

Marie Curie Briefing

Palliative care need in Scotland is projected to increase by up to 20% by 2040

The first study to project estimates of future palliative care need in Scotland. Research undertaken by Marie Curie, University of Edinburgh, Kings College London, and Public Health Scotland.

1. By 2040, up to 95% of all people who die may need a palliative care approach in Scotland. This could mean an additional 10,000 more people.
2. The number of people dying every year with over 40% of all people dying of at least two conditions by 2040.
3. To support this, the Integration Authorities must provide more sustained funding for palliative care services in communities and review single disease health and social care models to reflect increasing multi-morbidities in patients.
4. Without this investment, thousands of Scots could die without the right palliative and end of life care support.

Marie Curie is calling for:

1. The Scottish Government to introduce a new palliative care strategy, implemented by a new National Clinical Lead for Scotland to make care of terminally ill people and those at the end of life a much higher priority;
2. The Scottish Government to roll out the proposed National Digital Platform to better facilitate coordination of care and collaboration between all care providers and settings;
3. Integration Authorities to review palliative care models to reflect multi-morbidities, the projected increase in over 85s, and increase in those dying with dementia;
4. Integration Authorities need to invest more in community-based palliative care including care home capacity;
5. Invest in and upskill health and social care teams through training in palliative and end of life care and support anticipatory care planning.

The Study

This study estimated the prevalence of palliative care need by analysing the proportion of deaths from defined chronic progressive illnesses. It described linear projections up to 2040 using national death registry data and official mortality forecasts. An expert consultation and subsequent online consensus survey were carried out which generated recommendations on meeting future palliative care need.

This research was carried out prior to the COVID19 pandemic. However, we judge that the impact of COVID will not change the main conclusions of this paper. We would recommend that further research is carried out in due course to understand any impact COVID

Deaths in Scotland by 2040

This research projects that **deaths in Scotland are projected to reach 65,756 by 2040**, a 13.6% increase from 2017. The upper estimates of our projections suggest that **95% of those who die in 2040 will need a palliative approach** to support them in the period leading up to their death. This could be as many as 62,757 people and **10,609 more per year than in 2017**.

Increased palliative care need projection methods

This study estimated the prevalence of palliative care need by analysing the proportion of deaths from defined chronic progressive illnesses. It described linear projections up to 2040 using national death registry data and official mortality forecasts. The research used three methods to project this.

Method 1 – Using research that assumes that 75% of all people die from progressive terminal conditions with evolving and increasing healthcare needs, this percentage was used with projected population trends.

Results: 75% of people may benefit from a palliative care approach, which would lead to 5,914 more people dying with a palliative care by 2040.

