

How many people need palliative care?

Updated estimates of palliative care need across the UK, 2017-2021

Data and evidence briefing

July 2023

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Summary

About 90% of people who die are estimated to need palliative care...

- Assessments of how many people need palliative care have an important role to play in informing governments' and health bodies' palliative and end of life care strategies and commissioning plans. According to our updated analysis of mostly publicly available official statistics, an estimated 90% of people who die in the UK would benefit from palliative care. This means that in 2021, 600,000 people who died needed palliative care.
- The proportion of people who die with palliative care needs is broadly similar in each country of the UK. From 2017 to 2021, on average 90.4% of people who died in England, 88.1% of people who died in Wales, 89.0% of people who died in Scotland, and 90.5% of people who died in Northern Ireland would have benefitted from palliative care.
- There are a range of different ways to estimate palliative care need at the population level. The 90% estimate uses a method which counts the number of deaths that have specific diagnoses recorded as an underlying or contributory cause of death on the death certificate. One benefit of using a method which considers both underlying and contributory causes of death is that it better reflects growing levels of multimorbidity at the end of life as the UK population ages. Our analysis shows it also produces a more robust estimate at a time of large numbers of deaths, such as during the pandemic.
- Conversely, estimates of palliative care need based solely on underlying cause of death data should be treated with caution because they likely underestimate true need. This issue is particularly evident in the data following the onset of the pandemic, as many people who died from Covid-19 had pre-existing health conditions that would have benefitted from palliative care, such as dementia, heart disease, or chronic lower respiratory diseases^{1,2,3}.

... if current trends continue, by 2048 more than 730,000 people will die with palliative care needs each year...

- If need stayed constant at 90%, between 2023 and 2048 the number of people with palliative care needs in the UK would increase by more than 147,000, a 25% increase. This means that in 2048 more than 730,000 people would die with palliative care needs each year – but this figure is likely to underestimate need as it does not account for demographic changes which will mean more people die at older ages and with multiple, complex conditions.
- Northern Ireland is projected to have the biggest rise in demand for palliative care, with a 32% increase between 2023 and 2048.

... but more research is needed to understand unmet and future need and its implications for services.

- This report provides very basic estimates of future need. These figures indicate there will be significantly higher need for palliative care in future, but further analysis is needed to project future need and assess the related service implications.
- The methods used in this report can provide a headcount of how many people in the population need palliative care, but they do not indicate what the service implications are for meeting this need, what the gap is between need and the current provision of care and services, or which groups or individuals are most likely to miss out. More research is needed to model population need for different types of services, alongside improved data on service access, outcomes, and patient and carer experiences. Marie Curie will commission research to help answer these questions this year.

Estimating palliative care need in a population

Assessments of how many people need palliative care have an important role to play in informing palliative and end of life care strategies and commissioning plans. There are numerous ways to estimate palliative care need across a population. At the population-level, palliative care need can be defined as ‘people who would benefit from palliative care’⁴.

Two methodologies are frequently cited in the UK policy and research literature:

75% of deaths

This estimate has been widely cited in policy and planning documents^{5,6}. One source for this is the observation that at least 75% of deaths in high-income countries are caused by progressive advanced chronic conditions⁷. Analysis of mortality data and coroner service statistics to estimate how many deaths were predictable in England and Wales pre-2010 also produced a figure of 75%⁸. Limitations of this method include that it is based on old data, and it cannot tell us about how need is changing over time.

Analysis of disease-specific mortality data

The methodology developed in Murtagh et al. (2014)⁹ – referred to in this document as the Murtagh method - produces a range of estimates of population need by looking at underlying and contributory cause of death data for specified causes, recorded using International Statistical Classification of Diseases and Related Health Problems–10th Revision (ICD-10) codes (see Table 1). It has been widely used in the UK and internationally, and the conditions included in each estimate were decided through expert consensus.

| Table 1. Methods for estimating palliative care need included in Murtagh et al. | |
|---|---|
| Estimate | Method |
| Minimal | All deaths with any of the following recorded as the underlying cause on the death certificate: malignant neoplasm; heart disease, including cerebrovascular disease; renal disease; liver disease; respiratory disease; neurodegenerative disease; Alzheimer’s, dementia and senility; HIV |
| Intermediate | All deaths with any of the specific conditions in the minimal estimate recorded as either the underlying or a contributory cause on the death certificate |
| Maximal | All deaths except those ‘during pregnancy, childbirth or puerperium; originating during the perinatal period; resulting from injury, poisoning and other similar causes and those resulting from external causes’ |

