

# End of life and palliative care: the policy landscape

Report of a workshop held in February 2019

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All web references were accessed in March 2019

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## Contents

Executive Summary .....	4
Introduction .....	6
Context setting .....	9
Key themes in end of life and palliative care .....	14
Next steps .....	21
Annex 1 .....	22
Annex 2: Attendee List .....	24

# Executive Summary

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The projected growth in size of the UK population, the demographic shift in age, and the resulting changes in the future demographics of dying, were amongst the factors that prompted the Academy of Medical Sciences to embark on a major programme of work exploring both public and policy perspectives on death and dying in 2019. As part of this programme, a scoping workshop was held in February 2019 to explore the policy landscape around end of life and palliative care. The key themes that emerged from the workshop, and that would benefit from further exploration, were system fragmentation; need for patient and public involvement at all levels (notably faith and cultural perspectives); value for money of interventions; the lack of research funding; and the requirement for appropriate metrics.

The Academy convened a workshop on 12 February 2019 to discuss the policy issues associated with end of life and palliative care, bringing together stakeholders from a range of backgrounds, spanning the health and care sectors, patient groups, and faith experts, amongst others. The aim was to identify potential areas that might lead to future policy activity by the Academy and others.

This workshop formed part of a public engagement project called 'The Departure Lounge' with aims to encourage a broad conversation about death and dying to inform policy activities in end of life care and research. During the workshop, participants discussed key challenges and initiatives around palliative and end of life care, as well as the priority areas for action. These included identifying evidence gaps, understanding public views around end of life and palliative care, and the research funding landscape.

The key themes that emerged from the meeting in relation to end of life and palliative care included:

- **Overcoming fragmentation.** Delegates considered palliative and end of life care to be a public health issue requiring the involvement of stakeholders across the health and social care systems, with fragmentation being a key concern. They argued that, to overcome fragmentation, palliative and end of life care needs to integrate with many specialties, especially when multi-morbidity is a factor. They also suggested that incentives were needed to overcome fragmentation, including when many different medical specialties are involved, and understand its drivers.
- **Public and patient engagement.** Specific areas of action recommended by delegates ranged from promoting public dialogue, engaging different communities and faith groups to ensure culturally competent care, upskilling families and carers, and involving patients, carers and the public in co-designing research and care.
- **Value for money.** Although it is estimated that 20% of the health budget is spent on the last year of life, participants agreed often policy did not use evidence about successful and unsuccessful interventions, and that more evidence, generated in a timely way, was needed. They concurred that the evaluation of end of life and palliative care interventions should focus on improved patient outcomes, rather than cost-savings alone; and suggested a range of approaches were needed, that included continuous systems of evaluation, development and evaluation of complex interventions, and randomised trials of palliative care.
- **Increased and better targeted research funding.** Despite an apparent increase in the amount of end of life care research funding in recent years, trends are difficult to interpret as the amounts are comparatively small. Delegates concurred that the funding pot was much too small to meet the current and future challenges. They also agreed on the need to support research to facilitate testing of relevant interventions on a small scale to build evidence for larger scale interventions, and into how these interventions may be delivered in different communities to provide culturally competent care.

- **Better metrics.** Participants agreed that if used properly, metrics can be used to inform improvements, but noted the lack of reliable metrics to assess 'good care'. Some metrics such as number of deaths in hospital, can create perverse incentives and so need to be used with caution. Ideally metrics need to be related to the patient outcomes (and those who are important to them), supplemented by measures such as symptom management, quality of life or care, and a broader range of population based metrics, such as including the number of hospital admissions towards the end of life, time spent in hospital at the end of life and whether people can be cared for and die at home would be helpful.

Participants also contributed to the development of the workshops with recruited members of the public to be facilitated by Ipsos MORI as part of the Departure Lounge project. Key discussion topics identified for these workshops included understanding the public's first-hand experiences of death and dying; their awareness of palliative and end of life care, especially the modern interpretation of palliative care to help people live well despite serious or progressive illness, rather than simply end of life care; what a 'good death' means for them and those important to them; misconceptions and the importance of language; and minority perspectives, including cultural influences and faith journeys.

### ***Next steps***

Public engagement workshops with groups of various faiths, and with different age and social demographics, are planned to take place in Lewisham over the early summer 2019. The findings from this public engagement activity and the February policy workshop will go on to inform a further policy workshop in late 2019/early 2020.

# Introduction

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The projected growth in the UK population, the shift to increased numbers of people living longer, and future demographics of dying – through multiple long-term conditions for example – prompted the Academy of Medical Sciences to embark on a major project exploring both public and policy perspectives on death and dying in 2019. The workshop aimed 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.

## Aims of the meeting and background

This workshop held on 12 March 2019 aimed to explore the policy landscape around end of life and palliative care, and identify potential areas that might lead to future policy activity by the Academy and other organisations. Professor Irene Higginson OBE FMedSci, Professor of Palliative Care, and Director of Cicely Saunders Institute, King's College London, co-chair, opened the workshop and delegates were asked to consider the key challenges and initiatives around palliative and end of life care and priority areas for action. Participants came from a variety of backgrounds and included representatives from the health and care sectors, regulatory and national bodies, government, charities and patient associations.

### *Informing the Academy's public engagement*

This policy workshop was organised as part of the Academy of Medical Sciences public engagement project 'The Departure Lounge', which aims to encourage a public conversation about death and dying to inform policy activities in end of life care and research. For further information visit [www.departure-lounge.org](http://www.departure-lounge.org). The Academy has a Content Advisory Group for the public engagement project, several of whom participated in the policy workshop.

