	24
	Universal Credit ill health	90	6
	Carers Allowance	50	3
	Housing benefit	40	2
Pensionable age	State Pension	7,300	458
	Pension credit	60	4
Total estimated spend		8,180	512

Note: service spend may not add up due to rounding.

Wales

Nation context

- Health and social care in Wales is the responsibility of the Welsh Government. Social security is largely managed by the UK Department for Work and Pensions.
- Aspirations for palliative and end of life care (PEOLC) in Wales are set out in the Welsh Government's Quality Statement for Palliative and End of Life Care.
- The NHS Wales Executive provides strategic direction to health boards and other relevant bodies via the National Palliative and End of Life Care Programme Board.
- Delivery of PEOLC is the responsibility of health boards in their respective areas. Local authorities are responsible for the delivery of social care. Regional Partnership Boards bring together health boards, local authorities and the third sector to meet the care and support needs of people in their area.[38]
- Work to develop a palliative and end of life care service specification and review commissioning arrangements for hospices is ongoing.[39]
- Findings from the Marie Curie Better End of Life report 2024 indicate that patterns of provision are similar in Wales and England.[40] Stakeholders indicated that some areas of Wales have limited access to specialist services, particularly in sparsely populated areas.

Data notes and caveats

- We were provided with unpublished data on activity for people in the last year of life from the end of life care dashboard.[28] Rates of emergency admission for people in the last year of life were lower relative to other UK nations, and this is reflected in the lower overall spend on health care in Wales.
- Separate unit cost data was not available for Wales: we used an average of England, Scotland and Northern Ireland costs, as summarised in the hospital care section of Appendix 4.
- Health boards in Wales fund the salaries of specialist palliative care consultants, including for their work in independent hospices. This is reflected in the relatively lower spend per head on hospices.
- All prescriptions are free in Wales.

Overall findings

Our analysis estimates that public expenditure on health care, social care and social security in Wales for people aged 18 or older, in 2022, to be in the region of £1 billion – or £33,680 per person who died. When we modelled the impact of uncertainty on the results in a probabilistic sensitivity analysis, the probabilistic estimate was £1.2 billion with a 95% credible interval of £1.19 billion to £1.22 billion.

One-way sensitivity analyses highlighted that the most influential parameters were emergency admissions, State Pension, elective admissions, outpatient appointments and prescribing.

Table A1.9. Estimated spend on people in the last year of life by sector, Wales, 2022

Sector	Spend per person, £	£millions	%
Health care	17,170	610	51
Social care	8,070	287	24
Social security	8,430	300	25
All sectors	33,680	**1,197**	

Note: There were 35,500 deaths of people 18 and over in Wales in 2022.

Health care

Total expenditure and expenditure per person on health care is summarised below, along with the activity estimates used.

Table A1.10. Estimated spend on health care in the last year of life by health care service, Wales, 2022

Setting	Subtype	Mean activity/ event per person who died	Spend per adult who died (£)	Total spend (£millions)
GP practice	Contacts	20.2	440	16
	Prescribing	--	920	33
	Subtotal	--	1,360	48
Community	**Subtotal**	10.0	640	23
Hospice care*	Inpatient	--	160	6
	Community and outpatient	--	150	5
	Subtotal	--	310	11
Unplanned care out of hospital	Ambulance	0.9	350	12
	NHS 111	0.7	30	1
	Subtotal	--	370	13
Unplanned care in hospital	ED visits	1.4	340	12
	Emergency admissions	1.4	9,260	329
	Subtotal	--	9,600	341
Planned care in hospital	Elective admissions	1.2	3,730	133
	Outpatient appointments	4.6	1,160	41
	Subtotal	--	4,900	174
Hospital care (all unplanned and planned care in hospital)	**Subtotal**	--	14,500	515
Health care	**Total**	--	17,170	610

Note: *NHS hospices and specialist services included in relevant sub-sector spend; service spend may not add up to sub-totals due to rounding.

Social care

Total expenditure and expenditure per person on social care in Wales is summarised below, along with the activity and cost estimates used in estimation.

Table A1.11. Estimated total spend of social care in the final year of life, Wales, 2022/23

Social care	Social care service type	Spend per adult who died (£)	Total spend (£millions)
Local authority funded	Residential and nursing care	4,980	177
	Home care	900	32
	Other (including equipment and adaptations)	280	10
	Subtotal	6,150	219
CHC	**Total**	1,920	68
Social care	**Total**	8,070	287

Note: service spend may not add up to sub-totals due to rounding.

Social security

Total expenditure and expenditure per person on social security in Wales is summarised below, along with the activity and cost estimates used in estimation.

Table A1.12. Estimated spend on social security in the last year of life by benefit type, Wales, 2022

Benefit	Social security benefit	Spend per adult who died (£)	Total spend (£millions)
Working age	Attendance Allowance	240	8
	Personal Independence Payment	390	14
	Universal Credit ill health	90	3
	Carers Allowance	70	3
	Housing benefit	40	1
Pensionable age	State Pension	7,530	268
	Pension credit	70	3
Total estimated spend		**8,430**	**300**

Northern Ireland

Nation context

- Health, social care and social security in Northern Ireland are the responsibility of the Northern Ireland Executive.
- Northern Ireland has integrated health and care trusts that provide both health and social care.
- At present, Northern Ireland does not have an overarching palliative and end of life strategy, with the most recent document published in 2010.
- Historically, spending on social care has been higher in Northern Ireland than elsewhere in the UK.

Data notes and caveats

- We were not able to identify Northern Ireland-specific research papers, or routine published health service statistics specifically for people at the end of life. Therefore, in many cases, we used a combination of English or Welsh estimates instead (see Appendix 4). English and Welsh activity estimates were generally similar. However, the breakdown of costs should be interpreted with caution.
- Unit cost data for Northern Ireland is published at a granular level for individual treatments. Previous analysis by the Nuffield Trust identified consistently higher unit costs for comparable treatment to England.[17] The findings from this research were used to adjust unit costs for Northern Ireland (see Appendix 4: Hospital care).
- Prescriptions in Northern Ireland are free.
- The breakdown for people who have been identified as terminally ill on Universal Credit is not available for Northern Ireland. We have therefore made an estimate based on an average across England, Scotland and Wales.
- Spend on social security per adult who died is higher in Northern Ireland for Pension Credit compared to other UK nations: the average weekly amount received from Pension Credit is higher in Northern Ireland compared to other nations.

Overall findings

Our analysis estimates that public expenditure on health care, social care and social security in Northern Ireland for people aged 18 or older, in 2022, to be in the region of £688 million – or £40,410 per person who died.

When we modelled the impact of uncertainty on the results in a probabilistic sensitivity analysis, the probabilistic estimate was £690 million with a 95% credible interval of £682 million to £699 million. One-way sensitivity analyses highlighted that the most influential parameters were emergency admissions, State Pension, elective admissions, outpatient appointments and prescribing.