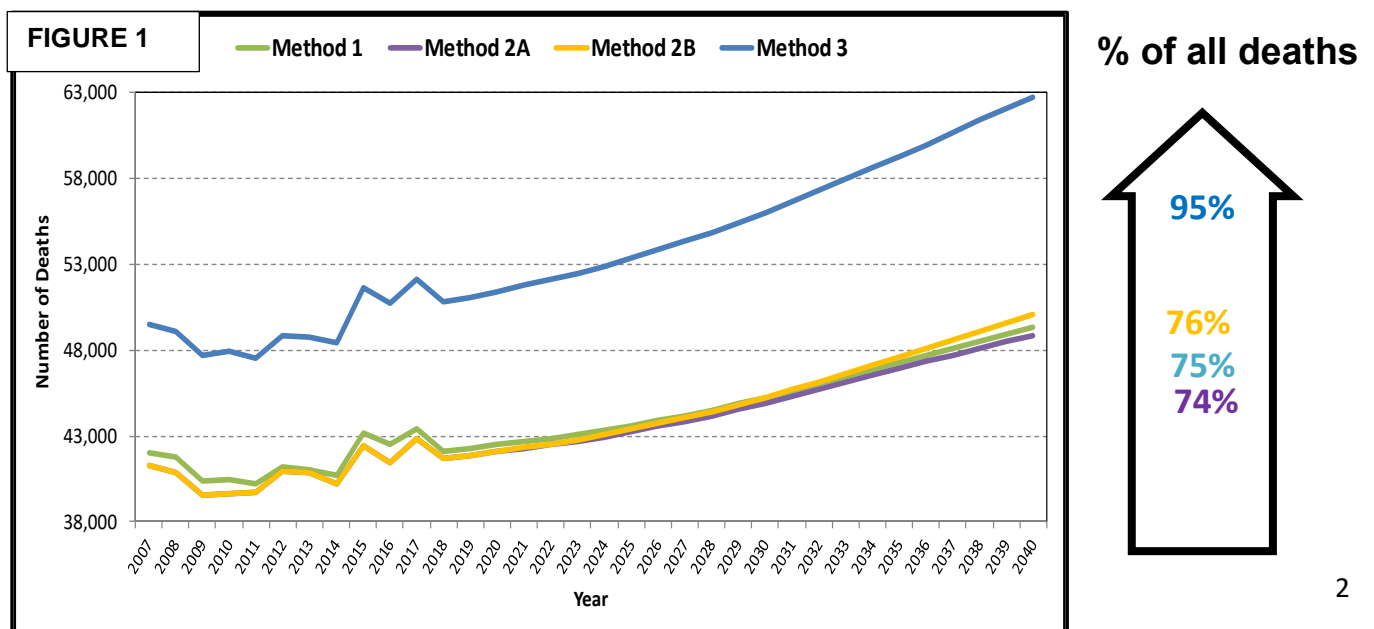
Method 2 – Future palliative care need was calculated using two scenarios (2A and 2B). For method 2A we calculated the number and proportion of age and gender specific deaths in 2017 where a disease associated with palliative care was recorded as the main underlying cause of death. Researchers have previously established a set of diseases associated with palliative care needs. Where one of these diseases was recorded as the main underlying cause of death, this was considered a death associated with palliative care need. We then applied this proportion to mortality forecasts for each year up to 2040, with no adjustments. For method 2B we calculated the average annual change in the proportion of deaths requiring palliative care between 2007 and 2017.

Results: At least 14% more people will need a palliative approach by 2040 compared with 2017. This would lead to 6,053 more people dying with a palliative care need under method 2A and 7,268 more people dying with a palliative care need under method 2B.

Method 3 – For projecting future palliative care need based on diseases associated with palliative care that were the main underlying cause of death **and/or** a contributory cause of death we used the same scenario calculations as method 2.

Results: Up to 20% more people will need a palliative approach by 2040 compared with 2017. This would lead to an additional 10,609 people needing the support of a palliative approach by 2040. This would mean 95% of all people dying in 2040 could benefit from a palliative approach.

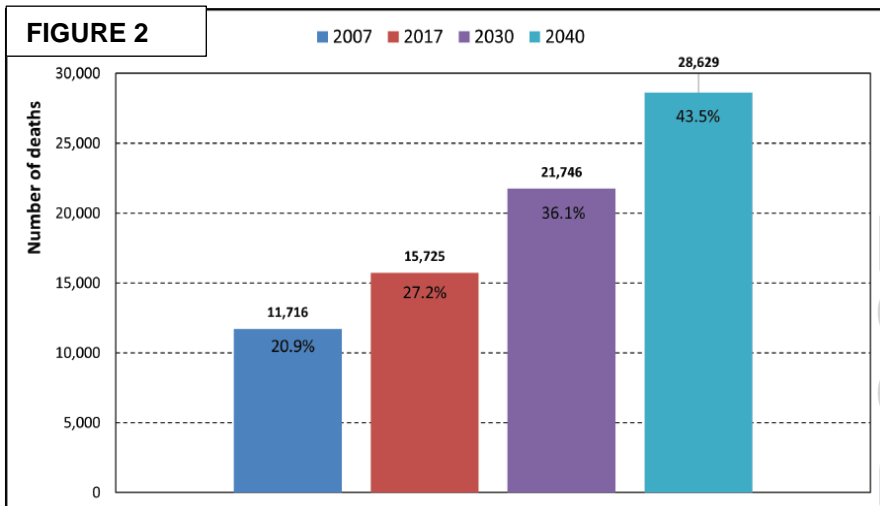
Figure One below shows the different levels of projected changes in palliative care based on each of the scenarios explored in the study.