This workshop included a session led by Ipsos MORI, to shape the content of six group discussions they will facilitate as part of The Departure Lounge project. Workshop attendees were asked to identify policy topics and questions it would be most useful to hear public views on (**see Box 2**).

Representatives from The Liminal Space, the creative consultancy the Academy has partnered with to develop The Departure Lounge, attended the workshop to capture views from the workshop including recording interviews with participants for use in the pop up installation due to open in Lewisham in South London in May/June 2019.

### *Background*

In recent years, the end of life has increasingly become a priority issue for UK policy-makers. The UK population reached a new high of 66 million in 2017, and is projected to grow to almost 73 million by 2041.<sup>1</sup> In parallel, the population is ageing: 18.2% of the UK population were aged 65 years or over in mid-2017, a 2.3% increase from 2007, a figure that is projected to grow to 20.7% by 2027.<sup>2</sup>

More importantly, on top of this the number of annual deaths is projected to grow. By 2040, annual deaths in England and Wales are projected to rise by 25% (from 501,424 in 2014 to 628,659). The main causes of death will change, with more deaths from dementia, cancer and multimorbidity. This will likely result in a 42% increase in need for palliative care.<sup>3</sup> It will also affect where people can be cared for. To sustain current, small increases in home and community (e.g.

care home) deaths (which are often favoured), end-of-life care provision in care homes and the community will need to double by 2040. If this capacity does not become available it is likely that the additional deaths occur in hospital, which is not preferred by many people.<sup>4</sup>

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.<sup>5</sup> Research has found that 69–82% of those who die need palliative care, often as a result of multiple symptoms.<sup>6,7</sup> Although relevant data for the last year of life are not collected in England, the Institute for Fiscal Studies estimates that 10% of hospital care costs are spent in the last year of life, and among the population aged 65 and over, 20% of healthcare costs are incurred during that period.<sup>8</sup>

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) further serves to indicate that end of life is a growing area of interest to policy-makers.

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## References

1. Office for National Statistics (2018). *Overview of the UK population: November 2018*. <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/november2018>
2. *Ibid.*
3. Etkind SN, *et al.* (2017). *How many people will need palliative care in 2040? Past trends, future projections and implications for services*. BMC Med. **15(1)**, 102.
4. Bone AE, *et al.* (2018). *What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death*. Palliat. Med. **32(2)**, 329-336.
5. The Academy of Medical Sciences (2018). *Multimorbidity: a priority for global health research*. <https://acmedsci.ac.uk/file-download/82222577>
6. Murtagh FE, *et al.* (2013). *How many people need palliative care? A study developing and comparing methods for population-based estimates* Palliat. Med. 28(1), 49-58.
7. Solano JP, Gomes B & Higginson IJ (2006). *A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease*. J. Pain Symptom Manage. **31(1)**, 58-69.
8. Institute for Fiscal Studies (2016). *The distribution of healthcare spending: an international comparison*. <https://www.ifs.org.uk/publications/8737>

# Context setting

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In recent years, end of life and palliative care have increasingly become a priority issue for policy-makers, as highlighted by the presentations that set the context for the workshop and in the [background document](#) prepared in advance of the meeting. However, further efforts are needed to tackle the complexities of this landscape and the multiple drivers that influence it.

## Overview of the landscape

In her presentation, Dr Katherine Sleeman, NIHR Clinician Scientist and Honorary Consultant in palliative medicine, reported key statistics around death and end of life care. She explained how the demographics of deaths are changing, with older and more complex deaths becoming more prevalent.<sup>9</sup>

As highlighted in the meeting's background document, the World Health Organisation has estimated that annually, more than 20 million people (adults and children) need palliative care at the end of life. This number increases to at least 40 million when those that could benefit from palliative care earlier in their care are included,<sup>11</sup> and looks set to rise. In England and Wales, the number of people dying each year is projected to increase by 25% over the next 20 years, reaching more than 600,000 by 2040.<sup>12</sup> Dr Sleeman noted that the projected number of people dying with palliative care needs in England and Wales will rise by 40% over the same time period, such that by 2040 between 500,000 and 600,000 people will die annually with palliative care needs<sup>13</sup> a picture echoed in many other countries.

## The UK research funding landscape

The presentation from Dr Sabine Best, Head of Research at Marie Curie, set the scene for the discussion about the current research funding landscape in the UK. She explained that, according to a 2014 Health Research Analysis report, the proportion of total research spending on end of life care doubled from 0.08% in 2004/05 to 0.16% in 2014.<sup>14</sup> Although, it is very difficult to make a judgement about this increase, as the actual amounts are small and one single grant can make a big difference. The following year, a James Lind Alliance Priority Setting Partnership involving patients, carers and professionals, identified the top unanswered questions for palliative and end of life care.<sup>15,16</sup> These included, among others, better access to palliative care services, better coordination of services, and advance care planning (See Box 1). 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'.<sup>17</sup>

A subsequent grant-mapping analysis of the UK Clinical Research Collaboration's Health Research Classification System dataset in 2014, mapping active research grants against the 83 questions identified in the Palliative and end of life care Priority Setting Partnership with the James Lind Alliance, highlighted gaps in current research. For example, it identified the need for more research into palliative and end of life care, and the need to develop and test interventions that address patient and carer needs (see 'Research funding').<sup>18</sup>

