End of life and palliative care: Policy catalysis workshop

Report of a workshop held on 30 January 2020

The Academy of Medical Sciences

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Opinions expressed in this report do not necessarily represent the views of all participants at the event, the Academy of Medical Sciences, or its Fellows.

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Foreword

The COVID-19 pandemic has brought unprecedented impacts on the health of the public. A prominent matter at the forefront of the pandemic has been the challenges facing end of life and palliative care. With over 63,000 excess deaths in the UK, many of which have occurred among older people, high-risk communities and in settings such as intensive care units and care homes, the COVID-19 pandemic has highlighted the importance of the Academy's programme of work on end of life care, including this policy catalysis workshop and its wider public engagement piece, *The Departure Lounge*.[1,2]

Although the workshop took place before the COVID-19 pandemic unfolded, many end of life care issues discussed in the workshop have been reinforced by the pandemic. Most notably, the importance of preparedness for end of life, and the need for mechanisms for individuals, particularly those at high risk, to communicate their preferences for care and treatment in the event of uncertainty and at the end of life. Equipping the public, doctors, and other health and social care professionals to support these types of conversations will be vital ahead of any future resurgence of COVID-19.

With the ever increasing evidence base on COVID-19 being collated and assisting in the understanding of the disease progression, symptom management tailored to the physical, mental and emotional experiences of COVID-19 is necessary to prevent avoidable suffering.[3,4] Alongside this sits a need for open discussion with patients and the public about decisions on the appropriateness of interventions in hospital, with clear explanations when treatments may not be in the patient's interest, and the development of care pathways to support this decision making.

As identified at the policy catalysis meeting, a number of mechanisms should be used to support end of life care, including having advance care planning conversations. These conversations are set out to explore which treatments someone would or would not accept, aiming to give back autonomy without making unrealistic promises. For clinicians facing challenging situations, a consistent set of evidence-based guidelines and principles about best practice in palliative and end of life care would help to ensure equitable treatment across all healthcare providers.

Protocols and strategies should also be employed to support those people who are closest to patients, such as families and carers, who may be struggling with bereavement, increased burdens of care when patients are at home, or the challenges of not being able to spend time with patients who are in care homes or hospitals. In the context of COVID-19, there is an imperative to explore how family members or loved ones can participate in palliative and end of life care to provide support and comfort. It is vital that we remember the views expressed in our public engagement work of the need to focus on the individual and what matters to them at the end of life, and not just what's the matter with them.

The key issues raised by COVID-19 make the findings from this policy catalysis workshop ever more important. With the increase in willingness from members of the public to offer voluntary support in the face of a public health crisis, there is a vital and timely opportunity to mobilise social and community resources and networks, as identified at this workshop. The Academy is committed to widely disseminating the outputs from our series of work on *The Departure Lounge* and we now look to those in the sector to engage as a network and coordinate efforts to urgently address preparedness for high quality end of life care in the context of COVID-19 and other emerging infections. The Academy has supported The Liminal Space's upcoming project, LIFE SUPPORT, which provides an opportunity for further public and patient engagement on death and dying. LIFE SUPPORT will provide an online resource for individuals to understand and plan for the end of life through personal contemplation and in conversation with their family and loved ones.[5] We encourage those interested in this to identify areas for collaboration and to share the resource with their communities.

A challenge posed to all in the palliative and end of life care sector will be how to move forward in the shorter and longer term to address the issues from this report.

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Co-chair

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Executive summary

Given its expanding and ageing population, the UK is likely to see increasing rates of co-morbidity and annual numbers of deaths in the coming years, bringing future death demographics into increasing focus for policymakers. Yet, in the face of a fragmented health and social care landscape, the absence of systematic patient and public involvement, and a lack of consistent evidence-based practice, death remains a taboo for many, and support at the end of life a confusing – and often unknown – interface to navigate. In light of such issues, the Academy of Medical Sciences undertook a major programme of work to explore public perspectives on death, dying and end of life care, and considered policy solutions to improve end of life and palliative care. It will be important to focus on the policy priorities identified at this meeting to address the ongoing challenges faced as the number of deaths increase. The Covid-19 pandemic has emphasised this, and highlighted the need to ensure robust and universal provision of end of life and palliative care in the future.

As part of this work, the Academy convened a policy catalysis workshop on 30 January 2020 aimed at exploring the policy priorities for end of life care, and catalysing future policy activity for partners across the sector. Representatives from across policy and service delivery, academia, the NHS, and patient and public forums were informed by findings of the Academy's public engagement activity, *The Departure Lounge*, and an earlier policy scoping workshop. The aim was to discuss the challenges and opportunities for the field in overcoming fragmentation in the health and social care system; increasing patient and public involvement in end of life care; and improving evidence-based practice across the sector. The following key themes emerged from the workshop.

Overcoming fragmentation

- **Integrating locally-led initiatives with national provision**: National and local resource is poorly understood, with urgent efforts required to map and link ongoing activities. Participants called for a scoping review of national end of life services, to determine if and where efforts link and how they could be integrated in future. Focus should be given to assessing the provision of community development workers, with a need to integrate such roles into clinical teams.
- **Building community capacity**: Communities can provide much value in terms of upstream prevention, circumventing hospital admissions, and delivery of personalised care, especially through the existence of supportive networks. Increased resource provision to improve the infrastructure and sustainability of communities, and recognition of their value across the wider sector, could help to achieve this.
- **Upskilling healthcare professionals, patients and carers**: Upskilling patients and carers – for example through training in manual handling – could empower such groups, and shift the locus of control that currently rests across services. Moreover, training for healthcare professionals on the broader aspects of death could bridge some of the existing provision gaps, with further opportunities to create a dedicated 24/7 helpline to increase support coverage.

Increasing patient, carer and public engagement

- **Enabling increased patient and public involvement (PPI) in research**: More systematic PPI is needed in palliative and end of life research studies, particularly with those with the highest need for end of life and palliative care, and with carers. A number of barriers exist, including burdensome ethics and governance processes, and issues pertaining to patient recruitment. In future, it will be important to emphasise the value of

PPI in research, supported by efforts to streamline ethics and governance, including making palliative care a speciality in the Clinical Research Network.

- **Co-production:** Greater levels of co-design and co-production – where stakeholders including patients, researchers and commissioners work in equal partnership from the earliest stages of a project – are required, for a more holistic approach to end of life and palliative care policy, service delivery, research and support. Such efforts would help to prioritise lived experience and ensure a person-centred system that reflects the needs and wishes of service users. Moreover, partnering earlier with stakeholders could improve the chances of the outcomes of research being implemented.
- **Further communication on death and dying:** Ongoing engagement with the public, patients, carers and healthcare professionals is critical, with better communication needed on the types of end of life support available and what should be expected at the end of life. Further communication is also needed with healthcare professionals, to help them understand the social aspects of death, and recognise that medical involvement may not always be central at the end of life.