How we produced our estimates

Following the Murtagh method¹⁰, we analysed mortality data for specific ICD-10 codes for the years 2017-2021 from the Office for National Statistics (ONS), National Records of Scotland (NRS) and Northern Ireland Statistics and Research Agency (NISRA). Underlying cause of data used to produce the minimal and maximal estimates were largely publicly available, while access to data on contributory causes for the intermediate estimates required submitting bespoke requests to each of the statistical bodies.

Table 2 shows the ICD-10 codes used, associated conditions, and how these relate to different disease groups¹¹.

| Table 2. ICD-10 codes used to estimate palliative care needs and groupings | | |
|--|------------------------------------|--|
| Grouping | Code | Conditions included |
| Cancer | C00-C97 | All deaths from malignant neoplasms |
| Organ failure | I00-I52 (excl. I12 & I13) | Heart disease and heart failure |
| | J40-47, J96 | Chronic lower respiratory disease, respiratory failure |
| | I12, I13, N17, N18, N28 | Reno-vascular disease, renal failure |
| | K70-K77 | Liver disease |
| Dementia | F01, F03, G30, R54 | Dementia, vascular dementia, Alzheimer's disease, senility |
| Other | G10, G12.2, G20, G23.1, G35, G90.3 | Huntingdon's disease, motor neurone disease, Parkinson's disease, progressive supranuclear palsy, multiple sclerosis, multi system atrophy |
| | I60-I69 | Haemorrhagic, ischaemic and unspecified stroke |
| | B20-24 | HIV |

Caveats and limitations

The effect of the Covid-19 pandemic

Covid-19 resulted in many deaths and brought significant disruption to health and care systems across the UK. Research has shown the pandemic's impact on death, dying and bereavement in the UK¹², and the relevance of palliative care to the treatment of people severely ill with Covid-19 during the height of the pandemic¹³. There is no formal consensus on whether Covid-19 deaths should be included in palliative care estimates, though typically deaths from acute infectious diseases such as pneumonia and influenza are excluded.

In alignment with the Murtagh method and other studies using this methodology, deaths where Covid-19 is the underlying cause have not been included in our findings. A forthcoming paper will explore the effect of including deaths from Covid-19 in estimates of palliative care need.

The benefits of earlier integration of palliative care

Using mortality data means that this methodology can only tell us about the number of people who died with palliative care needs each year. There is growing evidence of the benefits of incorporating palliative care earlier into disease-specific care, even at the point of diagnosis¹⁴. However, people who live with palliative care needs for more than the final 12 months of their life are not captured by this methodology and our analysis may under-estimate true population need.

How many people need palliative care?

This section lists the findings of our analysis for the UK and each nation. It then takes a closer look at mortality data in England and Wales over the past decade; finally, provides basic projections of how need may change in the next 25 years.

Findings for the UK

- The intermediate estimate includes deaths where a condition that would benefit from palliative care is included on the death certificate as either an underlying or contributory cause. By considering both underlying and contributory causes, it better reflects the high prevalence of multimorbidity in the population. According to this method, **about 90% of people who died in the UK between 2017 and 2021 would have benefitted from palliative care.**
- The minimal estimate includes deaths where a condition that would benefit from palliative is listed as the underlying cause of death on the death certificate. For 2017-19, it estimated that approximately 74% of people who died in the UK would benefit from palliative care, meaning it was broadly in line with the crude 75% estimate often cited in policy documents. This equates to roughly 450,000 people.
- As the number of people who died increased sharply following the onset of the Covid-19 pandemic in 2020, the minimal estimate decreased to approximately 66% for 2020-21. A key reason for this is that many people who died from Covid-19 had pre-existing health conditions that are not captured if we look at underlying cause of death data alone.
- The maximal estimate includes all deaths except those relating to pregnancy, injury, or external causes. This remains broadly stable through 2017-2021, at approximately 96% of deaths.