As highlighted in the background document, this analysis was used by the NIHR to inform its recent Evaluation, Trials and Studies Coordinating Centre (NETSCC) call on end of life care. The Neuberger report 'More Care, Less Pathway' also highlighted the lack of adequate research into palliative and end of life care interventions before implementation.<sup>19</sup> The 2016 publication from the Royal College of Physicians, '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.<sup>20</sup>

## Recent initiatives and reports

Professor Bee Wee, National Clinical Director for End of Life Care at NHS England, spoke about the recent initiatives and reports addressing palliative and end of life care issues, highlighting the identification of six 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020' by the National Palliative and End of Life Care Partnership.<sup>21</sup> The government made a six-point commitment to people facing the end of their lives including:

- Ensuring 'each person is seen as an individual' and 'care is coordinated', namely opportunity and support for honest conversations.
- Informed choices.
- Personalised care planning and sharing of those plans with professionals involved in their care, involving families and carers to the extent that they wished.
- Knowing who to contact for help and support.

Professor Wee also noted that NHS England's Long Term Plan sets, among other priorities, improved end of life care.<sup>22</sup> As noted in the background briefing, the National Institute for Health and Care Excellence (NICE) has published guidelines and a quality standard on 'End of life care for adults in the last year of life'.<sup>23,24</sup>

## Public and patient engagement

The importance of a public dialogue emerged numerous times during the workshop. Dr Kathryn Mannix, Palliative care doctor and author of *With the End in Mind*,<sup>25</sup> said that with the continuous successes of medicine, our society has become unfamiliar with death and dying. This loss of familiarity led to a change of expectations, where the general assumption is that a transition from acute illness to wellness is the norm. A paradigm shift is needed, she argued. Dr Mannix identified several key questions:

- Are we trying to 'solve' death? (E.g. cure it? postpone it? isolate it? manage it?)
- Is the problem death itself? Or the time around death or issues such as loneliness.
- Do we have unrealistic expectations as a society about death?

In parallel, she said that public views are changing: they are engaging with documentaries, books and podcasts; end of life companionship is reappearing; and compassionate communities are flourishing. Dr Mannix concluded by expressing her doubts about whether death is a medical issue only, rather than a broader societal one.

## Engaging communities and faith groups

The importance of considering different faith groups was highlighted by Dr Mehrunisha Suleman, Research Associate at the Centre for Islamic Studies at the University of Cambridge. In her presentation, she noted that the Muslim population is growing in England, making up an average of 1 in 20 of the population (1 in 5 to 1 in 10 in Birmingham and London respectively). She also pointed out that women in these communities report significantly higher levels of ill health than men.

Dr Suleman drew attention to the fact that when end of life care – and the overarching discussions about evidence-based care, care planning and prevention of hospital admission in the last few weeks of life – encounters minority perspectives, the result could be a mismatch in values. While there has been very little work done so far on minority perspectives, Dr Suleman suggested ways in which this could be improved. For example, the gathering of thousands of people in the Muslim community for Friday prayers can be used as a bridge between the health infrastructure and the community. The presence of 'trusted people in trusted places' can help starting and sustaining discussions, so the needs of these populations can be understood and met.

## Other initiatives and schemes

The background document produced for the meeting highlighted other initiatives and schemes. For example, the 'Better Care Fund' and the NETSCC call for research in 'End of Life Care' have been released to promote not only integrated health and social care, but also more targeted efforts to tackle these issues.<sup>26</sup>

The Royal College of General Practitioners published a position statement on Palliative and End of Life Care providing an overview of current priorities, and entered into a partnership with Marie Curie in 2013 to improve the provision of care by GPs.<sup>27</sup> In 2018, the Royal College of Physicians released its report 'Talking about dying: How to begin honest conversations about what lies ahead', which aimed to offer advice and support for doctors holding earlier conversations with patients after the diagnosis of a progressive or terminal condition.<sup>28</sup> As noted in the meeting, the Lancet Commission on the 'Value of Death' will explore the relationships within our societies, of medicine, to death, consider failures in the relationship, and share ideas on how it might be improved.<sup>29</sup>

Professor Wee highlighted the progress made by organisations such as Dying Matters and Compassion in Dying to raise public awareness and promote open dialogue about dying, death and bereavement.<sup>30,31</sup> For example, 'Every moment counts', produced by the charity coalition National Voices together with the National Council for Palliative Care, 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.<sup>32</sup>

Delegates at the meeting also highlighted policy campaigns that charities are engaging with, including campaigns on welfare benefits<sup>33</sup> and emergency hospital admissions<sup>34</sup> led by Marie Curie; a resource by Hospice UK, End of life care for the homeless, LGBT, Gypsy and Traveller community<sup>35</sup> which seeks to address inequalities in care; and a resource for health professionals<sup>36</sup> based on the Human Rights Act produced by Sue Ryder. Many charitable organisations also have a focus on bereavement.