Table A1.13. Estimated spend on people in the last year of life by sector, Northern Ireland, 2022

Sector	Spend per person, £	£millions	%
Health care	20,490	349	51
Social care	11,700	199	29
Social security	8,210	140	20
All sectors	40,410	**688**	

Note: There were 17,000 deaths of people 18 and over in Northern Ireland in 2022.

Health care

Total expenditure and expenditure on health care is summarised below, along with the activity estimates used.

Table A1.14. Estimated spend on health care in the last year of life by health care service, Northern Ireland, 2022

Setting	Subtype	Mean activity/ event per person who died	Spend per adult who died (£)	Total spend (£millions)
GP practice	Contacts	20.2	440	8
	Prescribing	--	1,020	17
	Subtotal	--	1,460	25
Community	**Subtotal**	10.0	640	11
Hospice care*	Inpatient	--	370	6
	Community and outpatient	--	440	7
	Subtotal	--	810	14
Unplanned care out of hospital	Ambulance	1.5	550	9
	NHS 111	--	--	--
	Subtotal	--	550	9
Unplanned care in hospital	ED visits	1.6	390	7
	Emergency admissions	1.6	11,450	195
	Subtotal	--	11,840	202
Planned care in hospital	Elective admissions	1.3	3,970	68
	Outpatient appointments	4.6	1,230	21
	Subtotal	--	5,200	89
Hospital care (all unplanned and planned care in hospital)	**Subtotal**	--	17,040	290
Health care	**Total**	--	20,490	349

Note: *NHS hospices and specialist services included in relevant sub-sector spend; service spend may not add up to sub-totals due to rounding.

Social care

Total expenditure and expenditure per person on social care in Northern Ireland is summarised below.

Table A1.15. Estimated total spend of social care in the final year of life, Northern Ireland, 2022/23

Social care	Social care service type	Spend per adult who died (£)	Total spend (£millions)
Integrated health and social care trusts	Residential and nursing care	7,210	123
	Home care	1,300	22
	Other (including equipment and adaptations)	400	7
	Subtotal	8,920	152
CHC	Total	2,790	48
Social care	Total	11,700	199

Note: service spend may not add up to sub-totals due to rounding.

Social security

Total expenditure and expenditure per person on health care is summarised below, along with the activity and cost estimates used in estimation.

Table A1.16. Estimated spend on social security in the last year of life by benefit type, Northern Ireland, 2022

Benefit	Social security benefit	Spend per adult who died (£)	Total spend (£millions)
Working age	Attendance Allowance	200	3
	Personal Independence Payment	660	11
	Universal Credit ill health	120	2
	Carers Allowance	50	1
	Housing benefit	60	1
Pensionable age	State Pension	7,000	119
	Pension credit	120	2
Total estimated spend		8,210	140

Appendix 2

Evidence review and stakeholder engagement

We used a range of methods to identify relevant information sources for the estimates, validate assumptions and understand data sources and gaps.

We conducted a literature review to identify relevant published papers, alongside grey literature identified from previous work and stakeholders. We identified published data from NHS and statistics authorities in each UK nation. We also requested data using Freedom of Information requests and obtained unpublished management data from Hospice UK and NHS organisations.

We met with 50 stakeholders (listed below) and held a workshop with 24 people to review the interim findings. Individual meetings were held with stakeholders based on their areas of expertise, to identify additional sources of information that were not routinely published, and to understand the implications of gaps in data for the analysis. At the workshop, the interim high-level findings were presented, with feedback providing a sense-check of findings. Workshop attendees were then split into four groups and the detailed methodology used was presented and feedback sought, for social security; social care; community, primary and hospice care; and hospital and ambulance services.

Additional information was provided by stakeholders after the workshop, and we followed up with stakeholders undertaking similar analyses to test and refine assumptions.

Literature review

We carried out a literature review across three databases: Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Health Management and Information Consortium (HMIC). The search was carried out by Birmingham Library Service.

There was no time restriction applied to the literature search and search terms for the four nations were included. The search terms included a combination of: “last year of life”, “expenditure”, “health expenditure”, “cost or cost analysis”, “palliative care”, “terminal care”, “end of life” and “hospice”.

A total of 422 papers were identified in the search. Of these, 34 were reviewed in detail. Papers were included if the research contained either service activity or unit cost data for people at the end of life in the UK. After a full review of the data produced in the studies, a total of 25 papers were included as having relevant information. Notably, some of these 25 were identified and provided by stakeholders.

Stakeholders

Table A2.1. Stakeholders consulted during the analysis

Name	Role	Organisation
Amie Fairs	Senior Analyst	Office for National Statistics
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Appendix 3

Contextual information

Numbers of deaths by UK nation

Table A3.1 shows counts of deaths registered in 2022 for each UK nation, highlighting the total numbers of adult deaths. It also includes breakdowns by age group.[41-43]

Table A3.1. Deaths registered in 2022 by UK nation. Percentages are of all deaths in each nation (all ages, children, adults 18+), or of all adult deaths in each nation (age bands 18-44 to 85+).

Age at death	England		Scotland		Wales		Northern Ireland		UK	
All ages	540,333	100%	62,941	100%	35,694	100%	17,159	100%	656,127	100%
Children 0 - 17	3,607	0.7%	270	0.4%	162	0.5%	122	0.7%	4,161	0.6%
Adults 18+	**536,726**	**99.3%**	**62,671**	**99.6%**	**35,532**	**99.5%**	**17,037**	**99.3%**	**651,966**	**99.4%**
18-44	14,817	2.8%	2,025	3.2%	898	2.5%	529	3.1%	18,269	2.8%
45-54	20,745	3.9%	2,820	4.5%	1,321	3.7%	699	4.1%	25,585	3.9%
55-64	44,429	8.3%	6,174	9.9%	2,916	8.2%	1,592	9.3%	55,111	8.5%
65-74	85,443	15.9%	11,551	18.4%	6,163	17.3%	2,902	17.0%	106,059	16.3%
75-84	157,321	29.3%	18,789	30.0%	10,820	30.5%	5,057	29.7%	191,987	29.4%
85+	213,971	39.9%	21,312	34.0%	13,414	37.8%	6,258	36.7%	254,955	39.1%

Age standardised death ratios, UK nations

We adjusted death rates for age differences to allow us to take account of different population age profiles in some analyses. These are given in Table A3.2.

We calculated these for 2022, using mid-year population estimates,[44] and counts of deaths[41-43] by nation. We used single year-of-age figures (ages 18 to 89, and 90+ as one group) for the calculations.

The standardisation was carried out via two different methods, broadly reflecting indirect and direct standardisation methods. The two methods produced similar results; here we describe briefly the latter method for Scotland vs England (the same approach was taken for Wales and Northern Ireland).

For each of the 73 age groupings separately (individual years 18 to 89, and 90+), we calculated Scotland's death rate per head of population and multiplied this figure by England's population for the specific age year (or group for 90+).