Number and percentage of people with palliative care needs in the UK, 2017-2021

| Year | Minimal estimate | | Intermediate estimate | | Maximal estimate | | Total deaths |
|------|------------------|--------|-----------------------|--------|------------------|--------|--------------|
| | Count | % | Count | % | Count | % | Count |
| 2017 | 451,031 | 74.42% | 547,399 | 90.32% | 580,959 | 95.86% | 606,049 |
| 2018 | 453,285 | 73.74% | 554,462 | 90.20% | 587,386 | 95.56% | 614,690 |
| 2019 | 447,012 | 74.08% | 545,157 | 90.34% | 576,226 | 95.49% | 603,419 |
| 2020 | 454,445 | 65.98% | 619,343 | 89.92% | 662,138 | 96.13% | 688,806 |
| 2021 | 441,245 | 66.19% | 599,461 | 89.92% | 638,963 | 95.85% | 666,629 |

Findings for England

- According to the intermediate estimate, **about 90% of people who died in England between 2017 and 2021 would have benefitted from palliative care.**
- According to the minimal estimate, for 2017-19, approximately 74% of people who died in England would benefit from palliative care, meaning it was broadly in line with the crude 75% estimate often cited in policy documents. This equates to roughly 370,000 people.
- As the number of people who died increased sharply following the onset of the Covid-19 pandemic in 2020, the minimal estimate decreased to approximately 66% for 2020-21. A key reason for this is that many people who died from Covid-19 had pre-existing health conditions that are not captured if we look at underlying cause of death data alone.

- The maximal estimate remained broadly stable through 2017-2021, at approximately 96% of deaths.

| Number and percentage of people with palliative care needs in England, 2017-2021 | | | | | | | |
|--|------------------|--------|-----------------------|--------|------------------|--------|--------------|
| Year | Minimal estimate | | Intermediate estimate | | Maximal estimate | | Total deaths |
| | Count | % | Count | % | Count | % | Count |
| 2017 | 372,056 | 74.58% | 451,755 | 90.55% | 479,395 | 96.09% | 498,882 |
| 2018 | 373,919 | 73.92% | 457,898 | 90.52% | 484,470 | 95.77% | 505,859 |
| 2019 | 368,536 | 74.25% | 449,910 | 90.64% | 475,267 | 95.75% | 496,370 |
| 2020 | 375,313 | 65.88% | 513,569 | 90.15% | 549,015 | 96.37% | 569,700 |
| 2021 | 362,444 | 65.98% | 495,307 | 90.16% | 527,828 | 96.08% | 549,349 |

Findings for Wales

- According to the intermediate estimate, **about 88% of people who died in Wales between 2017 and 2021 would have benefitted from palliative care.**
- According to the minimal estimate, for 2017-19, approximately 73% of people who died in Wales would benefit from palliative care, meaning it was broadly in line with the crude 75% estimate often cited in policy documents. This equates to roughly 25,000 people.
- As the number of people who died increased sharply following the onset of the Covid-19 pandemic in 2020, the minimal estimate decreased to approximately 67% for 2020-21. A key reason for this is that many people who died from Covid-19 had pre-existing health conditions that are not captured if we look at underlying cause of death data alone.
- The maximal estimate remained broadly stable through 2017-2021, at approximately 96% of deaths.

| Number and percentage of people with palliative care needs in Wales, 2017-2021 | | | | | | | |
|--|------------------|--------|-----------------------|--------|------------------|--------|--------------|
| Year | Minimal estimate | | Intermediate estimate | | Maximal estimate | | Total deaths |
| | Count | % | Count | % | Count | % | Count |
| 2017 | 24,452 | 73.54% | 29,159 | 87.70% | 31,887.00 | 95.91% | 33,248 |
| 2018 | 25,118 | 73.00% | 30,208 | 87.80% | 32,994.00 | 95.90% | 34,406 |
| 2019 | 24,432 | 73.63% | 29,267 | 88.20% | 31,845.00 | 95.97% | 33,183 |
| 2020 | 24,823 | 66.37% | 32,965 | 88.14% | 36,179.00 | 96.74% | 37,399 |
| 2021 | 24,299 | 67.25% | 32,093 | 88.81% | 34,724.00 | 96.10% | 36,135 |

Findings for Scotland

- According to the intermediate estimate, **about 89% of people who died in Scotland between 2017 and 2021 would have benefitted from palliative care.**