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## References

9. Bone AE, *et al.* (2018). *What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death.* *Palliat. Med.* **32(2)**, 329-336.
10. Barnett K, *et al.* (2012). *Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study.* *Lancet* **380(9836)**, 37-43.
11. Worldwide Palliative Care Alliance and World Health Organisation (2014). *Global Atlas of Palliative Care at the End of Life.* [https://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](https://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf)
12. Etkind SN, *et al.* (2017). How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med.* **15(1)**, 102.
13. *Ibid.*
14. UK Clinical Research Collaboration (2015). *UK Health Research Analysis 2014.* [http://hrcsonline.net/wp-content/uploads/2017/09/UK\\_Health\\_Research\\_Analysis\\_Report\\_2014\\_WEB.pdf](http://hrcsonline.net/wp-content/uploads/2017/09/UK_Health_Research_Analysis_Report_2014_WEB.pdf)
15. Palliative and end of life care Priority Setting Partnership (2015). *Palliative and end of life care Priority Setting Partnership final report* <https://palliativecarepsp.wordpress.com/finalreport/>
16. Palliative and end of life care Priority Setting Partnership (2015). *Palliative and end of life care Top 10.* <http://www.jla.nihr.ac.uk/priority-setting-partnerships/palliative-and-end-of-life-care/top-10-priorities/>
17. National Institute for Health Research Dissemination Centre (2015). *Better Endings - Right care, right place, right time.* <https://www.dc.nihr.ac.uk/themed-reviews/end-of-life-care-research.htm>
18. Marie Curie (2017). *Does current palliative and end of life care research match the priorities of patients, carers and clinicians? A grant mapping analysis of the UK Clinical Research Collaboration's Health Research Classification System dataset 2014.* <https://www.mariecurie.org.uk/globalassets/media/documents/research/publications/grant-mapping-report.pdf>
19. Department of Health and Social Care (2013). *Review of Liverpool Care Pathway for dying patients.* <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>
20. Royal College of Physicians (2016). *End of Life Care Audit – Dying in Hospital: National report for England 2016.* <https://www.rcplondon.ac.uk/projects/outputs/end-life-care-audit-dying-hospital-national-report-england-2016>
21. The National Palliative and End of Life Care Partnership (2015). *Ambitions for Palliative and End of Life Care.* <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>
22. NHS (2019). *The NHS Long Term Plan.* <https://www.longtermplan.nhs.uk/>
23. NICE (2019). *End of life care for adults in the last year of life: service delivery.* <https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799>
24. NICE (2019). *End of life care for adults: Quality standard.* <https://www.nice.org.uk/guidance/qs13>
25. Mannix K (2017). *With the End in Mind: Dying, Death and Wisdom in An Age of Denial.* HarperCollins Publishers. Bishopsbriggs, Glasgow.
26. NHS England (2019). *Better Care Fund.* <https://www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan/>
27. Royal College of Physicians (2016). *Palliative and End of Life Care.* <https://www.rcgp.org.uk/policy/rcgp-policy-areas/palliative-and-end-of-life-care.aspx>
28. Royal College of Physicians (2018). *Talking about dying: How to begin honest conversations about what lies ahead.* <https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead>
29. Smith R (2018). *Lancet Commission on the Value of Death.* *Lancet* **392(10155)**, 1291-1293
30. <https://www.dyingmatters.org/>

- 
31. <https://compassionindying.org.uk/>
  32. National Voices and The National Council for Palliative Care (2015). *Every Moment Counts: A Narrative for Person Centred Coordinated Care for People Near the End of Life*. <https://www.nationalvoices.org.uk/node/1078>
  33. Marie Curie (2019). *Scrap six months*. <https://www.mariecurie.org.uk/policy/campaigns/scrapsixmonths>
  34. Marie Curie (2019). *Emergency hospital admissions*. <https://www.mariecurie.org.uk/policy/campaigns/emergency-admissions>
  35. Hospice UK (2018). *New resource highlights successful approaches to widen access to end of life care*. <https://www.hospiceuk.org/about-hospice-care/media-centre/press-releases/details/2018/12/10/new-resource-highlights-successful-approaches-to-widen-access-to-end-of-life-care>
  36. Sue Ryder (2016). *A human rights approach to end of life care*. <https://www.sueryder.org/press-release/a-human-rights-approach-to-end-of-life-care>

# Key themes in end of life and palliative care

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Participants identified challenges and initiatives around end of life and palliative care, together with priority areas of action. Five key themes emerged from the discussions: system fragmentation, public and patient engagement, value for money, research funding and metrics. Participants also helped identify potential questions for public engagement activities.

## System fragmentation

Delegates agreed that end of life care is a public health issue that requires the involvement of stakeholders across the health and social care systems. However, despite the recent efforts from government to progress their ambitions in end of life care, fragmentation between and within the health and social care systems emerged as a key concern.<sup>37</sup> Participants highlighted the need for a systems-based approach: so far, palliative care ‘owns’ this space, but end of life care involves many specialties, especially when multimorbidity is a factor. The involvement of many different disease-based specialties can increase fragmentation for patients and those important to them.<sup>38,39</sup>

One participant argued that palliative care should have ‘leadership, but not ownership’ of this space and suggested a change in language from ‘end of life care’ to ‘care of the patient’ could help engage other specialties. Expanding safe places for all medical professionals – not only palliative care and gerontologists – to talk about these issues was suggested as another complementary strategy to overcome fragmentation. Another participant suggested that the strategy to personalise end of life care in NHS England’s Long Term Plan could be broadened beyond end of life specialisms to involve others.