For example, for 60-year-olds: in Scotland, 609 deaths in a population of 78,472 was equivalent to 0.0078 deaths per person in the year. If England (population of 60-year-olds of 728,806) had this same rate, we would have expected 0.0078 X 728,806 = 5,656.1 deaths (note that in fact England had 4,521 deaths of 60-year-olds).

We summed all of these Scotland-rates-applied-to-England-population figures across all ages 18 to 90+ (result = 639,939.6) and compared this number with England's observed total count of deaths (536,726), giving us the ratio 1.19. This ratio is interpretable as saying that Scotland had 19% more deaths than England, adjusting for population age structure.

The ratios in Table A3.2 are similar to ones we can calculate from figures published by ONS for 2020 for all ages.[45]

Table A3.2. Adult death ratios vs England, standardised by age (by single year of age, 18–89, and 90+), 2022

	UK nation			
	England	Scotland	Wales	Northern Ireland
Age standardised ratio of deaths vs England, 2022	1 (reference population)	1.19	1.09	1.04

Appendix 4

Methodology and data sources for costs and activity

Health care introduction

Key evidence sources

- The Nuffield Trust (2023) published data on use of hospital and GP practice services in the 12 months before death for two cohorts: those who died before the Covid-19 pandemic and those who died during the Covid-19 pandemic.[24] This research was undertaken using a large representative sample of the population of England from the OpenSAFELY system. The data included individual electronic health records of people registered at English GP practices using TPP SystmOne software. The analysis captured around 40% of all registered deaths, and the analysis cohort was representative of all deaths by sex, age group, cause of death and place of death.

- We also used results of further research on health care use at end of life from the same data source as above, but extended over a longer period of time.[14] We used data on emergency department (ED) visits, hospital admissions and outpatient appointments in the last month of life.[14]

- Luta et al (2020) reports on health care utilisation and costs in the last year of life in England by adults aged 60 and over who died in England between 2010 and 2017.[46] The analysis used Clinical Practice Research Datalink (CPRD) data, which is broadly representative of the UK general population in terms of age, sex and ethnicity.

- Mason et al (2020) summarise the results of an analysis of patterns of use and costs of unscheduled services for people aged 18 or older, in the last year of life in Scotland in 2016.[35]

- NHS England published experimental data on end of life referrals to community services as recorded in the Community Services Data Set (CSDS) in 2022/23.[47] Although this data is experimental and may not capture all people at the end of life, nor all community referrals, it was the most reliable source available at the time of analysis.

- The Marie Curie Better End of Life report 2024[40] on the findings from a national post-bereavement survey, the QUALYCARE survey, conducted in 2023 across England and Wales, was also used to derive several estimates of service use at the end of life.

We also obtained information directly from stakeholders:

- For Wales, unpublished data was provided to us by NHS Wales on NHS 111 contacts, ambulance activity, ED visits, and emergency and elective admissions.
- Hospice UK provided management data on cost-of-service provision, and funding from statutory and voluntary sources.

Dealing with gaps in evidence

The methods we took to overcome evidence gaps are summarised below:

1. We aimed to prioritise data on resource use for those who died in 2022, for which the most comprehensive data was available.
2. In the absence of 2022 data, we used data from earlier time periods.
3. In cases where data for a specific nation was unavailable, we used data from another nation as a proxy. When applying estimates from one nation to another, we attempted to account for differences in population demographics wherever possible. We acknowledge that service provision and healthcare usage patterns differ between nations.
4. We also encountered inconsistencies in how service use was reported. For example, proximity to death was reported in varying timeframes. As an example, 2022 data was only available on the number of non-elective admissions in the last month before death. Therefore, we adjusted the number using data from other sources to estimate non-elective admissions over the last 12 months of life.

Furthermore, estimating the costs of service use posed a challenge because there is no dedicated source of unit costs specifically for end of life care. End of life care often involves supporting individuals with more complex needs and intensive treatment; this is more expensive than the costs of care provided to the general population. We have used nation-specific data on unit costs for England[48] and Scotland.[36] We were able to uplift some unit costs for Northern Ireland using information published by Nuffield Trust (2022).[17] In discussion with stakeholders, and where data allowed, we applied an adjustment to amend (often increase) unit costs using additional data sources (e.g. unit costs for admissions were adjusted to take account of longer lengths of stay for people at the end of life). However, our analysis may underestimate actual expenditure, as we may not have been able to take full account of differences in complexity of need.

Approach

Full details of how each measure was calculated is included below. For most measures, we took the following approach:

Step 1: Estimated average activity use per person who died

- Where available, we used nation-specific data and evidence for people who died in 2022. However, this was not possible for all metrics. See below for full details on methods and data sources for each metric.

Step 2: Calculated average costs per person by multiplying activity estimates by unit costs

- The main sources of unit cost data were health service cost collections from NHS England and NHS Scotland. In addition, some unit costs were taken from the literature or derived using information from several sources.

Step 3: Estimated total spend for 2022

- We multiplied average costs per person by the number of people who died in 2022.

Health care activity and unit costs – detailed methods

General practice

GP practice spend includes two separate categories:

- Contacts with a health care professional
- Prescribing.

GP practice contacts

Care contacts

The mean number of in-hours GP practice contacts was estimated using data published by the Nuffield Trust (2023) as part of an analysis of health care activity of people at end of life.[24] This gave us data on GP practice contacts in the last 12 months of life for people who died after the start of the Covid-19 pandemic (as research indicates there has been a sustained increase in GP contacts by people at end of life since the onset of the pandemic).[14] This data had been published by place of death. So we estimated an England-level average (weighted by place of death) using information on deaths in England in 2022.[47] While the estimate of 18.3 contacts per person is specific to England, it is assumed to be the same across all four nations of the UK.

We also had information on out-of-hours contacts at the end of life.[35] The figure of 1.9 contacts per person who died relates to those aged 18 or older who died in Scotland in 2016. While this estimate is specific to Scotland, it is assumed to be the same across all four nations of the UK.

The number of out-of-hours contacts was added to the in-hours contacts, to give an average of 20.2 contacts per person in the last year of life.

Unit costs

We know that the cost of GP practice activity differs depending on how and by whom appointments are delivered. To account for this, we used 2022 data on appointments that took place in general practice in England to estimate the proportion of appointments by health care professional and mode of delivery.[49]

We then applied these proportions to the total estimated mean number of GP contacts (20.2) for the last year of life, as shown in Table A4.1, to derive estimates of mean end of life care contacts by health care professional and mode of delivery. Estimates for unit costs were taken from PSSRU (Personal Social Services Research Unit) 2022/23:[50]

- GP face-to-face contact: unit cost per surgery consultation lasting 10 minutes
- GP telephone contact: unit cost of a telephone call as part of e-consultation
- Other health care professional face-to-face contact: this was estimated using cost per hour of a Band 5 GP practice nurse (£53), assuming 10-minute consultations
- Other health care professional telephone contact: same as above.