Improving evidence-based practice

- **Working across sectors and specialisms:** An existing disconnect between research, health and social care, and policy-making is restricting improvements in evidence-based practice for palliative and end of life care. Efforts to move beyond the 'palliative care box', involve more specialities in the end of life care agenda, and partner more frequently with the social care sector will be crucial in future. While there is good scientific evidence that specialist palliative care improves the quality of life, access to this evidence by all those who need it will be vital. Better utilisation of existing pathways, policies, networks, and digital resource could support such efforts.
- **Communicating the value of research in the health and social care sector:** Patient, public and carer involvement in research has many benefits, not least the links to improved care outcomes within healthcare settings. More needs to be done to communicate the value of research, and to encourage research uptake and involvement in settings across the landscape, including hospitals, hospices and care homes.
- **Increased provision of and better targeted funding:** Insufficient funding remains a major barrier for palliative and end of life care research. Systematic increases in infrastructure and resource levels are urgently needed in order to bridge current gaps and meet future challenges. Amongst other factors, better support for implementation research and methodology development will be important, along with increased coverage of patient and public engagement activities.

Next steps

Priorities that were highlighted for action in the immediate and shorter-term include a focus on:
- Forging better links with health and social care and informal services, supported by increased resource provision in community settings and greater remit for community efforts.
- A scoping review of existing local initiatives and their links with national initiatives along with link roles such as Community Development Workers.
- Further efforts to increase public awareness on what to expect from end of life care and the types of support available, particularly by improving the accessibility of information.
- Greater promotion of the value of research to stakeholders across the board, including patients, the public, carers and health care settings.
- Addressing the disconnect between research and healthcare settings by moving beyond the 'palliative care' box and emphasising cross-sector and cross-specialty working, for a more robust approach to evidence-based practice.
- Further training for health and social care professionals on the broader implications and social aspects of death, to achieve a more universal provision of support and tackle the disconnect with patients, families and carers.

The meeting catalysed a number of actions, with participants committing to or expressing an interest in: facilitating conversations with the Health Research Authority (HRA) around palliative and end of life care ethics and governance processes, and the oversight of research happening in social care and hospices; training of researchers and ethics committees in relation to end of life care ethics applications; utilising the networks formed at the meeting to create cross-sector partnerships and closer working between research, the NHS and policy; shared learning, ideas and resources on methods for public engagement on the topic of death and dying; and continued funding for research in this area.

Introduction

In the coming years, a continually expanding and ageing UK population will likely culminate in large increases in the number of deaths occurring annually. Shifts in death demographics – for example a rise in multiple long-term conditions and increasing rates of dementia – are also transpiring, forecast to result in a sharp increase in the need for palliative and end of life care by 2040.[6] Despite this, death and dying remains a taboo topic for much of the public, and there is uncertainty around the dying process.[7]

Aims of the meeting and background

In recent years, end of life care has increasingly become a priority issue for policymakers. The UK population reached a new high of 66.4 million in 2018, and is projected to continue growing to almost 73 million by 2041.[8] In parallel, the population is ageing: 18.3% of the UK population were aged 65 years or over in mid-2017, a 2.4% increase from 2007, and this is projected to grow to 24.2% by 2028.[9]

In light of the increasing importance of the topic, the Academy convened a workshop on 30 January 2020, co-Chaired by Professor Dame Jessica Corner DBE FMedSci, Vice Chancellor, Research and Knowledge Exchange at the University of Nottingham, and Professor Irene Higginson OBE FMedSci, Professor of Palliative Care and Director of Cicely Saunders Institute at King's College London, as part of a major project aimed at encouraging people to talk about death and dying, and ensuring that policy is developed in line with public views.

The workshop aimed to explore the policy priorities for palliative and end of life care, in order to catalyse future policy activity by individuals and organisations active in this space. Discussions were informed by an initial context-setting workshop[10], held by the Academy in February 2019, and the findings of the Academy's public engagement activity, *The Departure Lounge*, an immersive installation that aimed to provide information and encourage discussion about death and dying.[11]

Participants were drawn from a variety of backgrounds, including policy and service delivery, clinical settings, academia, and community and patient groups, to:

- Discuss the findings of *'The Departure Lounge'* public engagement exercise and the themes identified at the earlier landscape workshop, and their wider implications.
- Define the immediate priorities and policy gaps within end-of-life and palliative care.
- Explore and identify deliverable solutions, taking into account existing end-of-life care initiatives and how these might be developed to address gaps going forwards.

The discussions focused on the priorities and future opportunities for overcoming fragmentation across health and social care systems; increasing engagement with the public, patients and carers; and improving evidence-based practice in end of life and palliative care.

This report provides a summary of the discussions which took place during the meeting. It does not necessarily represent the views of all participants at the event, the Academy of Medical Sciences or its Fellows. A list of participants and the full meeting programme are provided in Annexes 1 and 2.

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Context setting: The Departure Lounge – Public attitudes to death and dying

Amidst growing cultural and media interest in death and dying, the impact of an ageing population and increasing healthcare costs remain largely unexplored with the public, and death remains a taboo. To explore this paradigm, the Academy of Medical Sciences commissioned *The Departure Lounge* public engagement programme in May 2019, aimed at promoting conversations around death and dying, exploring public views on the topic, and empowering people to make choices informed by research related to the end of life.

This chapter summarises the findings of *The Departure Lounge*. Professor Irene Higginson OBE FMedSci, Professor of Palliative Care and Director of Cicely Saunders Institute at King's College London, noted that the key themes that emerged from the Academy's earlier policy landscape workshop resonated with the findings of the public engagement exercise.[12] These included a need to focus on:

- **Overcoming fragmentation** in palliative and end of life care across the health and social care systems.
- Enhancing **public and patient engagement** in end of life and palliative care.
- **Improving the evidence base** to inform the use of interventions.
- **Increased and better targeted research funding** to meet current and future challenges.
- **Better metrics** to assess 'good care' to inform improvements.

It was stressed that whilst much good work is happening in these areas, this meeting provided an important opportunity to discuss further deliverable solutions that could address remaining issues and gaps in end of life and palliative care.

The Departure Lounge: public attitudes to death and dying

Nick Hillier, Director of Communications at the Academy of Medical Sciences, gave an insight into *The Departure Lounge* installation (developed in partnership with The Liminal Space) and other communications and engagement activities connected to the project.

The pop-up installation was open over four weeks in May and June 2019 in Lewisham Shopping Centre. It aimed to initiate a public conversation on death and dying and explore existing views on the topic. Opening in one of London's most diverse boroughs, the installation aimed to reach a wider public demographic, but also bring such conversations to a space where visitors would not expect to interact with the topic of death and dying. In total, over 25 days, 2,551 visitors interacted in the space in some way, with many others engaging with the shop's externally facing content.