Whilst there was consensus that fragmentation of the health and care systems wastes resources, the suggestion that data and technology could promote integration, was challenged by the lack of evidence to support this intervention. The need to introduce incentives to overcome fragmentation, and to understand its drivers before taking action were also highlighted. There is evidence that earlier palliative care can reduce costs and improve care coordination and quality.<sup>40,41,42</sup>

Finally, it was agreed that a systemic change is needed in our health and care systems, given that the NHS *per se* is already fragmented.<sup>43</sup> Professor Wee suggested there were three opportunities to place end of life care and palliative care in the broader health and social care system:

1. Embedding end of life care in personalised healthcare.
2. Including end of life care within the primary care network.
3. Integrating health and care systems.

However, she also highlighted key challenges that included clinical engagement, public dialogue and metrics. Participants highlighted the need to ensure that new interventions are evaluated through research. In the case of the Liverpool Care Pathway, some delegates suggested this type of evaluation had not always happened. This is a key role for more programmatic research funding.

## Public and patient engagement

The Dying Matters surveys showing that two thirds of the British public say they are comfortable talking about dying with family and friends, was highlighted in one discussion, where it was also noted that the British public consider dying to be one of the topics they personally feel least comfortable discussing.<sup>44</sup> Some delegates suggested that misunderstanding, lack of information, and fear, fuelled by communication barriers with the medical profession, could underlie this. Participants agreed that we should encourage the public to talk about dying, regardless of their age, and start by considering how we can make the issue more familiar by creating space for discussion.

Some delegates suggested that education in schools could be a 'quick win' – and an initiative developed by Dying Matters in Scottish schools was considered to be a good case study.<sup>45</sup> Others thought that the introduction of CPR (Cardiopulmonary resuscitation) into the school curriculum in England, could be an opportunity to initiate dialogue about death, given so few people survive CPR.<sup>46</sup> Language was also considered by many to be an important issue: death is not just the end of life, but the last year/phase of life, or the 'natural end of life' and more broadly, and palliative care is about living well. Participants agreed that the word 'choice' should be avoided to prevent unrealistic expectations.

## Engaging communities and faith groups

Delegates noted the importance of trying to offer culturally competent palliative and end of life care, but also observed that because non-English speakers and people at end of life are often excluded from research there is a lack of research evidence with which to inform service improvement.

The frequent exclusion of non-English speakers and people at the end of life from research results in a lack of evidence with which to inform service improvement. This lack of an evidence base from different ethnic and faith groups was seen by delegates as a limitation when applying for funding for research to better understand these groups, creating a causality dilemma. To this end, there was a call for seed funding to support smaller scale projects that enable the mapping of the evidence-base to inform the development and testing of culturally competent interventions and support funding applications.

The importance of understanding social networks where people receive support around death and dying was also raised by workshop participants, with the Afro-Caribbean community being cited as an example of where this can work effectively.

These discussions also went on to inform the session on public engagement led by Ipsos MORI.

## Upskilling families and carers

Participants agreed that families and carers have a huge role in managing death and dying, especially considering the lack of 24/7 services and the fact that 'out of hours' in reality represents more than two thirds of the week. However, given the lack of understanding amongst the public of the process of dying, there was strong support for the need to upskill and invest in families and carers, allowing them to help manage symptoms and support their loved ones, reduce their anxieties and boost their confidence, increase possibility of care in the patient's preferred place, and potentially reduce inappropriate emergency admissions.

## Co-design

There was wide consensus that co-design between patients, carers, researchers and clinicians is needed in developing interventions and identifying research funding priorities. So far, this strategy has not been adopted enough in palliative and end of life care, but could be easily used to reach a common understanding of public, patient and carers' concerns, and identify local priorities. One participant said the research funding figures were 'shocking' from patient and public perspectives, and symptomatic of the current emphasis on 'cure' (i.e. medicalisation of death) rather than 'care'. All agreed that there is a need to involve patients and the public much more when making research funding decisions.

## Value for money

Dr Sleeman pointed out that one of the biggest challenges faced by society is how to provide care for all of those in need, and that evidence-based solutions will be key to addressing this. She noted that healthcare for people who are dying takes considerable resource<sup>47</sup>, as previously mentioned, for those over 65, up to 20% of which is spent in last year of life<sup>48</sup>, with the cost growing exponentially around the time of death. Professor Wee noted that most of this expense is incurred during emergency hospitalisations. Dr Sleeman noted the strong evidence that people supported by palliative care specialists are more likely to die at home rather than emergency settings, with associated reduction in costs. She added that specialist palliative care is associated with better outcomes, including more home deaths<sup>49</sup>, fewer emergency department admissions<sup>50</sup>, better quality of life and symptom burden<sup>51</sup>, and is cost-saving or cost-neutral.<sup>52</sup> She concluded that palliative care is a high-value intervention, which provides better care and lower costs, with value being defined as a function of improvement in outcomes offset by any increases in costs.

Participants agreed that there is an evidence gap for both successful and unsuccessful interventions; and that better outcomes, rather than lower costs, should be considered when evaluating end of life and palliative care interventions. Moreover, there was consensus on the difficulties of running randomised trials in palliative care (as opposed to palliative medicine), and that adopting a continuous evaluation system for such studies may be helpful. Finally, it was pointed out that to build evidence for larger interventions, there was a need to facilitate (and fund) testing on a small scale.