We multiplied the unit costs by the estimated mean contacts per adult who died, and summed across all categories to derive an overall estimated cost per adult who died (Table 2 and Appendix 1 tables).

Table A4.1. Estimates of GP activity and unit cost

Proportion of activity by professional and model of delivery (%)			Estimated mean number of contacts per adult who died (N)	Unit cost (£)	Spend per adult who died (£)
General Practitioner	Face-to-face	29.3	5.9	49	290
	Telephone	23.0	4.6	14	70
Other health care professional	Face-to-face	38.0	7.7	9	70
	Telephone	9.8	2.0	9	20

Prescribing

We calculated a nation-specific average spend per adult who died aged 18 or older, weighted by age, using evidence from the literature,[46] national prescribing statistics[51] and information on deaths by age in 2022.[41-43]

England-specific prescribing data, published by Luta et al (2024),[46] provided data on primary care prescribing spend per person in the last year of life for those aged 60 or older by 10-year age bands. This was combined with national statistics on net ingredient costs (NIC) per head of population to estimate spend in the other three nations.[51]

We adjusted the England data by applying the proportionate difference in NIC costs per person between England and each nation. For example, prescribing costs per head were 22% higher in Scotland than in England in 2022/23. Therefore, we assumed that prescribing costs would be higher by the same amount across all age groups.

For those aged below 60, we assumed that average spend was equivalent to NIC per head of population.

We then calculated a nation-specific weighted average spend per adult who died aged 18 or older – see Table A4.2.

Table A4.2. Estimated spend on prescribing in the last year of life per person who died

	Average spend per person (£)
England	780
Scotland	950
Wales	920
Northern Ireland	1,020

Community

Care contacts

Marie Curie (2024) found that approximately 40% of people who died in England and Wales received input from a community or district nurse in the last three months of life.[40] Based on this, we made a conservative assumption that 40% of those who died in 2022 had a referral to an end-of-life (EoL) community service in the last year of life.

To estimate the number of contacts per person who died, we divided the population of people who died in each nation according to those who had a referral and those who did not. Using 2022/23 data from England, we estimated that individuals who were referred to an end of life community service had an average of 16.5 care contacts.[47] For those who did not receive a referral, we assume that they had on average 5.5 contacts, based on the mean number of contacts per referral in England in 2021/22.[52]

This method was applied to all four nations as data was only available for England.

Unit costs

The unit costs for England (£80) and Scotland (£47) were taken from their respective national cost collections[36, 48] and the average of both (£64) was used for Wales and Northern Ireland (Table A4.3).[36,48]

Table A4.3. Community care contacts and unit costs

	Average number of contacts per person who died (N)	Unit cost (£)	Average spend per person who died (£)
England	10.0	80	800
Scotland	10.0	47	470
Wales	10.0	64	640
Northern Ireland	10.0	64	640

Unplanned care out of hospital

NHS 111/NHS 24

Care contacts

Information on the mean number of contacts (1.7) in Scotland was published in Mason et al (2020),[35] while NHS Wales (0.7) provided data directly. The average of both was used as an estimate of the mean number of contacts (1.2) in England only and no information was included for Northern Ireland since there is no similar service in operation.

Unit costs

We used the unit cost included in Mason et al (2020) (£30.78),[35] inflated to 2022 prices, which was provided direct by NHS 24. We applied this across England, Scotland and Wales.

Table A4.4. NHS 11/NHS 24 contacts and unit costs

	Average number of contacts per person who died (N)	Unit cost (£)	Average spend per person who died (£)
England	1.2	37	50
Scotland	1.7	37	60
Wales	0.7	37	30
Northern Ireland	--	--	--

Ambulance

Care contacts

Information on the mean number of contacts (1.7) in Scotland was published in Mason et al (2020),[35] whereas it was provided directly by NHS Wales (0.9). The mean number of contacts for England (1.9) was derived using England-specific data reported in the Marie Curie Better End of Life report 2024[40] on contacts in the last three months of life, uplifted to 12 months by assuming the same proportionate difference between three- and 12-month activity reported in Mason et al (2020).[35] The mean number of contacts in Northern Ireland (1.5) was assumed to be the crude average of the three other nations.

Unit costs

Unit costs specific to England[48] were used (taken from NHS National Cost Collection [NCC], 2022/23) and assumed to be the same across all four nations. Since unit costs for ambulances vary depending on whether an ambulance crew is dispatched and/or whether a patient is transported to hospital, we aimed to account for this by splitting the mean number of ambulance contacts according to NHS NCC categories for England: "hear and treat", "see and treat", and "see and convey".[48]

We used ambulance activity data from the NHS NCC to do this and assumed that the distribution of incidents across all three categories was the same for those who died as it was for the general population. This is likely an underestimation of actual spend given that elderly people are conveyed at a higher rate than younger people.

Table A4.5. Ambulance service contacts

	Average number of contacts (N)	Average spend per person who died (£)
England	1.9	680
Scotland	1.7	620
Wales	0.9	350
Northern Ireland	1.5	550

Hospital care – unplanned and planned

Hospital care was categorised into the following types of activity:

- **Unplanned care:** emergency department visits and non-elective admissions
- **Planned care:** elective admissions and outpatient appointments.

England

Care contacts

Care contacts for hospital care were derived from data on the average number of contacts a person had during the last month of life in 2022,[25] scaled up to cover 12 months using findings from prior analyses of healthcare activity, which included a breakdown of activity in the last one, three and 12 months of life.[24]

Unit costs

We used unit costs on ED visits and outpatient appointments directly from NHS NCC 2022/23.[48] However, we adjusted NHS NCC unit costs for elective and non-elective admissions to estimate a unit cost for admissions at end of life as we know that the length of stay differs as people approach the end of life.[53] The results of an analysis of 2022 hospital activity by the Health Foundation found the average length of stay for non-elective and elective admissions to be 9.1 and 5.1 days respectively.[53] In contrast, research by the Nuffield Trust, on activity by people who died in 2018/19, reported average lengths of stay of 19.6 days and 2.7 days respectively.[24]

To account for this variation, we calculated an implied "cost per bed day" by dividing the NHS NCC unit cost by the average length of stay for all admissions, according to the Health Foundation (2023).[48, 53] We then multiplied this "cost per bed day" by the average length of stay at the end of life reported by Nuffield Trust (2023) to derive an adjusted unit cost for admissions at end of life.[24] This method assumes that daily costs are uniform throughout a hospital stay.

Table A4.6 provides a summary of the mean number of contacts, unit costs and spend per person used for England in the analysis.