To ensure visitors were supported, 35 Guides of varying backgrounds, professions, and lived experiences were recruited to support conversations in the shop. All Guides received a three-day training session facilitated by the Academy, alongside a range of background information and supporting documents. Three actors were also recruited as hosts, with the aim of encouraging visitor interactions, providing continuity and enabling shared learning.

Several features prompted visitors to interact within the installation, including:

- A 'Departures Board' containing answers to common questions about the end of life, in both text and recorded form.

- 'Windows on your world' – a light installation for visitors to write personal stories and share their hopes for a final journey.
- Suitcases displaying key statistics and information as well as lived experience stories.
- A private booth for visitors to spend time in quiet contemplation, should they require it.[13]

It was also highlighted how the travel-inspired theme aimed to reflect death as a destination for all, and to echo that experiences will differ dependent on preparedness. Further, it enabled the installation to play on cultural references and expectations, and to communicate key information about end of life care and research.

An extensive local and UK media campaign reached over 7 million people and received coverage in outlets such as the BBC, The Guardian, and Time Out, helping to raise awareness of the project and encourage a nationwide conversation.

A range of other linked activities were carried out in parallel with, or following, the installation, including: a dedicated website, translating content into a digital resource to engage wider audiences;[14] a programme of events such as 'dead beats' - a comedy evening exploring the intersection between music and death; hosted visits from community groups, including a pensioners forum and a carers network; and 60 flat pack versions of *The Departure Lounge,* distributed across the country for volunteers to host smaller, community-based events.

The Departure Lounge also looked for ways to collect and analyse the information exchanged during discussions with the public. To do so, Ipsos MORI was commissioned to survey 966 adults ahead of opening, and run seven focus group workshops during its course (further information below).

An independent evaluation of the installation reported that:[15]

- *The Departure Lounge* created a space for the public, where unusually open conversations about death, life, loss and family occurred.
- Personal stories and conversations with hosts and Guides were key in easing past the initial hesitancy of many visitors.
- Following a visit, many members of the public showed awareness that they do have agency and control, with some resolving to take action.
- Many people expressed that they would use the installation as a tool to scaffold difficult conversations they felt they needed to have with family and friends.

The Departure Lounge – findings and reflections

Sarah Castell, Head of Futures at Ipsos Mori, followed with an overview of the key findings from data collected prior to, and during, *The Departure Lounge* exercise, and how this could translate into recommendations for policy and research. The overarching aims of data collection were to:
- Understand public perceptions of death and dying.
- Understand the needs, hopes and fears of the public relating to the end of life.
- Identify any gaps pertaining to this area, and where they could be better served by policy and research.

To collect and analyse this information, seven workshops with 56 pre-recruited members of the public were conducted during the installation, involving: faith specific groups (Muslims and Christians); older people with and without multiple health conditions (aged 60-85); younger people (aged 25-35); and the squeezed generation (aged 35-65, mixed experience and non-experience of bereavement; caring responsibilities for children and/or the elderly).[16] Sixty four forms were also completed by Guides during conversations with visitors, and curated data from a range of social sources were used to inform final conclusions.

Findings revealed that, overall, the public found it difficult to talk about death: in a poll of 966 British adults, conducted in April 2019 using Ipsos MORI's face-to-face "capibus" methodology, one third of the public opted to not answer questions about the end of life.[17] Similar views emerged in dialogue workshops, where participants adopted an initial approach of

caution, and age differences prevailed, with younger people less comfortable engaging with – and lacking familiarity around – the topic of death.

However, on the whole, the public valued the experience of talking about death and dying once presented with this opportunity.

Discussions with the public imparted a number of other key insights, such as:

- **A lack of understanding around palliative care and the end of life**: this includes what palliative care constitutes, where it can be provided and the benefits; confusion also exists around what happens in the last moments of life and the care provided during this time.
- **What constitutes a good death and good care**: the public prioritised flexibility, control, and agency in end of life care, particularly allowing for the expression of personal values, beliefs and cultural differences. Muslim communities especially felt it should more be widely acknowledged that death need not be entirely medicalised, with some situations lacking remit for primary medical care involvement.
- **The importance of supporting autonomy and personalisation**: a decline in organised religion and the growth of informal support networks demonstrate the increasing focus on autonomy and personalisation. In the end of life context, the rise of Death Cafés, which bring people together to "eat, drink, and discuss death" is a leading example.[18]
- **Consideration of wider social trends**: growing social trends that could impact the dying process include: 'Death Doulas' – individuals who offer emotional, practical and spiritual support to dying individuals and family members;[19] augmented reality graveyards, which allow users to create a permanent online memorial linked to individual gravestones; and sustainable 'eco-funerals'. Social media and digital legacy will also warrant increasing consideration in future.

Implications for policy and practice

Several key implications for policy and practice emerged from *The Departure Lounge* public engagement activity. In particular, further communication around the physiological and emotional aspects of dying will be crucial, especially in the last hours and minutes of life, along with communicating the role of hospitals and hospices in delivering care. Concluding comments also stressed the importance of offering culturally sensitive care at the end of life, including a need to respect the wishes of those that may not wish to engage in these types of conversations. In future, greater awareness of emerging social trends could be one way of supporting the expression of personal values and beliefs at the end of life.

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Overcoming fragmentation

Delivery of end of life and palliative care requires involvement of stakeholders across the health and social care systems. However, fragmentation exists across the sector, making the coordination of care at the end of life particularly challenging. Discussions at the workshop explored how such fragmentation could be overcome, including via efforts to build community capacity and mechanisms to improve links with this setting.

Patient-focused care

Delegates felt that the current palliative and end of life care landscape was driving a disconnect between healthcare professionals, patients and carers, with the current locus of control sitting firmly with healthcare professionals as opposed to patients and their carers. Where the balance of power is fragmented across specialisms and services in the absence of integration across the health and social care systems, patients, families and external agencies often lack opportunities for optimal involvement in care planning. Urgent priority should be given to shifting the locus of control in end of life and palliative care and placing greater emphasis on holistic patient-focused provision of care in future.