## Research funding

From her analysis of the National Cancer Research Institute (NCRI) Cancer Research Database (CaRD)<sup>53</sup>, Dr Best noted the total amount spent on cancer-related end of life care research. Between 2002 and 2017 NCRI partners spent £7.4 billion on cancer research, but only 0.18% (£13.3 million) of this was spent on end of life care research. She noted that Marie Curie's funding of end of life care research increased substantially from 7% in 2002/03 to 63% in 2015/16. After 2013/14, Marie Curie grants make up more than 50% of the research spend on cancer-related end of life care in the CaRD database.<sup>54</sup>

As previously mentioned, Dr Best noted that when looking at the overall health-related research in the UK, the UK Clinical Research Collaboration (UKCRC) and Health Research Classification System (HRCS) grant data set shows that 0.08% of total health-related research funding supported end of life care research in 2004/05. This increased to 0.1% in 2009/2010 and to 0.16% in 2014 though numbers are small which makes trends difficult to interpret. She also noted that in 2014 a total of £3 billion was spent on 17,000 active health-related research (£2 billion on research projects, £1 billion in infrastructure), of which only £3.25 million was spent on end of life care research in the UK (excluding infrastructure).

The Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance was established in the same year, bringing patients, carers and health and social care practitioners together to identify and prioritise their evidence uncertainties. The PeolcPSP questionnaire about treatment and care at the end of life obtained more than 1400 responses (the project excluded researchers). A prioritised list was agreed by consensus and a full report published in 2015. The top 11 unanswered questions are listed in Box 1.

## Box 1 The top 11 unanswered questions identified and prioritised by patients, carers and health and social care professionals to inform the future of palliative and end of life care research in order of priority.

Source: Palliative and end of life care Priority Setting Partnership in partnership with the James Lind Alliance.

1. What are the best ways of providing palliative care outside working hours?
2. How can access to palliative care services be improved, regardless of where there are in the UK?
3. What are the benefits of listening and incorporating patients' preferences via e.g. Advanced Care Planning?
4. What information and training do carers and families need?
5. How can adequate training for staff (including healthcare assistants) to deliver palliative care be ensured?
6. What are the best ways to determine patient needs and deliver palliative care for those with non-cancer diseases?
7. What are the core palliative care services that should be available to everyone?
8. What are the benefits of providing care in the patient's home?
9. What are the best ways of ensuring continuity of care for patients at the end of life, in terms of staff they are contact with?
10. What are the best ways of assessing/treating pain and discomfort for those with communication or cognitive difficulties?
11. How can people who live alone and do not have friends or family nearby receive adequate palliative care?

As reported by Dr Best, an analysis of the 2014 UKCRC HRCS grant data set shows how active palliative and end of life care funding maps to the PeolcPSP research priorities. In 2014, the Department of Health and Social Care (England), Marie Curie and the Arts and Humanities Research Council were the top three funding bodies.

Since 2014, there have been positive developments, with a recent NIHR end of life care call in programmes spanning Public Health Research, Efficacy and Mechanism Evaluation, Health Services and Delivery Research and Health Technology Assessment. Moreover, the Marie Curie Research Grants Scheme has partnerships with the Chief Scientist Office, Scotland, as well as Pancreatic Cancer UK, the Brain Tumour Charity, and the Motor Neurone Disease Association.

Many participants agreed that there are ongoing challenges of getting research funding, and of ensuring that research evidence influences both funding decisions and adoption.

## Metrics

Participants agreed that there needs to be careful consideration of the metrics related to palliative and end of life care, and were concerned about the lack of reliable metrics to assess 'good care'. It was noted that metrics are only useful for improvements when they are fully understood, and that a single measure may be too simplistic a way to approach the complexities of end of life and palliative care.

For example, it was noted that although NHS targets aim to encourage more deaths at home and ensure patients and families can exercise more informed choice; these very targets can mask inequalities in offering patients and families a meaningful choice, as BAME communities are currently under-utilising palliative and end of life care services, so are more likely to die at home, thereby contributing to meeting the target of more deaths at home, but not actually being offered culturally competent palliative and end of life care services.

There was consensus that such 'place of death' metrics could be replaced – for example, with measures such as the number of hospital admissions in the last three months of life. Given their potential to conflict with each other, it was suggested that separate population and individual metrics are needed. It was additionally highlighted that 'process metrics' and 'society metrics' are liable to create perverse incentives, as seen with the Liverpool care pathway<sup>55</sup>. Finally, it was agreed that, if used properly, metrics can be used to inform improvements, with some participants proposing the use of metrics in three domains – metrics for research, metrics for accountability, and metrics for improvement.

## Public engagement activities

In a session led by Sarah Castell from Ipsos MORI, workshop participants were asked to contribute to the development of the Ipsos MORI facilitated workshops with recruited members of the public and an omnibus poll. The key topics identified are shown in **Box 2**.

Public engagement workshops with groups of various faiths, and with different age and social demographics are planned to take place in Lewisham in early summer 2019.