- According to the minimal estimate, for 2017-19, approximately 73% of people who died in Scotland would benefit from palliative care, meaning it was broadly in line with the crude 75% estimate often cited in policy documents. This equates to roughly 43,000 people.
- As the number of people who died increased sharply following the onset of the Covid-19 pandemic in 2020, the minimal estimate decreased to approximately 67% for 2020-21. A key reason for this is that many people who died from Covid-19 had pre-existing health conditions that are not captured if we look at underlying cause of death data alone.
- The maximal estimate remained broadly stable through 2017-2021, at approximately 94% of deaths.

| Number and percentage of people with palliative care needs in Scotland, 2017-2021 | | | | | | | |
|---|------------------|--------|-----------------------|--------|------------------|--------|--------------|
| Year | Minimal estimate | | Intermediate estimate | | Maximal estimate | | Total deaths |
| | Count | % | Count | % | Count | % | Count |
| 2017 | 42,822 | 73.98% | 51,965 | 89.78% | 54,629 | 94.38% | 57,883 |
| 2018 | 42,653 | 72.91% | 51,978 | 88.85% | 55,011 | 94.03% | 58,503 |
| 2019 | 42,493 | 73.13% | 51,691 | 88.96% | 54,344 | 93.52% | 58,108 |
| 2020 | 42,478 | 66.28% | 56,849 | 88.70% | 60,293 | 94.07% | 64,093 |
| 2021 | 42,982 | 67.60% | 56,211 | 88.40% | 59,820 | 94.08% | 63,587 |

Findings for Northern Ireland

- According to the intermediate estimate, **about 90% of people who died in Northern Ireland between 2017 and 2021 would have benefitted from palliative care.**
- According to the minimal estimate, for 2017-19, approximately 73% of people who died in Northern Ireland would benefit from palliative care, meaning it was broadly in line with the crude 75% estimate often cited in policy documents. This equates to roughly 12,000 people.
- As the number of people who died increased sharply following the onset of the Covid-19 pandemic in 2020, the minimal estimate decreased to approximately 66% for 2020-21. A key reason for this is that many people who died from Covid-19 had pre-existing health conditions that are not captured if we look at underlying cause of death data alone.
- The maximal estimate remained broadly stable through 2017-2021, at approximately 94% of deaths.

| Number and percentage of people with palliative care needs in NI, 2017-2021 | | | | | | | |
|---|------------------|--------|-----------------------|--------|------------------|--------|--------------|
| Year | Minimal estimate | | Intermediate estimate | | Maximal estimate | | Total deaths |
| | Count | % | Count | % | Count | % | Count |
| 2017 | 11,701 | 72.97% | 14,520 | 90.55% | 15,048 | 93.84% | 16,036 |
| 2018 | 11,595 | 72.82% | 14,378 | 90.30% | 14,911 | 93.65% | 15,922 |
| 2019 | 11,551 | 73.30% | 14,289 | 90.68% | 14,770 | 93.73% | 15,758 |
| 2020 | 11,831 | 67.17% | 15,960 | 90.61% | 16,651 | 94.53% | 17,614 |
| 2021 | 11,520 | 65.61% | 15,850 | 90.27% | 16,591 | 94.49% | 17,558 |

How do these findings compare with previous estimates?

Our findings are similar to previous studies that have used the same methodology, including:

- The first application of the Murtagh method, which used data from 2006 to 2008 for England and estimated that 63-97% of all deaths may need palliative care¹⁵ (note that changes to the way dementia deaths were coded between 2010 and 2011 contributed to a significant rise in the minimal estimate and explain to a large extent the lower finding of 63% here¹⁶)
- Analysis of underlying cause of death data (the 'minimal estimate') from 2006 to 2014 for England and Wales, which estimated palliative care need to be 75%¹⁷
- Analysis of data for the period 2012 to 2014 for England, Wales and Northern Ireland, which found a minimal estimate of 74% and intermediate estimates of 87-90%¹⁸
- Analysis of Scottish data from 2007 to 2017, which produced a minimal estimate of 74% and an intermediate estimate of 88-90%¹⁹

In summary, most recent studies in the UK have produced minimal estimates of 74-75% - reflecting the broadly used estimate of 75% produced by other methodologies - and intermediate estimates of approximately 90%.