Conversations highlighted a number of good practice initiatives taking place in this area, including:

- **My Life, My Wishes** – an NHS Wales initiative to support the public in drawing up Advanced Care Plans and upload onto GP systems.[20]
- **The British Geriatric Society's online resources** – relating to Advance Care Planning.[21]
- **Patients Know Best** – a platform which enables patients to collate medical records in one place, under the patient's control, with access provided to healthcare professionals. [22]
- **Scotland's Anticipatory Care Planning** – promoted by the Scottish Government and devolved health boards to encourage individuals to think considerably in advance about end of life care.[23]
- **NHS England and NHS Improvement Peer Leadership Academy** - offering people with lived experience of caring for someone at the end of life personal development opportunities, by becoming peer leaders and playing active roles in the development of personalised care plans at national, regional and local levels.[24]

Better utilisation of technology and digital capacity could offer patients, carers and families' greater autonomy in future. Resources such as the NHS App could provide a useful platform for signposting and information sharing, with the benefit of 24/7 information availability.[25] Other suggestions included exploring the use of messaging platforms such as WhatsApp to better coordinate care, especially for use within the community.

Delegates highlighted current work taking place around the use of Electronic Patient Care Coordination Systems (EPaCCS), which can be used to record and share key details about care at the end of life. They agreed that it would be important to build upon these efforts and ensure the spread of such resource going forwards.

There is a priority need for the sector to support the roll-out of patient-focused initiatives more systematically to support efforts to overcome fragmentation, improve communication and empower patients, families and carers. Encouragement for the public and professionals to improve their standards of expectation, and to hold services to a greater account, will also be important.

Recognising the value of community networks in delivering better care

Fragmentation across the health and social care systems and poor utilisation of community groups were viewed as compounding issues in relation to lengthy discharge times in acute care settings. Participants reflected upon the scale of the issue, noting occurrences of long hospital stays even where patients had Advanced Care Plans in place.
Efforts such as the *Older Person's Assessment and Liaison Service* (OPAL) (Box 1) led by acute clinical teams to improve patient pathways, could help to prevent avoidable hospital admissions for patients nearing the end of life in future. However, to accompany such efforts, there is also a need for greater recognition of the central role which communities can and do play in the provision of holistic care, and better incorporation of such efforts in the future care delivery and support.

Box 1: Older Person's Assessment and Liaison Service (OPAL)

The Older Person's Assessment and Liaison Service (OPAL) aims to improve hospital pathways for frail older patients by removing barriers that can lead to longer stays and ensuring safe and efficient discharge into the community.

As part of the seven-day service, a multi-disciplinary team undertakes frailty syndrome assessments, earlier comprehensive geriatric assessment's (CGAs), and engagement with local community care providers, to allow early intervention and appropriate diversion of patients when they arrive in hospital.

A number of trusts across the UK have adopted the OPAL service, such as Ashford and St Peter's Hospitals NHS Foundation Trust, where the scheme was introduced in October 2013. Clear improvements in acute pathways were recorded in the first six months, including:

- Significantly fewer patients converted from the medical admissions unit (MAU) to ward admissions, falling from 90% to 81% (and to 75% in 2015).
- A reduction in the percentage of patients readmitted within 30 days, dropping by almost a quarter from 20.7% to 15.3%.
- Length of hospital stay reduced from 10.1 to 9.1 days.
- Improvements in patient and carer satisfaction, with 100% of relatives/carers and 94% of patients reporting feeling involved with care planning. [26,27]

Discussions highlighted the importance of communities as a mechanism for upstream prevention or 'wellbeing promotion,' for instance via reduced unnecessary hospital admissions and support for healthcare professionals to navigate individual wishes. Participants also voiced a current lack of understanding of, and appreciation for, the amount of care already provided outside of mainstream services (by families, carers, volunteers and local groups, among others), particularly within acute teams.

Encouraging a change in the wider relationship between formal and informal healthcare should be prioritised going forwards, to allow greater agency of community efforts and place emphasis on patient-centred care.

Building supportive networks in communities

Efforts to bolster community capacity will harbour increasing importance. Current projections suggest end of life care provision in care homes and the community will need to double by 2040 in order to alleviate pressures on hospitals to provide end of life care; otherwise deaths in hospitals will increase.[28]

Participants felt that greater capacity building within communities could have a number of positive outcomes. Reductions in the number of contacts with frontline services is one such example, with schemes such as the *'Okay to Stay'* initiative (Box 2) demonstrating the impact that supportive networks can have in better identifying and assisting individual care needs. Large amounts of value could also be added in terms of capturing 'unseen gaps' in palliative care need – such as elderly and frail individuals who may not come into contact with primary care services – as well as offering greater numbers of those nearing the end of life the choice of dying in the community.

Box 2: 'Okay to stay' initiative

The 'Okay to Stay' at home initiative is a collaborative approach lead by Sheffield Teaching Hospitals alongside community nursing teams, GP practices, and Age UK, with the aim of supporting more people with long term conditions to manage their conditions at home. Individual care plans are formulated with and for the benefit of patients, to include information on medications, mobility and access to, or lack of, at home support. Plans can be accessed by urgent care professionals such as paramedics and out of hours GPs to support decision making and avoid unnecessary hospital admissions, with greater insight into how the individual manages at home, what their 'norms' might be, and where any support gaps should be addressed.

Of the 36 'Okay to stay' plans completed as part of the initial pilot, results suggested the plan had a significant impact on patient quality of life and use of emergency care services, including:
- A 41% reduction in emergency hospital admissions.
- A 50% reduction in Out of Hours GP calls.

Of the 10 patients who had not had an emergency admission prior to having a plan, all but one has remained at home since initiation of the plan.[29]

Upstream work by local hospices and established care settings to initiate community networks could be one way of building future capacity, with initial efforts enabling communities to expand and strengthen networks across local areas. Participants highlighted the respective efforts of the *Compassionate Neighbours* project, and work undertaken in Frome, Somerset (see Box 3) to implement a *Compassionate Communities* lead approach. They agreed upon the need to implement such schemes more systematically going forwards, to promote greater social connectedness and fill current gaps in care and support.

Box 3: Compassionate Neighbours and Compassionate Communities initiatives Compassionate Neighbours project, London

The *'Compassionate Neighbours'* project, initiated by St Joseph's Hospice, provides community-led support for those living with a long-term or terminal illness, or socially isolated individuals and those without traditional access to hospice services due to language, culture or lifestyle barriers.

Underpinned by the public health principles of the *Compassionate Communities*[30] initiative, the project aims to promote and protect health and well-being via organised efforts and places emphasis on the collective responsibility of communities.

Local hospices support individuals to become compassionate neighbours with training and a pairing scheme which matches those with shared interests. Forms of assistance include: regular visits; friendship and emotional support; carrying out activities; and helping stay connected to communities, family and friends.