Table A4.6. Mean contacts, unit costs and average spend per person on hospital care, England

		Average number of contacts (N)	Unit cost (£)	Average spend per person (£)
Unplanned care	ED visits	1.9	263	500
	Unplanned admissions	1.7	5,506	9,360
Planned care	Elective admissions	1.3	2,566	3,340
	Outpatient appointments attended	4.6	225	1,030

Scotland

Care contacts

Care contacts for unplanned care (ED visits and unplanned admissions) were taken from Mason et al (2020).[35] We were unable to find Scotland-specific data for elective admissions and outpatient appointments attended in the last year of life. Therefore, the estimate for elective admissions was assumed to be a crude average of England and Wales, and outpatient activity was assumed to be equivalent to England (as this was the only source across the four nations).

Unit costs

For Scotland, we used unit costs included in NHS Scotland's Costs Book for ED visits and outpatient appointments.[36]

However, estimating unit costs for non-elective and elective admissions in Scotland presented several challenges, as NHS Scotland only provides a unit cost for all admissions combined. In 2022, the unit cost for all admissions, excluding long stays*, was £3,254, with an average length of stay of 4.8 days.[54] However, no Scotland-specific data on hospital length of stay for individuals at the end of life could be identified.

To address this, we derived unit costs for elective and non-elective admissions at end of life by first accounting for the different length of stay typically observed at the end of life and then splitting the overall unit cost into non-elective and elective components. The adjustment for length of stay was carried out using a similar method to that used for England. Specifically, we calculated an implied "cost per bed day" using Scotland-specific data on the average length of stay and cost per admission. In the absence of data on length of stay at end of life in Scotland, we assumed the proportional increase in length of stay at end of life relative to the average was the same as in England, i.e. the proportional difference between overall length of stay[53] and length of stay at end of life[24] in England.

Using this approach, the estimated cost per admission at end of life in Scotland was £8,046. To further derive unit costs for elective and non-elective admissions, we assumed that the relative cost of each type of admission to the overall cost mirrored the differences observed in England.

Table A4.7 provides a summary of the mean number of contacts, unit costs and spend per person for Scotland used in the analysis.

Table A4.7. Mean contacts, unit costs and average spend per person on hospital care, Scotland

		Average number of contacts (N)	Unit cost (£)	Average spend per person (£)
Unplanned care	ED visits	1.4	227	330
	Unplanned admissions	1.6	7,514	12,220
Planned care	Elective admissions	1.3	3,502	4,400
	Outpatient appointments attended	4.6	230	1,060

*Long stay patients include people who have been in hospital for longer than six months with no discharge date https://www.gov.scot/publications/inpatient-census-2022-hospital-based-complex-clinical-care-long-stay/pages/5/#:~:text=Number%20of%20HBCCC%20and%20Long,refer%20to%20all%20HBCCC%20patients.

Wales

Care contacts

NHS Wales provided data on the mean number of ED visits, non-elective and elective admissions. Outpatient activity was assumed to be equivalent to England as no alternative source was identified for Wales.

Unit costs

NHS Wales does not publish unit costs for activity. Instead, ED visit costs were assumed to be the average of those in England and Scotland. The remaining unit costs were assumed to be an average of England, Scotland and Northern Ireland. Table A4.8 provides a summary of the mean number of contacts, unit costs and spend per person for Wales used in the analysis.

Table A4.8. Mean contacts, unit costs and average spend per person on hospital care, Wales

		Average number of contacts (N)	Unit cost (£)	Average spend per person (£)
Unplanned care	ED visits	1.4	245	340
	Unplanned admissions	1.4	6,781	9,260
Planned care	Elective admissions	1.2	3,075	3,730
	Outpatient appointments attended	4.6	252	1,160

Northern Ireland

Care contacts

Unfortunately, we found no data specific to Northern Ireland and we therefore took the average values of the other nations where these were available.

Unit costs

Similar to Wales, Northern Ireland does not publish unit costs for health care activity.

However, we were able to uplift unit costs for England using prior research by the Nuffield Trust on the difference between the cost of health care in England and Northern Ireland.[17]

Table A4.9 provides a summary of the mean number of contacts, unit costs and spend per person for Northern Ireland used in the analysis.

Table A4.9. Mean contacts, unit costs and average spend per person on hospital care, Northern Ireland

		Average number of contacts (N)	Unit cost (£)	Average spend per person (£)
Unplanned care	ED visits	1.6	245	390
	Unplanned admissions	1.6	7,323	11,450
Planned care	Elective admissions	1.3	3,156	3,970
	Outpatient appointments attended	4.6	267	1,230

Hospice care

Data on public expenditure on independent hospices was provided by Hospice UK, a membership organisation for independent hospices, and relates to the year 2021/22. It does not cover inpatient hospice units or other specialist palliative care services provided within the NHS: the costs of these would be subsumed within the broader health estimates discussed above.

Hospice UK provided underlying data used to produce their key facts on hospice care (Table A4.10).[55] Annual expenditure includes total charitable expenditure on services provided by hospices, along with elements of this that were funded from statutory sources, which includes services commissioned by the NHS, and government grants. Expenditure by hospices on fundraising or retail activities is excluded. Only the statutory expenditure is included in the public expenditure in the last year of life. Expenditure on hospices providing services only to children was excluded.

Expenditure per person who died was calculated using the total number of deaths of people aged 18 and over in 2022.

Table A4.10. Hospice expenditure 2021/22

	England	Scotland	Wales	Northern Ireland	UK
Charitable spend £millions	795.2	81.4	33.7	30.3	940.6
Public expenditure £millions	350.1	38.7	10.9	13.8	413.6
% public	44%	48%	32%	46%	44%
People who died aged 18+	536,726	62,671	35,532	17,037	651,966
Total expenditure per person who died	£1,482	£1,299	£948	£1,780	£1,443
Public expenditure per person who died	£652	£618	£308	£813	£634

Activity data from Hospice UK's key facts was used to estimate expenditure on hospice inpatient services. We used a published estimate of daily cost for inpatient hospice care (£823) and applied this to the proportion of hospice inpatient bed days funded from statutory sources.[56] Expenditure on all other hospice services was estimated by subtracting the inpatient expenditure from total expenditure.

Social Care

LA-funded (and equivalent in NI)

Data sources

We used two primary sources of information.

The first was a study of final year of life health and social care service activity and costs for more than 73,000 people who died over a three-year period in seven English local authority (LA) areas.[6]

The second was annual expenditure data on social care services in England and the other UK nations. These were themselves from two different sets of data. We used English Adult Social Care Activity and Finance Report[57] information to derive an estimate of final year of life care spend as a proportion of all social care expenditure. We then applied this proportion to expenditure for all nations (modified as noted below) as recorded in the Country and Regional Analysis statistical publications.[58]

We additionally used two further types of data – deaths[41, 42] and population[43,44] information for 2022 – to compare standardised adult death rates between UK nations (see Appendix 3).

Methodology

Estimate of final year of life expenditure as a proportion of all social care expenditure, England

Georghiou and others (2012) found that total costs of LA-funded social care services in the final year of life were on the scale of £255 million for 73,243 people who died (£3,486 per person who died). The 2012 study did not aim to calculate the costs of services for all people in the study areas, and so did not estimate final year costs as a proportion of all social care service costs. We aimed to do this as a first step.