How have palliative care needs changed in the last decade?

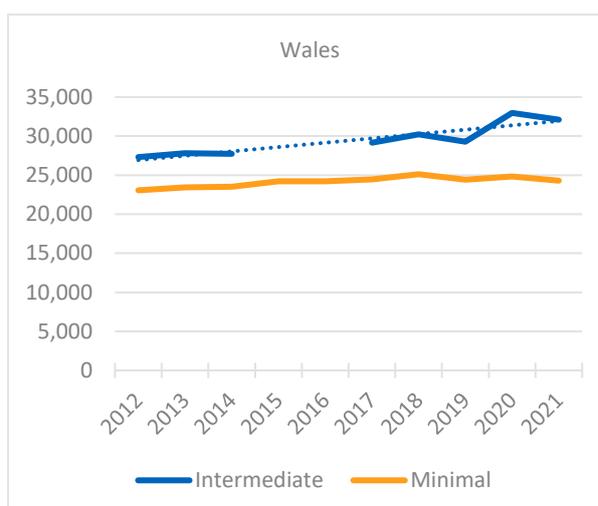
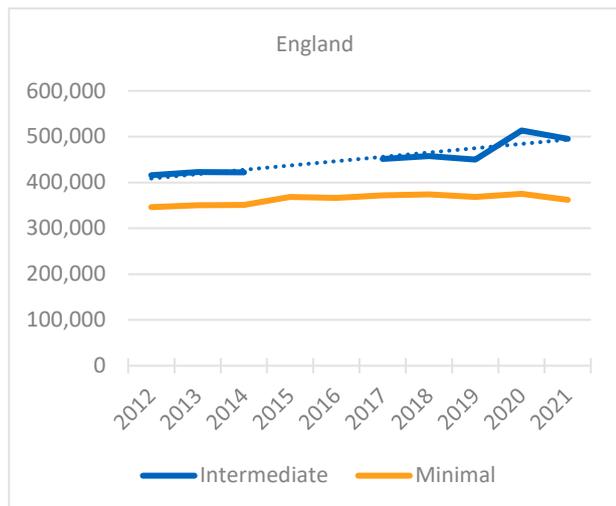
The ONS Nomis service makes underlying cause mortality data available for England and Wales from 2013. Data for 2012 are available from a previous study²⁰. This means it is straightforward to look at how the minimal estimate and related disease groupings have changed over time, for different age groups, and at a more local level. This is useful to understand trends so services can be planned accordingly. As previously discussed, the minimal estimate is likely to underestimate palliative care need; however, it is not possible to run the same analysis for the intermediate estimate through Nomis because contributory cause of death data must be requested from statistical bodies.

Increasing need

Since 2012, the number of people needing palliative care has increased in both England and Wales regardless of which methodology is used. This reflects that more people are dying each year. If we look only at underlying cause of death data (the minimal estimate), the number of people dying with palliative care needs in both England and Wales has increased by about 5% from 2012 to 2021.

The intermediate estimate, which also includes contributory causes of death and therefore better reflects multimorbidity, has increased by 19% in England and 18% in Wales over the same time period.