In collaboration with St Christopher's Hospice, the scheme is currently being rolled out to seven other Hospices across Greater London.[31]

Compassionate Communities Model, Frome Somerset

The Frome Model of Enhanced Primary Care (FMEPC) was rolled out in Frome, Somerset in 2013, as a collaboration between Frome Medical Practice and Health Connections Mendip. The approach combines the compassionate communities' model of community development with routine medical care, and involves three main components:

1. Mapping community resources - including peer support networks, community groups and the use of volunteer support, which are placed on a central directory and used to identify gaps where communities can be developed further.
2. One to one support for patients and carers - to build and enhance their naturally occurring supportive networks, including patient-centred goal setting and care planning.
3. Community connectors – volunteers from the community who are trained to help people via signposting to services such as health, housing and financial support, and information resource.

Results have included a reduction in the percentage of emergency admissions by 15% within Frome during a time when those across the remainder of Somerset rose by 30%.[32,33]

However, participants stressed that at times hospitals or hospices may be the most appropriate place for an individual to receive care, and advised caution over placing too great a focus on dying at home. They agreed that metrics used to inform service delivery such as place of death statistics could be misleading and in some cases, unfit for purpose.

Delegates highlighted the need for due consideration of additional challenges associated with an increasing relocation of care into community. This includes potential legal issues around a patient's ability to remain at home, where the overall decision is based upon healthcare professionals assessing a sufficient range of capacity (e.g. vital values and mental capacity), and the resource requirements of continuously updating the information contained in care plans, which supportive networks and healthcare professionals would rely upon to deliver appropriate care.

Participants valued the pre-existence of government commitments to encourage wider community involvement in end of life care, and agreed upon the important priority of ensuring implementation of these commitments. The National Palliative and End of Life Care Partnership's *'Ambitions for Palliative and End of Life Care: A National framework for local action 2015-20'*[34] was viewed as a particularly positive example, with scope in future to use its co-production approach and focus on bottom-up implementation as a template model to inform the development of national policies.

Improving links with community settings

Major challenges exist to integrate locally-led work into national service provision, policies and even research, with better links needed in future to ensure a more universal provision of care. Participants acknowledged that whilst good practice examples do exist, the value of such schemes is often lost amidst the disjointed health and social care landscape.

Link staff such as Community Development Workers were viewed as a crucial conduit between health and social care services, in particular offering opportunities for 'social prescribing' and resource location beyond frontline services. Despite intermittent efforts to integrate such resource into clinical care teams, participants cited inconsistent and inequitable provision across the sector, with an urgent need to develop and exploit these roles more systematically. Discrepancies in terminology and job description pose an added challenge in navigating such resource, with services using titles including 'coordinators', 'community builders', or 'health connectors' for corresponding roles. Participants agreed it would be an immediate priority to conduct a review of the provision of such link roles, for use in informing future workforce planning; in the longer term, core inclusion in all clinical care teams should be encouraged, with coordination happening via Palliative Care Networks.

Delegates highlighted opportunities to further train health professionals linked to frontline services, such as 999 call handlers, paramedics and ambulance staff, who respond to emergency calls from the community. Efforts should look to upskill staff on matters relating to end of life care, including better assessment of whether hospital admission is necessary, or if a patient has the capacity to remain at home. NHS 111 staff, who also act as a pivotal point of contact, will be a crucial service to involve in these efforts.

Participants suggested developing a central point of resource similar to the NHS 111 helpline to offer 24/7 specialised end of life care support. This could have many benefits for care coverage, with the likely advantage of diverting calls around 999 and reducing pressures on emergency services.

Further training healthcare professionals

To catalyse change in the operating model of palliative and end of life care, participants agreed that wider efforts were needed to train medical professionals across the landscape in softer skills, and better engagement with the topic of death. Delegates noted that recent work undertaken to build professional confidence in having conversations around death, including the Royal College of Physicians' *Talking about dying* resource.[35] They also highlighted a key need to 'de-medicalise' dying and focus on the social aspects of death, with acknowledgement that whilst medical involvement is essential, it may not be central to all at the end of life.

Participants highlighted key gaps in the current post graduate curriculum, which currently focuses solely on the pharmacological aspects of palliative care. They agreed it would be a priority to adapt the medical curriculum to include some of the broader social aspects of death.

Upskilling patients, families and carers

Participants felt there were further opportunities to upskill patients, families and carers in matters relating to palliative and end of life care, including training in manual handling and better signposting of available support. Schemes like the *Compassionate Neighbours* project (mentioned above) could provide one mechanism of doing so. Such efforts could also benefit from engaging individuals who have previously refrained from community care involvement due to concerns around safeguarding and training.

However, participants expressed caution against automatically relinquishing the responsibilities of healthcare services onto carers and families, who are in many cases elderly or frail, have other caring responsibilities, and/or are dealing with co-morbidities themselves, and may therefore be unable to manage certain types of care. Whilst upskilling patients, families and carers will be integral to building community capacity, the sector must ensure this is accompanied by a continued delivery of high quality care and support via mainstream services.

Scoping review of services

Delegates discussed current confusion around existing end of life care schemes, initiatives and services and agreed that gaps in public and professional knowledge were driving fragmentation further.

As a next step, there is a priority need for a comprehensive scoping review of local and national end of life care services, initiatives, and resource provision – including community link workers as described above – to ascertain how efforts are coordinated and to whom and where they link. This will be crucial in understanding the current state of play, synthesising activities where appropriate and improving access to support in future. Participants called for such a review to be led by an impartial organisation or government body, working in partnership with key stakeholders across the sector.

Funding and sustainability

There was widespread agreement that at present, end of life and palliative care lacks the level of infrastructure of many other specialities, with better provision of funding needed to implement and support new and ongoing activities. Staffing issues were highlighted as a key concern, with a lack of continuity driven by high-turnover and poor retention rates preventing conversations around care packages, and hindering the delivery of more personalised care.
Better infrastructure provision in future would help to both ensure sustainability of activities and support communities to mobilise behind a drive in patient-focused care. Examples of success have been seen in other sectors, for instance with the development of *Maternity Voice Partnerships*,[36] where central services joined with the social movement to impact change. There was broad agreement that greater resource provision could have similar outcomes for end of life care.

Next steps

Participants proposed the following as important next steps:

- Improving links between health and social care - to address the medical and social aspects of end of life and palliative care as one entity. This should involve greater consideration of informal methods of care such as digital technologies, and place emphasis on community initiatives.
- A scoping review of existing locally-led initiatives and how they link into national initiatives - including further scoping for roles such as Community Development Workers, and how these are defined.
- Greater resource provision – to ensure 24/7 availability of central resource, achieved via further training of health care professionals, and an end of life specific 111 style service.
- Efforts to build community capacity – encouraging supportive networks and upskilling communities, families and carers for greater upstream prevention and circumventing hospital admissions.
- A need for further initiatives that aim to deliver patient-focused-care – to re-distribute the locus of power and place weight behind lived experience. Efforts should be made to consider a broader diversity of voices (e.g. faith groups, cultures and backgrounds).
- Further training of healthcare professionals on the broader social aspects of death, especially within the post-graduate curriculum.