A calculation was made to restate the £255 million in terms of deaths during a single year (study sites had provided information on between one and three years of deaths covering 2007/08 to 2009/10). This was calculated to be £113 million. Table A4.11 shows the study totals and the single-year estimates, by type of activity.

Table A4.11. Costs of LA-funded adult social care services in final year of life

Type of social care service	Total in Georghiou others 2012, £millions (% of all)	Estimated total for a single year of deaths, £millions (% of all)	Estimated %: these costs as a proportion of all LA adult social care costs in 2008/09
All	255.3 (100%)	113.4 (100%)	11.8%
Residential and nursing care	204.7 (80%)	91.8 (81%)	9.5%
Home care	39.6 (16%)	16.6 (15%)	1.7%
Other	11.0 (4%)	5.1 (4%)	0.5%

We used Adult Social Care Activity and Finance Report information for seven recent years (2017/18 to 2023/24 inclusive) to calculate the seven study sites' "net current expenditure" (NCE; broadly this is expenditure minus capital costs and income) totals as a proportion of England's overall NCE. This was a mean of 6.9% over the seven years (with a narrow standard deviation of 0.2% and no appreciable time trend).

We assumed this ratio had been stable going back another decade, and applied this value to England's total NCE in 2008/09 to estimate the seven study sites' expenditure (prior to 2017/18, NCE data was not available by LA area). This was 6.9% x £13.85 billion = £961.6 million.

Final year of life costs as a proportion of this total estimated expenditure therefore was 113.4 / 961.6 = 11.8%. Table A4.11 also presents this estimate and breaks it down into key categories of social care activity.

Application to UK nations

Having estimated that 11.8% of social care costs in 2008/09 were spent on people in the final year of life, we next assumed that this was stable over time and applied it to England total social care expenditure for more recent years. The assumption that this is stable is something we were not able to test; ultimately, this is the only data point we have. It should be noted that others using the same source to provide unit costs for end of life care costs (via the Personal Social Services Research Unit costs of health and social care)[59] make similar – but implicit – assumptions, whereas our method makes this explicit (and also effectively adjusts for changes in activity over time, and not just inflation).

In applying this value to the other UK nations, we modified it to take account of differing rates of deaths in the populations, multiplying 11.8% by the standardised death ratio relative to England (these are given in Table A3.2).

The resulting nation-specific percentage estimates are given in Table A4.12.

Table A4.12. Percentage of total LA-funded (or equivalent in Northern Ireland) social care expenditure estimated as having been spent on people who were in the last year of life

	UK nation			
Type of social care service	England	Scotland	Wales	Northern Ireland
All	11.8%	14.1%	12.8%	12.2%
Residential and nursing care	9.5%	11.4%	10.4%	9.9%
Home care	1.7%	2.1%	1.9%	1.8%
Other	0.5%	0.6%	0.6%	0.5%

To apply these factors to recent expenditure data for all nations, including England, we switched source to Country and regional analysis statistics (Table A4.13). This data excludes income, but includes capital expenditure, and is considered to be the best source for comparative UK-nation activity. For England, we additionally added significant adult social care income from the NHS (including, but not limited to, Better Care Fund expenditure) as captured in Adult Social Care Activity and Finance Report data tables.

Table A4.13. From Country and regional analysis: total identifiable expenditure on services for adults, 2022-23. Personal social services categories, excluding "Family and children" and "Social exclusion"

UK nation			
England (£millions)	Scotland (£millions)	Wales (£millions)	Northern Ireland (£millions)
25,260	3,228	1,703	1,240

The factors in Table A4.12 applied (by simple multiplication) to the expenditure figures in Table A4.13 give us the results in Table A4.14.

Table A4.14. Estimates of LA-funded (or equivalent in Northern Ireland) expenditure on social care services for adults in the last year of life, 2022-23

	UK nation			
Type of social care service	England (£millions)	Scotland (£millions)	Wales (£millions)	Northern Ireland (£millions)
All LA-funded services	2,979.5	454.0	218.6	151.9
Residential and nursing care	2,410.1	367.2	176.8	122.9
Home care	435.9	66.4	32.0	22.2
Other (including equipment and adaptations)	133.4	20.3	9.8	6.8

The figures for the UK nations were difficult to validate using other evidence. As it made up by far the largest estimated proportion of expenditure, we focused on validating estimates of residential and nursing care expenditure only.

NHS Continuing Healthcare (CHC)

Data sources

We used data supplied by NHS England in response to a Freedom of Information request (FOI-2404-2091624). This data contained spend on NHS CHC over six years (2017/18 to 2022/23 inclusive), in England, in three categories of CHC service (standard, fast-track pathway and funded nursing care).

Methodology

Estimate of England-specific final year of life CHC expenditure

One CHC service type, fast-track, is considered to be substantially, although not necessarily entirely, relevant to end of life care. It is used for people with a rapidly deteriorating condition. To account for this, we applied an assumption that four-fifths (80%) of this category was final year of life care activity.

For the other two service types (standard and funded nursing), we have used the social care percentages calculated in the previous section to estimate the portion of expenditure relevant to final year of life costs.

Resulting estimates for England in 2022/23 are given in Table A4.15.

We acknowledge these estimates are less reliable than our other findings; there is little known at the national level about the people receiving CHC services (e.g. age profiles).

Table A4.15. 2022/23 NHS Continuing Healthcare costs, England (FOI source), and estimated portion spent on people in the final year of life

CHC category	Total expenditure, (£millions)	Estimated % final year of life	Estimated final year of life costs (£millions)
CHC – standard	3,003	11.8%	354.1
CHC – Fast-track	606	80%	484.7
Funded Nursing Care	782	11.8%	92.3
All	4,390.8	(21.2% equivalent)	931.1

Estimating for Scotland, Wales and Northern Ireland

The England CHC estimate of £931 million was equivalent to 34% of the 2022/23 LA-funded service estimate of £2,702 million (Table A4.14). In the absence of data for the other nations, we applied this 34% figure to Wales and Northern Ireland's LA or Integrated Trust-funded service estimate, to give a CHC estimate.

We decided that Scotland's replacement for CHC – Hospital Based Complex Clinical Care (HBCCC) – was not equivalent to NHS CHC, being only for people needing hospital care, and so have set Scotland's CHC costs to zero.

Estimates are shown in Table A4.16.

Table A4.16. Estimates of NHS CHC expenditure for adults in the last year of life, 2022-23, £millions

UK nation			
England	Scotland*	Wales	Northern Ireland
931.1	0	68.3	47.5

*In Scotland, CHC was replaced by Hospital Based Complex Clinical Care in 2015; for the purposes of this study, we considered this to be distinct from NHS CHC social care expenditure

Little is known about the recipients of NHS CHC services in England, let alone the other nations. This makes our estimates difficult to verify, but we found some evidence to suggest that the estimate for Wales was reasonable (details available on request).

