
Background

In recent years, end of life has increasingly become a priority issue for policy-makers. The UK population reached a new high of 66 million in 2017, and is projected to continue growing to almost 73 million by 2041.¹ In parallel, the population is ageing: around 18.2% of the UK population were aged 65 years or over in mid-2017, a 2.3% increase from 2007, and this is projected to grow to 20.7% by 2027.² In addition, at least 50 million people across the European Union are affected by multiple long-term conditions, or multimorbidity, the subject of a recent Academy of Medical Sciences report.³ Research has found that 69–82% of those who die need palliative care,⁴ often as a result of multiple symptoms and concerns.⁵

The World Health Organisation has estimated that annually, over 20 million people (adults and children) need palliative care at the end of life. This number rises to at least 40 million when they include those that could benefit from palliative care earlier in their care.⁶ These numbers are set to rise, predictions are that the numbers of people dying each year is set to increase by 25% in England and Wales, resulting in a 42% increase in the need for palliative and end of life care.⁷ This picture is echoed in many other countries.

The recent data addition by the Office of National Statistics of the number of people who die in their usual place of residence (i.e. home or care home),⁸ adds testimony to end of life care as a growing area of interest to policy-makers.

According to the most recent Office of National Statistics data available:

- 45.8% of all deaths in England occur in the usual place of residence, but there is a considerable variation in this figure across the country, with the lowest percentage being in urbanised areas and the highest in parts of southern and south-west England, parts of East Anglia and northern England.⁹ (Note: this is a July 2018 statistic – new figures are expected on 5 February 2019).

¹<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/november2018#statisticians-comment>

²<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/november2018#statisticians-comment>

³ <https://acmedsci.ac.uk/file-download/82222577>

⁴ <https://journals.sagepub.com/doi/10.1177/0269216313489367>

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<http://home.uchicago.edu/~tmurray1/research/articles/printed%20and%20read/a%20comparison%20of%20symptom%20prevalence%20in%20far%20advanced%20cancer%20AIDS%20heart%20disease%20chronic%20obstructive%20pulmonary%20disease%20and%20renal%20disease.pdf>

⁶ https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf

⁷ <https://bmcmedicine.biomedcentral.com/track/pdf/10.1186/s12916-017-0860-2?site=bmcmedicine.biomedcentral.com>

⁸ <https://www.gov.uk/government/publications/end-of-life-care-profiles-july-2018-data-update/statistical-commentary-end-of-life-care-profiles-july-2018-update>

⁹ <https://www.gov.uk/government/publications/end-of-life-care-profiles-july-2018-data-update/statistical-commentary-end-of-life-care-profiles-july-2018-update>

- In Wales, about 40% of deaths occur in an individual's usual place of residence, either at home (24%) or in a nursing/care home (16%), while 55% of deaths occur in NHS hospitals.¹⁰
- A Scotland-based report shows that 87% of the last six months of life is spent at home or in a community setting, with the remaining 13% spent in hospital.¹¹
In Northern Ireland, 47% of deaths occur in NHS hospitals, while 19% occur in other hospitals or nursing homes.¹²

If the projected growth in numbers of people dying is applied to where people die, it suggests that to sustain these current patterns and trends, end of life care provision in care homes and the community needs to double by 2040, otherwise deaths will increase in hospitals.¹³

Analysis of current state and future research needs in the UK

According to a 2014 Health Research Analysis report, the proportion of total research spending on palliative and end of life care doubled from 0.08% in 2004/05 to 0.16% in 2014.¹⁴ The following year, a James Lind Alliance Priority Setting Partnership involving patients, carers and professionals, identified the top priorities for palliative and end of life care.^{15,16} These included, among others, better access to palliative care services, better coordination of services, and advance care planning. This resonated with the independent review of NIHR research on end of life care services, which focused on three areas: 'right care', 'right place' and 'right time'.¹⁷

A subsequent grant mapping analysis of the UK Clinical Research Collaboration's Health Research Classification System dataset 2014 highlighted some gaps in current research, for example, the need for more research in the areas of palliative and end of life care.¹⁸ In particular, the need to develop and test interventions that address patient and carer needs in this area was highlighted. This analysis was used by the NIHR to inform their latest NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) call on end of life care.¹⁹ The Neuberger report 'More Care, Less Pathway' also highlighted the lack of adequate research into palliative and end of life care interventions before implementation.²⁰ The more recent 'The End of Life Care Audit – Dying in Hospital' revealed further challenges, such as the need for more experienced staff and specialist palliative care professionals, and research into how to improve this.²¹

Death and dying as a priority: recent programmes, grant schemes and reports

Recent initiatives and reports addressing palliative and end of life care issues include: the National Palliative and End of Life Care Partnership's 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020'; the recent NHS Long-Term Plansets, among other

¹⁰ <https://gov.wales/docs/dhss/publications/171220end-of-life-reporten.pdf>

¹¹ <https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2017-05-30/2017-05-30-End-of-Life-Report.pdf>

¹² <https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/RG2017.pdf>

¹³ <https://journals.sagepub.com/doi/abs/10.1177/0269216317734435>

¹⁴ http://hrcsonline.net/wp-content/uploads/2017/09/UK_Health_Research_Analysis_Report_2014_WEB.pdf