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Increasing patient, carer and public engagement

Patient and public engagement is vital in supporting a system of care that reflects and serves the needs and wishes of service users. Whilst there are many positive examples of activity across the sector, coverage and involvement remains intermittent, with a lack of clarity pertaining to the end of life, forms of available support, and how to navigate the landscape. Discussions explored opportunities to embed patient and public engagement more systematically in palliative and end of life care in future.

Improving communication with patients, carers and the public

Building on *The Departure Lounge* findings, participants discussed the vital need for further engagement and communication with the public on the topic of death and dying. They felt the issue was one for the wider health and social care sector to address, especially through increased and more systematic involvement of patients, carers and the public in research, service planning and delivery. Beyond this, participants agreed there was a need for greater efforts to 'normalise' death and respect the process of dying.

Delegates valued the existence of many initiatives, policies and schemes which already exist in this area, for instance the Sue Ryder Care '*What to expect in the last few days of life*'[37] and Jewish Care '*Let's talk about the end of life*'[38] resources, and national campaigns such as Marie Curie *TalkAbout* (Box 4). However, further work to raise public awareness of such efforts will be a crucial future priority, with greater reach and impact needed in order to support the public in understanding what they should expect from end of life care.

Box 4: Recent public engagement initiatives, policies and schemes on death and dying

- **Dying Matters awareness week 10th Anniversary (England only)** – an annual week of events aiming to put talking about dying, death and bereavement on the national agenda. 2020's theme '*Dying to be heard*' will focus on how to help by listening.[39]
- **Cicely Saunders Institute Public Involvement Forum** – a forum bringing together patients, families and the public to share ideas, enable involvement in palliative care and rehabilitation research, and ensure PPI voices are heard.[40]
- **Compassionate Communities international conference** – convenes stakeholders to explore the equal role of communities in providing quality healthcare at the end of life. The latest – '*Compassionate Communities in Action: Re-Claiming ageing, Dying and Grieving*' – took place in October 2019.[41]
- **Cruse Bereavement** *Bereaved Customers First* **campaign** – initiative aiming to reduce the emotional burden faced by bereaved people when contacting business to inform them of the death of a loved one; methods of support include written plans and training for staff in appropriate response.[42]
- **Sue Ryder Care** *What to expect in the last few days of life* **booklet** – a guide which sets out what to expect when an individual is in the process of dying, especially aimed at carers.[43]
- **Marie Curie** *TalkAbout* – campaign offering inspiration and support to help people talk about and prepare for death, dying and grief. An interactive website features stories, quizzes, videos and podcasts.[44]
- **Jewish Care** *'Let's talk about the end of life'* **guide** – offers practical tips and key things to consider in relation to the end of life.[45]

Improved framing of language and presentation of information will be central to ensuring resources are understandable and resonate with the public. This includes providing information in a wider range of formats and spoken languages, and exploring opportunities for a national awareness campaign that could enable better reach of information into communities.

Community networks will be fundamental in the efforts to bridge knowledge and communication gaps. Good practice examples of this value include the *Creating Conversations* project in Croydon,[46] which facilities conversations on the end of life in a variety of languages, through the provision of specially trained volunteers. Delegates also viewed *The Departure Lounge*, and associated 'flat pack' project, as a positive example of initiating death and dying conversations within communities. They suggested action could be taken to roll out such schemes more systematically across the UK.

Further, participants felt that more could be done to communicate appropriately at a national level, including within the *Ambitions Framework*.[47] They encouraged high-level policies and government documents to prioritise the use of the word 'death' more commonly, and increase references pertaining to the end of life in general.

Co-production and co-design of end of life care services, initiatives and research

Beyond involving and engaging patients, carers and the public, there was widespread agreement that it was necessary to move away from the traditional operating model of palliative and end of life care. More work should be done to communicate the need for meaningful PPI, emphasise shared-decision making and embed this across the sector, to avoid the risks of PPI becoming merely a 'tick box' exercise.

To catalyse change, delegates agreed on the need for greater focus on co-design and co-production – where stakeholders including patients, communities, researchers and commissioners work in equal partnership from the earliest stages of service design, development and evaluation.

Participants felt that much could be learned from work taking place in Scotland under the Government's *Realistic Medicine* programme[48]. Led by the then Chief Medical Officer, the initiative encourages all health and social care professionals to change their approach to patient support by: placing emphasis on delivering personalised care, ensuring the public are engaged in a way that resonates, and creating a safe space for public and professional engagement.

Replicating such efforts across the sector with greater emphasis on systematic public engagement will help to ensure that end of life care research, policy and practice serve and reflect the needs and wishes of service users. Central to achieving this is better communication of the value of co-production across health and social care, and stressing that true co-production is a step beyond public engagement.

It was also noted that where stakeholders have greater investments in a project due to earlier engagement, reduced attrition rates could be likely. Participants highlighted a priority need to engage stakeholders at the earliest possible stage of research and policy activity going forwards, with efforts to involve them as a core component throughout the project, as demonstrated in co-production models. This would ensure outputs that are relevant, implementable and adaptable.

Future approaches should also strive to create an 'equal playing field' of involvement through the inclusion of a diverse range of voices, cultures, beliefs, and backgrounds at every level, to better inform and shape research, service planning and delivery.

Greater flexibility in approach to patient recruitment

Participants also agreed that in future, research could benefit from taking a more flexible approach to the recruitment of patients, carers and the public, to allow a greater diversity of voices and perspectives, and better support the roll out of findings into practice.

Provision of dedicated staff to undertake outreach work, as deployed by the South London Clinical Research Network (CRN), could create opportunities in future (Box 5).

Box 5: South London Clinical Research Network

South London Clinical Research Network (CRN) brings together local hospitals, GP practices and other healthcare providers to collaborate on clinical research studies that could lead to better treatments for NHS patients.

Within the network, Clinical Research Nurses have been deployed to match and recruit patients to appropriate research studies, undertake clinical study requirements, and carry out patient follow up.

The Clinical Research Network is viewed as having had a transformational effect on recruitment and retention of patient and public representatives to research studies across the linked trusts, especially in terms of lower attrition rates for a number research studies.

In the wider sector, the existence of research nurses is noted to offer a number of benefits including decreasedcosts, added value to studies, and improved scale and efficiency of research.[49]

Utilising technology and digital resource could also provide opportunities for greater flexibility, such as the ability to conduct virtual meetings with PPI members, which would remove the need to travel and offset associated time and costs.

Delegates stressed the need to ensure financial and technological resources are available for studies, otherwise researcher efforts to introduce greater flexibility will be difficult to implement. Engagement-specific grants – such as the Higher Education Innovation Fund (HEIF) Small Grants Fund, which allocates £500 for engagement activities – were viewed as an effective way of enabling researchers to undertake dedicated PPI work, and could be a focus area for future funding. Participants agreed that small scale funds can be very helpful, particularly for junior researchers, and often act as seed funding that leads to much bigger opportunities.