Social security

Data sources and benefits included

We used Department for Work and Pensions (DWP) benefit data accessed using Stat-Xplore. For each benefit, the data was broken down by nation and age. For Northern Ireland, we used published data from the Department for Communities. For the most part, eligibility for benefits is the same across all UK nations. Table A4.18 summarises eligibility and data availability for the benefits we considered.

We chose to look at special rules for the end of life (SREL) for those benefits where this data is available. It is notable that there will be people in the last year of life receiving benefits not under SREL. However, we expect this number to be small based on stakeholder feedback. Further, there is no linked data publicly available that would allow us to make this estimate by linking deaths and social security data. SREL is therefore the best estimate we have for the number of people receiving benefits in last year of life.

Notably, a policy change around SREL was implemented in April 2023. Prior to this, SREL only applied to people who were likely to have six months or less to live. Now a person can apply for SREL if they are likely to have 12 months or less to live. The application should be supported by an SR1 form, completed by a clinician. In Scotland, the SREL differ slightly, as an open-ended definition of end of life is in place. As such, no timeframe before death is required to be eligible for benefits related to ill health.

Table A4.17. Summary of benefits that have been considered and brief overview of data availability

Benefit	Eligibility	Special rules for end of life	Data availability
Working age benefits			
Personal Independence Payment (PIP): daily living and mobility component	Between 16 and State Pension age. Need help with daily living or mobility.	Can claim PIP under the special rules for people at the end of life. Claim will be fast-tracked and enhanced rate of daily living component is given. Mobility component is not automatic; depends on the extent to which it's needed. Vast majority will receive highest rate. Can apply if healthcare professionals think you have less than a year to live.	UK-wide, claimants under special rules
Universal Credit: limited capability for work entitlement, carers entitlement and housing entitlement	Between 18 and State Pension age. Low income of below £16k.	Means tested. Can claim under special rules if health care professional thinks you have less than one year to live. Still have to meet the low-income criteria for Universal Credit, but benefit will be paid quicker and the limited capability for work and work-related activity element (LCWRA) will be provided.	England, Scotland and Wales, claimants listed as terminally ill.
Carers Allowance	Care for someone for at least 35 hours a week.	Means tested. No special rules for the end of life. A few pensioners may be eligible, but most will have income above the threshold.	
Pensionable age			
State Pension	State Pension age	No special rules and can't claim State Pension earlier than State Pension age regardless of health. Dependent on national insurance contributions over lifetime.	UK-wide
Pension Credit	State Pension age, low income.	No special rules and is means tested. Can also receive housing benefits or support for mortgage interest if receiving Pension Credit.	UK-wide
Attendance Allowance	State Pension age. Need support caring for yourself.	Can claim under special rules if healthcare professional thinks you have less than one year left to live. Claim will be fast-tracked and higher rate received.	UK-wide, claimants listed as terminally ill.

Different approaches were taken to determine the number of people claiming under SREL for each benefit, based on advice from stakeholders and availability of data. We could not include Employment Support Allowance (ESA) because no data on the number of people receiving ESA under special rules is available and, based on advice from stakeholders, there are challenges to using the available data to make a credible estimate. We did not include the carers element of Universal Credit as this is not provided for the end of life population and we expect the majority of public expenditure on carers will be Carers Allowance.

We were unable to include benefits paid by local authorities and for which there is no standardised approach across or within UK nations. For example, we have not allowed for expenditure on council tax exemptions or reductions. We expect this to be a small amount, particularly in comparison to the housing element of Universal Credit we have included. We have also not included bereavement payments, for which the amount is dependent on factors such as number of children and the number of people claiming is very small.

Personal Independence Payments (PIP)

Personal Independence Payment (PIP) is the only benefit where published data on the number of people claiming under SREL is available. We used the Cases with Entitlement dataset, which provides the number of people who were claiming PIP under SREL in each month. For Northern Ireland, we requested the number of SREL claims in payment for each month of 2022 from the Department for Communities.

To calculate the amount received by claimants, we used DWP data on the weekly rate of PIP and used this to obtain monthly values. We used the highest rate of daily living and mobility allowance. Then, ensuring the correct benefit value by financial year is applied to each month, we multiplied the number of claimants by the monthly amount of PIP received. We then totalled this number to give the overall amount for 2022.

In Scotland, the move to Adult Disability Payment (ADP) began in June 2022. However, the first reporting of this benefit was April 2023, meaning it's not possible to include these figures in the 2022 estimate. As such, the Scotland expenditure on PIP SREL will likely be a small underestimate as some people will have been moved to ADP at the end of 2022.

Attendance Allowance (AA)

For Attendance Allowance, we used the Cases with Entitlement: the Attendance Allowance dataset, which allows users to filter by medical condition. We therefore selected only those who were listed as "terminally ill". DWP defines "terminally ill" as: "For benefit purposes, DWP describes a terminally ill claimant as having a progressive disease or health condition and due to that condition, they may or may not have more than 12 months life expectancy."[60]

The data is presented quarterly. To calculate the amount received by claimants, we averaged the quarters to give an estimate of the number of people receiving AA for every month in 2022. We then took the highest weekly rate of AA, provided by DWP, and used this to obtain monthly values. Using the same approach to calculate PIP, we produced an overall amount for 2022.

Universal Credit

For Universal Credit, we used the health caseload dataset, which provides the

number of people on Universal Credit with a health condition or disability restricting their ability to work. The dataset allows you to select people who have been identified as "terminally ill" to estimate the number of people on Universal Credit under SREL.

To calculate the amount received by claimants, we used the standard monthly allowance for an individual over 25 as well as the extra monthly allowance for claimants who have limited capability for work and work-related activity.

We then applied the same approach used for PIP to produce an overall total amount in 2022. The breakdown for people who have been identified as terminally ill on Universal Credit is not available for Northern Ireland. To produce an estimate, we calculated the proportion of working age population that received Universal Credit who are terminally ill for England, Wales and Scotland and took an average of this proportion. We then applied this proportion to the working age population in Northern Ireland to give an estimate of the total number of people on Universal Credit who are terminally ill in Northern Ireland.

State Pension and Pension Credit

For State Pension and Pension Credit, we took a different approach to account for the fact that these benefits do not have special rules for the end of life. We used the State Pension dataset, which provides State Pension caseload and the mean of weekly amounts on a quarterly basis, and applied this to population data.

For each single year of age, we took the total population and the number of deaths and calculated the deaths per population as a proportion.

Using the State Pension data, for each age band we took the caseload and mean of weekly amount, uplifting this to a monthly amount, and multiplied these together to give the monthly spend on pension for each age band. We then applied this across the year 2022 and to every age band.