## Box 2: Areas proposed by participants to inform Ipsos MORI's evidence gathering during the public engagement.

Participants were asked to give inputs to be used as a starting point to develop the in-depth interviews and polling planned by Ipsos MORI. Key topics identified included understanding public perspectives on:

- First-hand experiences of death, and varied experiences of healthcare
- What they think they will want from healthcare – what matters to them, what should happen when, what conversations, and information should be provided and what should be the focus.
- What they know about palliative and end of life and care, what role does and should it play in society, what success looks like and how it should be measured
- What does a 'good death' mean for them and their families; what is the 'future of death and dying' and what is their interest in co-design
- Male vs female, and minority perspectives – for example, culture, faith journeys and contexts
- The importance of language, and dispelling myths and misconceptions

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## References

37. National Palliative and End of Life Care Partnership (2015) *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*. <http://endoflifecareambitions.org.uk/category/general/>
38. Evans CJ, et al. (2019). *Service Delivery Models to Maximize Quality of Life for Older People at the End of Life: A Rapid Review*. *Milbank Q.* **97(1)**, 113-175.
39. Daveson BA, et al. (2014). *The real-world problem of care coordination: a longitudinal qualitative study with patients living with advanced progressive illness and their unpaid caregivers*. *PLoS One* **9(5)**, e95523.
40. Ruiz S, et al. (2017). *Innovative Models for High-Risk Patients Use Care Coordination and Palliative Supports to Reduce End-of-life Utilization and Spending*. *Innov. Aging* **1(2)**, igx021
41. Higginson IJ, et al. (2014). *An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial*. *Lancet Respir. Med.* **2(12)**, 979-87.
42. May P, et al. (2018). *Economics of Palliative Care for Hospitalized Adults with Serious Illness: A Meta-analysis*. *JAMA Intern. Med.* **178(6)**, 820-829.
43. *Ibid.*, 42.
44. Dying matters coalition (2016). *Public opinion on death and dying*. [https://www.dyingmatters.org/sites/default/files/files/NCP\\_C\\_Public%20polling%2016\\_Headline%20findings\\_1904.pdf](https://www.dyingmatters.org/sites/default/files/files/NCP_C_Public%20polling%2016_Headline%20findings_1904.pdf)
45. Dying matters coalition (2018). *Scotland schools' conference: A sudden and traumatic death in your school community – let's talk about it*. <https://www.dyingmatters.org/event/scotland-schools%E2%80%99-conference-sudden-and-traumatic-death-your-school-community-%E2%80%93-let%E2%80%99s-talk>
46. Hawkes, C., et al (2017). *Epidemiology and outcomes from out-of-hospital cardiac arrests in England*. *Resuscitation*, **vol. 110**, 2017, pp. 133-140.
47. The Nuffield Trust (2010). *Social care and hospital use at the end of life*. <https://www.nuffieldtrust.org.uk/files/2017-01/social-care-hospital-use-summary-web-final.pdf>
48. Institute for Fiscal Studies (2016). *The distribution of healthcare spending: an international comparison*. <https://www.ifs.org.uk/publications/8737>
49. Gomes B, et al. (2013). *Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers*. *Cochrane Database Syst. Rev.* **6(6)**, CD007760.
50. Henson LA, et al. (2015). *Emergency department attendance by patients with cancer in their last month of life: a systematic review and meta-analysis*. *J. Clin. Oncol.* **33(4)**, 370-6.
51. Kavalieratos D, et al. (2016). *Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis*. *JAMA* **316(20)**, 2104-2114.
52. Smith S, et al. (2014). *Evidence on the cost and cost-effectiveness of palliative care: a literature review*. *Palliat. Med.* **28(2)**, 130-50.
53. National Cancer Research Institute (2019). *NCRI Cancer Research Database*. <https://www.ncri.org.uk/ncri-cancer-research-database/>
54. *Ibid.*
55. NHS (2013). *More Care less Pathway: A Review of the Liverpool Care Pathway*. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212450/Liverpool\\_Care\\_Pathway.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf)

# Next steps

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This first policy workshop reviewed the policy landscape and identified current gaps in end of life and palliative care, to inform potential future policy work by the Academy and others.

This workshop and the public engagement elements of The Departure Lounge will be used to inform a policy catalysis workshop at the late 2019 / early 2020. A presentation on the findings from the Ipsos Mori discussions and the other public contributions gathered through The Departure Lounge will be reported at the second policy workshop.

# Annex 1: Programme

Workshop on 'End of life and palliative care: the policy landscape' agenda

Tuesday 12 February, 09.00 – 13.30 (including a light lunch)  
Academy of Medical Sciences, 41 Portland Place, London W1B 1QH

09.00 – 09.30	<b>Registration and refreshments</b>
09.30 – 09.40	<b>Welcome and introduction</b> Professor Irene Higginson OBE FMedSci, Professor of Palliative Care; Director of Cicely Saunders Institute, King's College London
09.40 – 09.45	<b>Aims of the meeting and background</b> Professor Irene Higginson
<b>Session 1: Context setting and discussion</b>	
09.45 – 10.05	<b>Overview of the landscape</b> <ul style="list-style-type: none"> <li>• Dr Katherine Sleeman, NIHR Clinician Scientist and Honorary Consultant in palliative medicine, King's College London (context and key statistics)</li> <li>• Dr Kathryn Mannix, Palliative care doctor and author (social perspectives)</li> <li>• Dr Mehrunisha Suleman, Research Associate, Centre for Islamic Studies (Muslim and other faith/cultural perspectives)</li> <li>• Dr Sabine Best, Head of Research, Marie Curie (research landscape)</li> <li>• Professor Bee Wee, Director for End of Life Care, NHS England (current and future activities of NHS England)</li> </ul>
10.05 – 10.25	<b>Group discussion</b> Facilitated by Professor Irene Higginson
10.25 – 11.15	<b>Breakout sessions</b> Facilitated by Professor Irene Higginson; Professor Kay-Tee Khaw CBE, FRCP, FMedSci, Emeritus Professor, Gonville and Caius College, University of Cambridge and Dr Katherine Sleeman, NIHR Clinician Scientist and Honorary Consultant in palliative medicine, King's College London  <i>Discussion topics:</i> <ul style="list-style-type: none"> <li>• What are the key challenges and initiatives around palliative and end of life care?</li> <li>• What are the priority areas for action? For example: <ul style="list-style-type: none"> <li>- Identifying evidence gaps</li> <li>- Understanding public views around end of life and palliative care (including research)</li> <li>- Barriers to implementing evidence-based services and policy</li> <li>- Structures for health and social care to enable a "good death"</li> <li>- Funding landscape and research questions</li> <li>- Workforce and skills</li> </ul> </li> </ul>
11.15 – 11.30	<b>Coffee break</b> What do we want from public engagement?
<b>Session 2: Discussion, priorities and next steps</b>	