In future, both researchers and funders should consider how such flexibility is accounted for and financed at the planning stage of grant applications.

Ethics and governance

Participants felt difficulties pertaining to ethics approval for end of life and palliative care studies involving patients, carers and the public, were a major barrier to greater levels of co-production and co-design. They voiced that, with the best possible intent, ethics committees often adopt a protectionist, over-cautionary approach to approval of study applications in this area. This can hinder, and even discourage researchers to seek and recruit PPI voices. Delays in decision can further add to the frustration and difficulty of navigating ethics and governance process.

There was widespread consensus that sponsors and regulatory bodies such as the Health Research Authority should re-consider their approach to end of life research, to remove disincentives and unnecessary barriers to engaging patients,

carers and the public. To support this, it will be crucial to reinforce that such stakeholders do wish to be involved in research, alongside the longer-term value of involvement, particularly on care outcomes.

As a next step, participants called for palliative care to become a speciality in the Clinical Research Network, to foster a closer relationship between local trusts and clinical research recruitment. Such a move would support a more streamlined ethics and governance process and alleviate some of the issues mentioned above.

Shift to a focus on current and future need

Delegates cited a lack of systematic patient involvement in research studies, especially of those with high need for palliative and end of life care. They noted that accessing palliative care services was, in many cases, a challenge in itself for patients, with involvement in research a step beyond this, especially for those experiencing poor health and declining capacity.

Recent statistics highlight that approximately two-thirds of those dying are now aged over 75 years, with sizeable increases in the rate of deaths linked to dementia and an increasing occurrence of multiple long-term conditions.[50,51] As such, it will be an important priority for the research community to target and include older people, those with multiple conditions, frailty and dementia perspectives going forwards.

Examples can be drawn from the *EMBED-Care* research programme, which is aiming to generate a step-change in how care is provided for dementia patients and families informed by a collaborative network of stakeholders, including patients and families.[52]

Carer perspectives

Carers are likely to play an increasing role in end of life care, not least driven by an ageing population, and growing need for resources in the community to offset pressures on frontline services.[53] Delegates also cited the added value carers can offer with unique insight into the needs and wishes of patients on a level which, often, frontline healthcare professionals cannot. Despite the growing importance of this stakeholder group, gaps remain in provision of support.

Such gaps were highlighted in by a James Lind Alliance *Palliative and end of life care Priority Setting Partnership* (PeolcPSP), initiated by Marie Curie in 2013. This aimed to determine the most important unanswered questions for palliative and end of life care that could improve overall care and experience, as prioritised by families, carers, patients and health care professionals. In the top 10 unanswered questions to emerge, information and training required by carers and families to deliver the best end of life care was the fourth most prioritised on this list.[54,55]

To address such issues, greater awareness and inclusion of carer perspectives are needed, especially in research. Further consideration is needed on how research can capture carer perspectives before and after bereavement, including the impact of caring responsibilities and the loss of a loved one.

Participants highlighted that from a public health perspective, improved ways of 'caring for carers' could act as an important public health intervention. Global efforts are highlighting the importance of psychosocial and bereavement support for family caregivers. Preliminary findings of research undertaken at the Karolinska Institutet, Stockholm – aiming to evaluate the effect of spousal loss on health outcomes and mortality among older adults – indicate that bereavement has a significant and rapid impact on spousal health outcomes; crucially, on the risk of adverse event increases in the six-month period prior to loss.[56]

However, challenges exist to engage carers further, with individuals often lacking capacity to become involved due to time, energy and resource invested in caring responsibilities. Participants also noted that incentives such as payment are often not enough to justify the time and efforts spent being involved in research.

Going forwards, the research community should consider how to better motivate and support carers to become involved in end of life care research, especially by better communicating the longer-term value of research involvement. Utilising resources such as the Marie Curie *Research Voices* group, and INVOLVE – the National Health Institute for Health Research's (NIHR) patient and public involvement forum – could provide opportunities to identify, access and involve a larger number of carers in future.

Digital opportunities to enhance patient and public involvement

Participants highlighted the need for increased coverage and consistency of engagement activities in a diverse range of locations, and development and implementation throughout the year to increase visibility and accessibility. Digital technology and social media could provide opportunities to increase engagement, with delegates citing the broad reach and impact of forums such as Twitter and Facebook. Examples include the 'death cafe' Facebook forum, which is currently linked to over one million members of the public, whilst a number of other digital resources are engaging the public on the topic (Box 6).

Box 6: Digital public engagement initiatives

- Death over Dinner – Global project initiated by the University of Washington which offers users tools to plan and host a dinner with loved ones, co-workers and strangers to talk about death and dying.[57]
- Methodist website death and dying resources – a number of resources and signposts to online material designed to help users navigate and answer questions around death. The material reflects Christian faith perspectives, but is intended for all to use.[58]
- Dying Matters website – an online hub resources which encourage the public to talk about death, including leaflets, resources, podcasts and event signposting.[59]
- The Art of Dying Well – A website resource designed by St Mary's University which offers practical and spiritual support to those faced with the prospect of death and dying.[60]
- The Departure Lounge – 60 flat pack versions of the original installation have been created for use in community-based events across the country, and a digitised, web version of the pop-up materials is available for all members of the public to access.[61]
- Death Café Facebook forum - a global forum of over one million members that are interested in or involved with the Death Café movement, allowing users to share information on events and reflect upon personal experiences.

However, there is a danger that such approaches may only reach those already engaged with the topic of death and dying, and that too greater focus on digital realms could exclude certain audiences.

Further efforts to target the 'unseen gaps' in end of life care are needed, such as for elderly, frail patients, those with dementia, and those in social isolation, who may not have the ability to engage with modern forms of public engagement. Opportunities to explore broadcasting at a national level - perhaps via a public broadcaster - were discussed, with

widespread praise for the recent Marie Curie *'whatever you call it, we should talk about it'* TV campaign and its aim to reach a wider section of the population.[62]

Participants also reflected on the increasing need to consider new, emerging, technology-focussed schemes linked to the topic of death and the end of life, such as: the *Digital Legacy Association*, an organisation dedicated to ensuring end of life wishes are also met in the digital realm, and supporting the consideration of internet and social media presence after death; and the *Guardian Angel* Network, a free and online platform that aims to support people through the bereavement process. Delegates acknowledged current collaborative work between the Digital Legacy Association and the Law Commission around digital legacy, including the provision of information leaflets and training for solicitors.[63] They encouraged continued roll out of such activities in future.