Number of people estimated to need palliative care need, 2012-2021

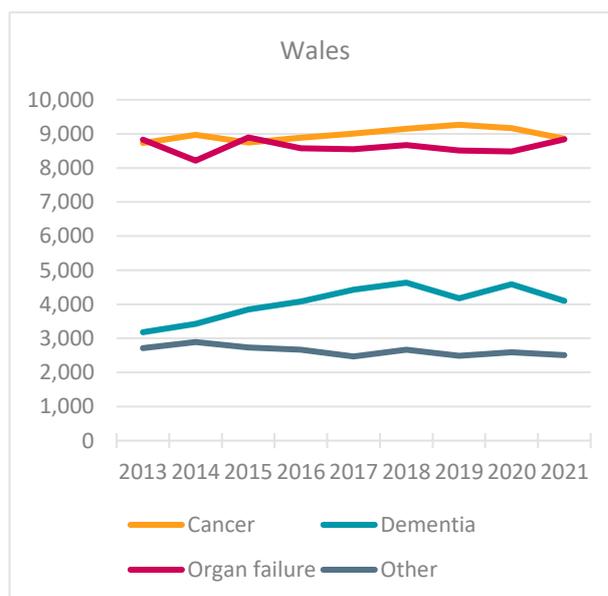
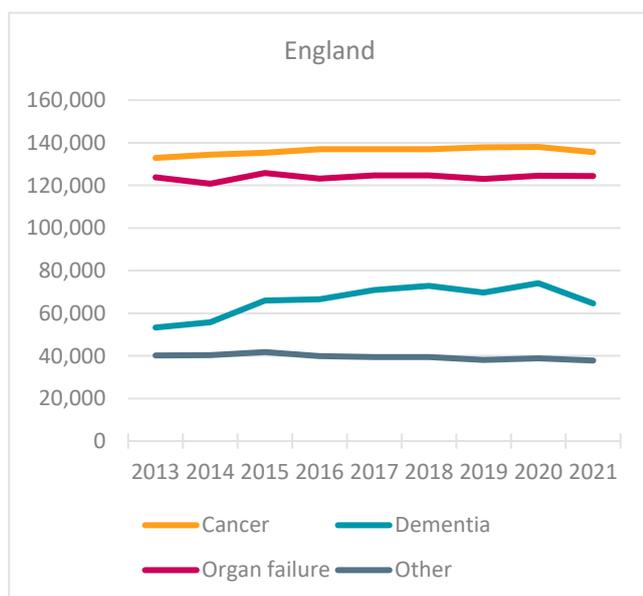


Conditions

When causes of death are grouped (as per Table 2, page 5), cancer was the most common cause of death for people who had palliative care needs in England in every year from 2013 to 2021. This was similar in Wales; however, here organ failure was the most common cause of death in 2013 and 2015, with a marginally smaller number of people dying from cancer in those years. In both England and Wales there is a steady trend for increasing deaths from cancer (though these trends are reversed in 2021 when deaths from Covid-19 were at a peak).

Prior to the pandemic, dementia was the fastest growing cause of death for people who had palliative care needs in both England and Wales. Fewer people died from dementia in 2021 than in previous years. Part of the explanation for this is that dementia was the most common pre-existing condition for deaths involving Covid-19, meaning there will be fewer than expected deaths recorded where dementia is the underlying cause²¹.

Number of deaths from underlying causes which need palliative care for all ages, 2013-21



Age

The numbers of people aged over 65 years with palliative care needs has been steadily increasing since 2013 in both England and Wales. Of conditions for which palliative care would be beneficial, for people aged 65-84 years cancer is the leading cause of death, and for people aged 85 years it is dementia, which has overtaken organ failure in both England and Wales in recent years.

Number of deaths from causes which need palliative care by age group, England and Wales, 2013-21



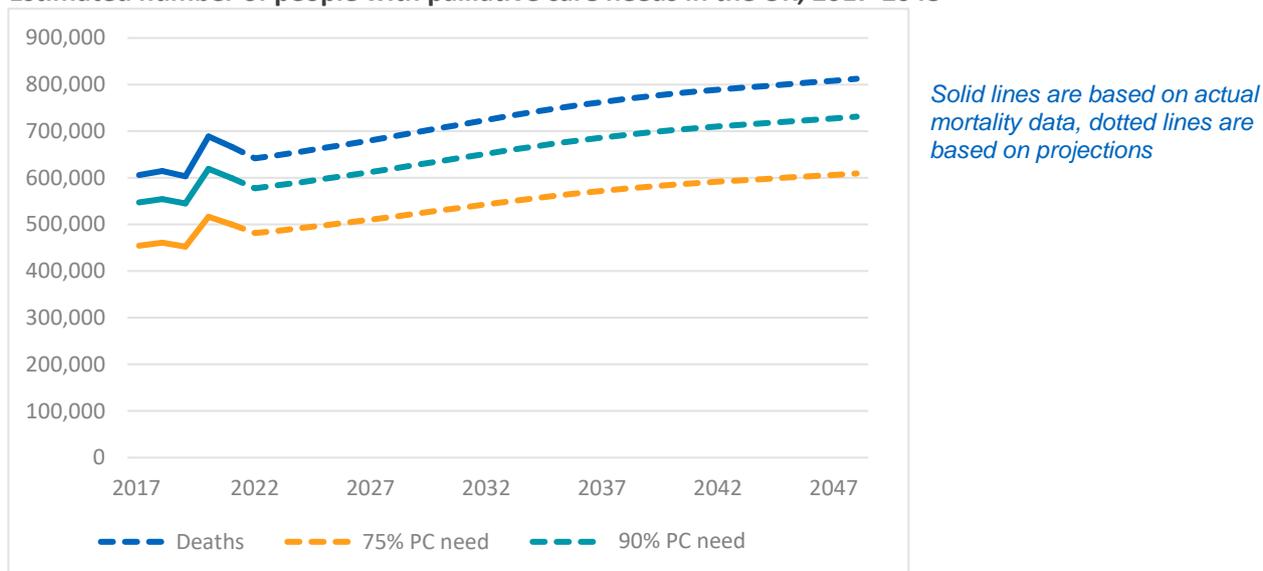
How will palliative care need change in the years to come?