11.30 – 11.50	<b>Feedback from breakout sessions</b> Professor Kay-Tee Khaw
11.50 – 12.35	<b>Group discussion and identification of priorities</b> Facilitated by Professors Kay-Tee Khaw and Irene Higginson
12.35 – 12.50	<b>What do we want to know from different sections of society?</b> Sarah Castell, Ipsos MORI
12.50 – 13.00	<b>Summing up and next steps</b> Professor Irene Higginson
13.00 – 13.30	<b>Lunch</b> The Liminal space will be interviewing selected delegates during the lunch break to discuss what we want to know from different sections of society.
13.30	<b>Close</b>

# Annex 2: Attendee List

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## *Delegates*

**Dr Sabrina Bajwah**, Consultant and Honorary Senior Lecturer, King's College London

**Jo Barratt**, Audio Producer, The Liminal Space

**Dr Sabine Best**, Head of Research, Marie Curie

**Liz Cairncross**, Research Manager, The Health Foundation

**Sarah Castell**, Head of Public Dialogue & Qualitative Methods, Ipsos MORI

**Dr Charles Daniels**, Medical Director, St Luke's Hospice

**Professor Douglas Davies FBA**, Professor in the Study of Religion, Durham University

**Simon Denegri OBE**, NIHR National Director Patients, Carers and the Public, National Institute for Health Research

**Baroness Ilora Finlay FMedSci**, Professor of Palliative Medicine and Chair, National Council for Palliative Care Medicine and Member of the House of Lords, University of Cardiff

**Dr Zoë Fritz**, Wellcome fellow in Society and Ethics and Consultant Physician in Acute medicine at Addenbrooke's Hospital, University of Cambridge

**Dr Wei Gao**, Senior Lecturer in Statistics and Epidemiology, King's College London

**Professor Rob George FRCP**, Medical Director at St Christopher's Hospice; Professor Palliative Care, Cicely Saunders Institute, King's College London, and Consultant Physician Palliative Care, GSTFT

**Professor Gunn Grande**, Professor of Palliative Care, University of Manchester

**Davina Hehir**, Director of Policy and Legal Strategy, Compassion in Dying

**Professor Irene Higginson OBE FMedSci**, Professor of Palliative Care; Director of Cicely Saunders Institute, King's College London

**Dr Ruth Joyce**, Senior Policy Manager, Human Tissue Authority

**Professor Kay-Tee Khaw CBE FRCP FMedSci**, Emeritus Professor, Gonville and Caius College, University of Cambridge

**Professor Thomas Kirkwood CBE FMedSci**, Emeritus Professor, Newcastle University Institute for Ageing, Newcastle University

**Sukhi Kaur**, Policy Officer, Alzheimer's Society

**Barbara Limon**, Head of Policy (Public), British Academy

**Dr Kathryn Mannix**, Palliative care doctor and author

**Professor Sir Jonathan Montgomery**, Professor of Health Care Law, University College London and Chair, Health Research Authority

**Dr Natalie Owen**, Health Improvement and Cross-cutting Team, Department of Health and Social Care

**Professor Gurch Randhawa**, Professor of Diversity in Public Health and Director, Institute for Health Research, University of Bedfordshire

**Toby Scott**, Head of Communications and Campaigns, Dying Matters

**Dr Emily Scott-Dearing**, Freelance consultant (Museums and Public Engagement)

**Scott Sinclair**, Head of Policy and Public Affairs, England, Marie Curie

**Dr Katherine Sleeman**, NIHR Clinician Scientist and Honorary Consultant in palliative medicine, King's College London

**Dr Richard Smith CBE FMedSci**, Commission on the Value of Death, The Lancet

**Dr Mehrunisha Suleman**, Research Associate, Centre for Islamic Studies, University of Cambridge

**Professor Christopher Todd**, Professor of Primary Care & Community Health, University of Manchester

**Professor Bee Wee FRCP FRCGP FAcadMed**, Director for End of Life Care, NHS England

**Dr Lucy Ziegler**, Associate Professor in Palliative Care, University of Leeds

## *Secretariat*

**Jonathan Cooke**, Communications Officer (Engagement), Academy of Medical Sciences

**Nick Hillier**, Director of Communications, Academy of Medical Sciences

**Dr Shaun Griffin**, Interim Head of Policy, Academy of Medical Sciences

**Sophia McCully**, Policy Officer, Academy of Medical Sciences

**Dr Rachel Quinn**, Director of Medical Science Policy, Academy of Medical Sciences

**Holly Rogers**, Communications and Engagement Manager, Academy of Medical Sciences

**Cristiana Vagnoni**, Policy intern, Academy of Medical Sciences



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