Dying with multi-morbidities in 2040

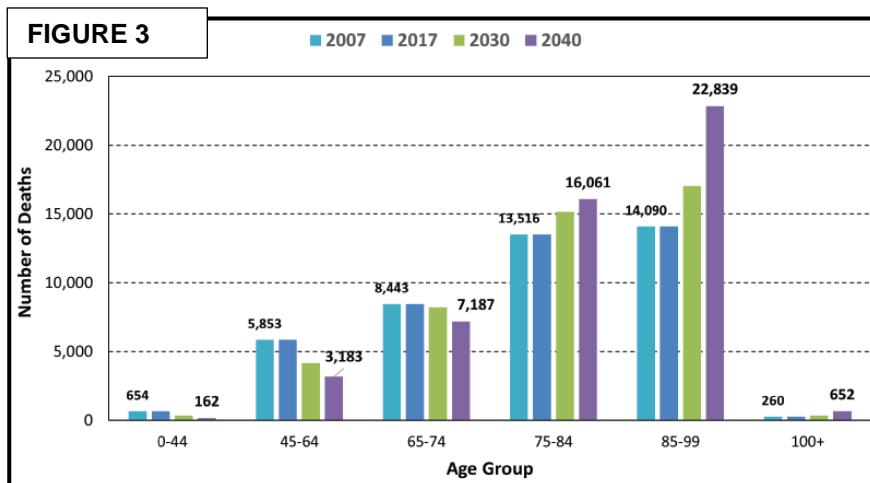
The research also looked at the current and projected rates of people dying with multi-morbidities. For the purpose of this study, multi-morbidity was defined as two or more registered causes of death from different disease groups (cancer, organ failure, dementia or other). By 2040, **the number of people who will die with multi-morbidities will increase by 82%** to over 28,600, accounting for 43.5% of all deaths or nearly half (46%) of palliative care deaths.

Multi-morbidities are becoming the norm in Scotland, starting earlier in life and rising steeply with age.



Those dying of two conditions often have more complex disease trajectories, as well as different and sometimes greater palliative care needs. For these people there is greater need for the coordination of relevant health and social care services.

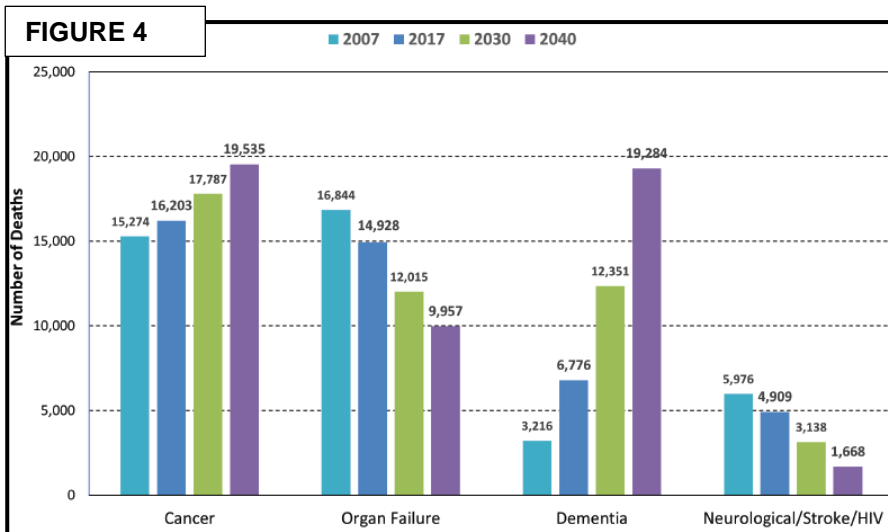
Figure 2 shows the projected number and percentage of people in Scotland dying from multimorbidity associated with palliative care need, 2017 to 2040. *Note: Data for 2007 and 2017 is actual deaths; data for 2030 and 2040 is projected deaths.*