The ONS projects that there will be a significant increase in deaths per year in the coming decades, with more and more people needing palliative care. We have applied the 75% estimate of palliative care need and the average intermediate estimate (using underlying and contributory cause of death data) from the period 2017-2021 (90%) to 2020-based mortality projections for the UK to give a rough idea of how much palliative care need will increase by.

Our analysis shows:

- (1) Assuming 75% of people who die have palliative care needs, between 2023 and 2048 the number of people with palliative care needs in the UK will increase by more than 122,000, a 25% increase. By 2048, about 610,000 people would die with palliative care needs each year.
- (2) Assuming the average intermediate estimate of palliative care need from the period 2017-2021 for the UK (90%) remains constant, between 2023 and 2048 the number of people with palliative care needs in the UK will increase by more than 147,000, a 25% increase. By 2048, more than 730,000 people would die with palliative care needs each year.

Estimated number of people with palliative care needs in the UK, 2017-2048



At the individual nation level, Northern Ireland is projected to have the largest proportional increase in need for palliative care, rising by 32% between 2023 and 2048:

| Projected palliative care need by UK nation (Assumes 90% of people die with palliative care needs) | | | |
|---|--------------|--------------|----------|
| | Need in 2023 | Need in 2048 | Increase |
| UK | 584,111 | 731,291 | 25.2% |
| England | 481,653 | 609,280 | 26.5% |
| Wales | 31,854 | 36,982 | 16.1% |
| Scotland | 55,161 | 64,587 | 17.1% |
| Northern Ireland | 15,443 | 20,443 | 32.4% |

However, these estimates are likely to underestimate future need because they do not account for demographic changes which will mean more people die at older ages and with multiple, complex conditions. In every country of the UK the population aged 85 years and over is set to increase massively in the next 25 years – in Northern Ireland it will more than double in this time.

| Projected number of people aged 85 years or over ²² | | | |
|--|-----------|-----------|----------|
| | 2023 | 2048 | Increase |
| England | 1,491,000 | 2,863,000 | 92% |
| Wales | 89,000 | 164,000 | 84% |
| Scotland | 135,000 | 257,000 | 90% |
| Northern Ireland | 42,000 | 89,000 | 112% |
| UK | 1,758,000 | 3,373,000 | 92% |

There is uncertainty about how the pandemic will affect population health and mortality in the long-term, and the ONS will soon introduce a new model for producing mortality projections²³. Projecting an intermediate estimate of need would also require further bespoke requests for data to the national statistical bodies across the UK. For these reasons, we have only provided very basic projections of future need as a basis for discussion and future research. These figures indicate there will be significantly higher need for palliative care in future, but further analysis is needed to explore how changing demographics will affect future need and to assess the related service implications.

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- ¹⁰ Murtagh et al. (2014) also include an additional intermediate estimate which requires hospital admissions data. This is rarely included in applications of the Murtagh method in the literature, and due to data accessibility challenges it has been excluded from the analysis which informed this report.
- ¹¹ We have adopted the same disease groups as previous studies: Etkind et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services (2017); and Finucane et al. How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery (2021).
- ¹² Better End of Life Report 2021 (mariecurie.org.uk)
- ¹³ Symptom Control and Survival for People Severely ill With COVID: A Multicentre Cohort Study (CovPall-Symptom) - Journal of Pain and Symptom Management (jpsmjournals.com)
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