¹⁵ <https://palliativecarepsp.wordpress.com/finalreport/>

¹⁶ <http://www.jla.nihr.ac.uk/priority-setting-partnerships/palliative-and-end-of-life-care/top-10-priorities/>

¹⁷ <https://www.dc.nihr.ac.uk/themed-reviews/end-of-life-care-research.htm>

¹⁸ <https://www.mariecurie.org.uk/globalassets/media/documents/research/publications/grant-mapping-report.pdf>

¹⁹ <https://www.nihr.ac.uk/funding-and-support/documents/current-funding-opportunities/hta/end-of-life-care-hta-round-two.pdf>

²⁰ <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

²¹ <https://www.rcplondon.ac.uk/projects/outputs/end-life-care-audit-dying-hospital-national-report-england-2016>

priorities, improved end of life care to support more people being able to die in a place they have chosen; the National Institute for Health and Care Excellence is currently developing guidelines on 'End of life care for adults in the last year of life'.^{22,23,24} In parallel, grant schemes such as the 'Better Care Fund' and the aforementioned NETSCC 'End of Life Care' grant have been released to promote not only integrated health and social care, but also more targeted efforts to tackle these issues.^{25,26}

The Royal College of General Practitioners published the 'Palliative and End of Life Care' report, a position statement providing an overview of current priorities in palliative and end of life care.²⁷ The Royal College of Physicians released the report 'Talking about dying: How to begin honest conversations about what lies ahead', with the aim to offer advice and support for any doctor on holding earlier conversations with patients after the diagnosis of a progressive or terminal condition.²⁸ The Lancet Commission on the 'Value of Death' will explore the relationship of medicine to death, consider failures in the relationship, and share ideas on how it might be improved.²⁹

In parallel, organisations such as Dying Matters and Compassion in Dying have developed initiatives to raise public awareness and promote an open dialogue about dying, death and bereavement.^{30,31} A 2016 Dying Matters survey on public opinion on death and dying showed that whilst nearly two thirds of people in Britain feel more comfortable discussing dying with family and friends than they did five years ago, only one third of adults have written a will.³² 'Every moment counts', produced by the charity coalition National Voices together with the National Council for Palliative Care and in partnership with NHS England, outlines five themes key to coordinated care near the end of life, ranging from honest discussion, to physical, emotional, spiritual and practical needs.^{33,34}

Meeting objectives

The Academy of Medical Sciences has embarked on a major project on death and dying, funded by the Health Foundation and Wellcome. The project has two interlinking strands of activity: one on public engagement (the Departure Lounge in partnership with the Liminal Space and Ipsos MORI), and a policy component, which will be scoped through this workshop.^{35,36}

This workshop aims to explore the policy landscape around end of life and palliative care, and identify potential areas that might lead to policy activity by the Academy and others. A further

²² <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

²³ <https://www.longtermplan.nhs.uk/>

²⁴ <https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799>

²⁵ <https://www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan/>

²⁶ <https://www.nihr.ac.uk/funding-and-support/documents/current-funding-opportunities/hta/end-of-life-care-hta-round-two.pdf>

²⁷ <https://www.rcgp.org.uk/policy/rcgp-policy-areas/palliative-and-end-of-life-care.aspx>

²⁸ <https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead>

²⁹ [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)32388-2/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)32388-2/fulltext)

³⁰ <https://www.dyingmatters.org/>

³¹ <https://compassionindying.org.uk/>

³² https://www.dyingmatters.org/sites/default/files/files/NCPC_Public%20polling%2016_Headline%20findings_1904.pdf

³³ <https://www.nationalvoices.org.uk/node/1078>

³⁴ <https://www.nationalvoices.org.uk/>

³⁵ <https://acmedsci.ac.uk/more/news/is-it-time-to-talk-about-death>

³⁶ <https://acmedsci.ac.uk/more/news/life-before-death--improving-and-discussing-end-of-life-care>

policy workshop is planned later in 2019, which will be informed by the outputs of the public engagement activity.

Workshop delegates will be asked at the meeting to explore the future and current landscape and to express their views on:

- The key challenges and initiatives around palliative and end of life care
- The priority areas for action (including the key decision-makers) in areas which might include:
 - Identifying evidence gaps.
 - Understanding public views around end of life and palliative care (including research).
 - Barriers to implementing evidence-based services and policy.
 - Structures for health and social care to enable a “good death”.
 - Funding landscape and research questions.
 - Workforce and skills.
- In order to inform public engagement activity we will also discuss what we want to know from different sectors of society.

These topics will be discussed during breakout sessions, and you may wish to consider them in advance of the meeting.

In the margins of the meeting, Liminal Space will seek to interview delegates to inform the public engagement activities for the Departure Lounge project.

Meeting Outcomes

A summary report will be published by the Academy following the meeting.

Timeline of the overall project:

- 12 February – Policy workshop at the Academy of Medical Sciences
- 1 May – Departure Lounge website online
- 1 May to 13 June – Departure Lounge pop up installation, with public engagement sessions and satellite events
- By May – Development of a flat pack version of the Departure Lounge to be used in 30 events across the UK
- Between 1 May and 13 June – Ipsos MORI social research activities
- By November – Feedback from all public engagement activities and independent evaluation
- Late 2019/early 2020 – policy implications workshop based on findings of public engagement report

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