For Pension Credit, we took the same approach using the Pension Credit dataset, which provides the same information as State Pension dataset. Pension Credit is means-tested. To account for this, we used findings from previous research. The Marie Curie Dying in Poverty report estimated that 16% of pension age people died in poverty. We therefore applied this 16% to the population that died.[8]

Northern Ireland doesn't have single age bands breakdown. We therefore used the available age band data and divided this by the number of single ages within the band to get single age estimates. We then applied the same approach as above to these single age estimates.

Housing benefits

Housing benefit is being replaced by Universal Credit. As the majority of households have moved to Universal Credit, we made an estimate based on the housing element of Universal Credit. There is no data available on the number of people on special rules at the end of life who receive the housing element of Universal Credit. We have therefore taken an approach to estimate this.

The amount received from the housing element varies based on factors such as the number of bedrooms and local authority.

DWP provides the average amount of Universal Credit received by those who

receive the housing element and the average amount for those who do not. We can calculate the difference in amount received to estimate the average housing element paid at household level. Using this same dataset, we were also able to estimate the proportion of people who are on Universal Credit that receive housing element.

We then applied this proportion to the number of people who are terminally ill receiving Universal Credit to produce an estimate of the number of people who are terminally ill that are receiving housing element.

To calculate the total cost, we multiplied this number by the average monthly amount received as housing element. We then totalled this up to give an overall amount for 2022.

We don't have this data for Northern Ireland on the housing element of Universal Credit, so we applied our estimate for the number of people in Northern Ireland who are terminally ill receiving Universal Credit to an average of England, Scotland and Wales average monthly amount of housing element received and proportion of people receiving housing element.

Carers Allowance

Carers Allowance has no special rules for the end of life, we have made an estimate based on previously published reports, census data and available DWP data.

We started with the number of people who are on special rules at the end of life for PIP and the number of people who receive Attendance Allowance who are terminally ill. In order to be eligible for Carers Allowance, carers must be caring for someone in receipt of these benefits.

To estimate the number of people who had an informal carer at the end of life, we used the Marie Curie Better End of Life report 2024.[40] The figures from this report, which is based on survey data from England and Wales, suggest that 74.7% of people who had died received informal care.

We then used census 2021 data to estimate the proportion of these informal carers who could be eligible for Carers Allowance based on the number of hours they cared for someone in a week (35+ hours). We used the census question: "Do you look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age?" The question then asks to select the number of hours spent caring. We used the number of people who selected 35 to 49 hours a week or 50 or more hours a week and divided this by the total number of people who answered "yes" to this question for each of the four nations. This gives us the proportion of people who are informal carers that could be eligible for Carers Allowance, based on the fact they spend over 35 hours a week as an informal carer.

However, Carers Allowance is means-tested, which means an even smaller proportion will receive it. To calculate this, we used the number of cases with entitlement for people on Carers Allowance in November 2021. This produces an estimate for the proportion of people who are eligible for Carers Allowance.

Using DWP data, we multiplied this number by the yearly amount received from Carers Allowance by a person in 2022.

Appendix 5

Uncertainty in our estimates

The impact of uncertainty on the total expenditure in the last year of life was explored using a probabilistic sensitivity analysis (PSA) and a one-way deterministic sensitivity analysis (DSA).

Probabilistic sensitivity analysis

A PSA was undertaken with 10,000 model simulations to capture the impact of parameter uncertainty on the results. The gamma distribution was used to inform the probabilistic values for cost and activity parameters. Where standard errors can be drawn from the literature or derived from datasets, these are used to inform the extent of uncertainty in the parameters; otherwise, we conservatively assume a standard error equivalent to the mean, as per the approach in Round et al (2015).[61] Where there is unlikely to be measurement error or uncertainty in the dataset – for example, number of adults who died, these parameters have not been varied in the PSA.

Deterministic sensitivity analysis

We explored the impact of varying inputs by +/- 10% on the total expenditure estimate in a series of one-way sensitivity analyses. The analyses identified the parameters that demonstrate the greatest deviation from the base case results.

Appendix 6

Comparison to all public expenditure

The estimates of expenditure related to different health care services that we have made in this study do not include all health care-related costs. Expenditure on mental health and public health services, and capital costs, for example, are not included directly in our estimates. Therefore, a comparison to total health expenditure in each nation (which will include these significant areas of expenditure and which are not generally broken down into the categories we have used) is not possible.

However, a recent detailed analysis of direct care health expenditure in England from the Nuffield Trust[16] enables a comparison for broad areas of spending (Table A6.1). We find that for hospital and ambulance services, final year of life expenditure is around 10% of total spend. For primary care, the figure is around 2%, and for community services, around 4%. Note that the total spend estimates will not include all activity (see Table A6.1 notes), and so these may be overestimates.

Table A6.1. Comparison of all health care expenditure and expenditure on people in the last year of life (England only)

	Last year of life total, £millions (cash)	Total estimated sector spend, £millions (cash) 2022/23*	Last year of life as % England total
GP primary care	237	11,510	2.1%
Community prescribing	418	9,780	4.3%
Community Healthcare	432	9,270	4.7%
Ambulance/NHS 111	389	3,580	10.9%
Acute healthcare	7,637	80,750	9.5%

Notes: *For acute, ambulance and community care, total spends are based on patient care income received by NHS provider trusts. Therefore, these don't include NHS expenditure on care purchased from non-NHS providers. For details on method for allocating provider income to care sector or area, see NT report https://www.nuffieldtrust.org.uk/resource/where-does-the-nhs-money-go. For GP primary care and community prescribing, total spend is NHS England total spend, as per 2022/23 accounts.

The methodology used for social care (Appendix 4: Social care) uses an estimate that local authority spend on people at the end of life is 11.8% of total social care expenditure. This was derived for England's population and death rates. Taking account of differing death rates in the other UK nations, we estimate that 12.1% of total LA-funded social care expenditure (including equivalent in Northern Ireland) was spent on people in the last year of life.

Social security spend for England, Scotland and Wales is published in government accounts.[62] For the benefits included in this report, expenditure on people in the last year of life accounted for 3.0% of total expenditure, ranging from 4.4% for the State Pensions to 0.3% for housing benefit (Table A6.2). If all benefits are included, the proportion of expenditure on people in the last year of life is estimated to be 2.4%.

Table A6.2. Comparison of all social security expenditure and expenditure on people in the last year of life (England, Scotland and Wales only)

Benefit	Last year of life (£millions)	All expenditure (£millions)	%
Attendance Allowance	175	5,578	3.1%
State Pension	4,804	109,050	4.4%
Pension Credit	45	4,910	0.9%
Personal Independence Payment	240	17,030	1.4%
Universal Credit including housing element	93	41,025	0.2%
Carers Allowance	43	3,206	1.3%
Total estimated spend	5,400	180,799	3.0%

Notes: All expenditure taken from government accounts. 2022 expenditure estimated from 2021/22 and 2022/23. https://assets.publishing.service.gov.uk/media/64a58054c531eb001364fed8/dwp-spending-and-budget-2018-2019-to-2024-2025.xlsx

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