Projection of palliative care need by age group up to 2040

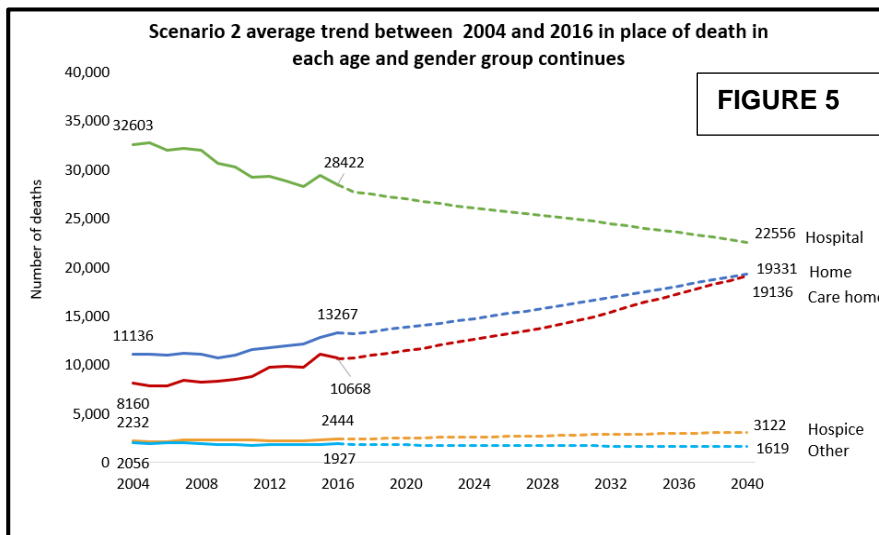
The **greatest increase in palliative care need will be in those aged over 85**, accounting for just under half (47%) of deaths with palliative care needs by 2040, as shown in Figure 3.

Projections of main underlying cause of death by disease group by 2040



Those dying from **dementia** as the main underlying **cause of death is expected to be nearly three times higher in 2040**. The number of people dying from cancer is also projected to increase, but deaths from organ failure and other conditions, including stroke, HIV and neurological diseases are expected to fall, as shown in Figure 4.

Where will people be dying by 2040?



Previous research by Marie Curie, University of Edinburgh and Kings College London showed (Figure 5) that **trends in place of death by 2040 show that two thirds of people in Scotland are likely to die in a community setting including their own homes, care homes and hospices, with hospital deaths accounting for 34% down from 50% in 2017**.

That research also suggested that **without investment in social care services this will not be possible**.

Data from the National Records for Scotland over the last five years (2014-2019) has already started to show an increasing shift in care to the community from hospital with more and more people dying at home or at their care home. This has been matched with a steady increase in the amount of time people spend in the community in their last six months of life in recent years¹.

The impact of Covid-19

There has been a substantial increase in the number of people dying at home during the Covid-19 pandemic; 4,000 more deaths at home in 2020 than in previous years. This has largely been driven by the need to free up hospital beds for patients with Coronavirus, however, it is unknown if terminally ill people, their families and carers received the palliative care support they needed during this time.

¹ <https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/End-of-Life-Care/>

Research References:

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. Authors:

Anne M. Finucane, Anna E. Bone, Simon Etkind, David Carr, Richard Meade, Rosalia Munoz-Arroyo, Sébastien Moine, Aghimien Iyayi-Igbinovia, Catherine J Evans, Irene J Higginson and Scott A Murray doi:10.1136/bmjopen-2020-041317

The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision Authors: Anne M. Finucane,

Anna E. Bone, Catherine J. Evans, Barbara Gomes, Richard Meade, Irene J. Higginson and Scott A. Murray <https://doi.org/10.1177/0269216320944810>

Further information:

Richard Meade

Marie Curie

Head of Policy & Public Affairs

richard.meade@mariecurie.org.uk

@MarieCurieSCO

@richardmeade13