Delegates agreed that in future, greater resources should be provided to undertake these important public engagement and dialogue initiatives, promote knowledge of their existence and ensure nationwide coverage. Representatives of *Dying Matters* expressed their willingness to collaborate with others across the sector to share learning and promote thinking on how best to engage with the public on the topic.

Next steps

Participants proposed the following as important next steps:

- Developing mechanisms to better communicate the types of support that are available to patients and the public – to help them realise what they should expect from the end of life, and support them to navigate this interface. Efforts should focus on improving the accessibility of information, particularly in high-level policy documents.
- More universal provision of public engagement activities – with a need to ensure coverage all year round, including roll out of schemes on a national level.
- Encouraging a more systematic focus on co-production – to achieve a more holistic model of research and service delivery, with learnings to be taken from the approach of the devolved administrations.
- Involving those with the highest need for palliative and end of life care in research more systematically – including older people and those with multi-morbidity, frailty and dementia.
- Greater involvement of carers in research – both in terms of PPI and efforts to capture carer experiences before and after bereavement, to reflect the important and ever-increasing contribution this group makes to end of life care.
- Enabling flexibility in approach to recruitment – and ensuring resource is available to support these efforts. Utilising technical capabilities such as webinars and virtual recruitment could help achieve this.

Making palliative care a speciality within the Clinical Research Network – to streamline the process for ethics and governess and remove associated barriers to patient and public involvement.

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Improving evidence-based practice

End of life care delivery spans a number of specialisms and settings, much beyond that of traditional palliative care. Despite this, siloed working remains the default and evidence-based practice is lacking, driven by views of end of life care as a singular space, and routes to inform policy-making poorly understood. Workshop discussions explored potential solutions to improve links across sectors, and enhancing collaborative working in future.

Greater collaboration with social care

Participants stressed the need for efforts to capture and reflect the large contribution of others beyond palliative care services in delivering care at the end of life. In particular, closer partnerships with care homes will be an immediate and increasing priority, where an ageing population is driving increased numbers of deaths in this setting, and projections suggesting it will become the most common place of death by 2040.[64,65]

Efforts to better engage stakeholders such as social workers and community GPs in the future research agenda will be an important accompaniment to support the increased focus on community care and efforts to build community capacity.

However, the lack of infrastructure in social care settings remains a major barrier to overcome, as well as high staff turnover, a lack of funding and excess treatment costs preventing these settings from engaging in research. Conversations reflected that such issues lead to inconsistencies in approach, difficulties in continued engagement, and low capacity within these settings to be able to take part in research.

Greater collaboration across specialisms

Participants agreed that in order to ensure patient-centred care and support in future, improved links were needed between research and healthcare settings. In particular, urgent efforts are needed to involve other medical specialities in research, as it currently operates a largely singular space dominated by palliative care.

Improvement could be catalysed with increased 'parallel planning' (e.g. planning for a liver transplant alongside planning for the end of life). Participants cited *The Lancet Liver Campaign*[66] as an effective example of cross-specialism collaborative working; they felt it had achieved added benefit in terms of encouraging the hepatology community to consider death and dying more broadly, as opposed to solely focusing on treatment and prevention.

Examples can also be drawn from the collaborative approach of the National Cancer Research Institute (NCRI), which provides a forum for cross-specialism working. Moreover, programmes such as Hospice UK's Research and Outcomes programme, aiming to encourage hospice settings to become research active,[67] and Marie Curie's Clinical and Academic Research Fellowships,[68] which allow clinicians to spend half of their contracted time in hospice settings, are leading examples of attempts to create research culture across communities.

Further, delegates reflected upon the significant amount of end of life related research taking place outside of traditional palliative care services, and/or undertaken by non-palliative care researchers, including work funded by disease specific

charities. They noted valuable funding that organisations such as Alzheimer's Research UK contribute to palliative care research, which could be utilised as a mechanism to promote cross-speciality working.

However, participants cited a current lack of guidance around research and governance in non-NHS sites, such as in hospices or care homes, and called upon the NIHR to take this forwards so that these settings can become more research-active in future.

Better utilising existing pathways, policies and networks

Participants also felt that it would be important for research to find ways to link better with policymakers, commissioners and primary health care services, to ensure evidence better informs practice. However, they viewed engagement with such stakeholders as a key challenge and noted that the ability to form such networks was often reliant on personal links and connections. Language barriers (e.g. differing medical terminologies), often driven by work undertaken in silos, were also conveyed as a specific challenge in cross-sector and cross-specialism collaboration.

To overcome such barriers, delegates agreed on the need for researchers to seek opportunities outside of the traditional 'palliative care box'. Specifically, they felt that opportunities could be created by honing in on policy levers and better interaction with current drivers, such as multi-morbidity, dementia and frailty, which have many links to palliative and end of life care.

A number of key opportunities were highlighted for end of life and palliative care to engage with service delivery more broadly to influence policy and practice, including:

- The NHS GP Contract deal – including the Enhanced Health in Care Homes service, which will offer GPs greater agency to support care within care homes to improve care delivery.[69]
- The NHS *Long Term Plan* – targeting more personalised care as one of its major changes over the next five years.[70]
- The Government's anticipated Adult Social Care Green Paper - likely to have many implications related to palliative and end of life care, with opportunities for research to mobilise efforts to influence this agenda.[71]

Suggested target networks and pathways for research to access in future included:

- NHS *Getting It Right First Time* – aiming to improve the quality of care within the NHS and reducing unwarranted variations.[72]
- NHS Improvement's *End of Life Care Programme Board* – set up to support the delivery of Government commitment on end of life and palliative care.[73]
- The Care Quality Commission – which maintains good links with social care settings such as care homes.
- Local Research & Development (R&D) networks – tapping into R&D networks could provide opportunities to better link with commissioners and influence service delivery at a local level.

Mapping stakeholders

Delegates described a current disconnect between research and the wider landscape, driven by a lack of understanding of existing networks, pathways and policies. They widely agreed that end of life and palliative care research could benefit from mapping its potential stakeholders - including social care, community links, policymakers, networks and pathways – at the start of the research process, to better understand these networks and their evidentiary requirements.

Moreover, participants felt this could have wider benefits for the dissemination and implementation of research. They agreed that in future, researchers should be encouraged to prioritise mapping stakeholders more effectively at the planning stage, which may help with the burden of frontloading this work before the study has started.

Delegates also agreed that dissemination can be neglected towards the end of a study, when projects are subject to increasing financial and time pressures, and often researchers have moved onto new studies or sites. Alongside better mapping of stakeholders, participants felt that greater efforts should be given to devoting the advised time stated in the funding guidance, to complement the efforts of identifying stakeholders early on, and ensure research outcomes reach these target groups and networks.

As for other stakeholder groups, there was widespread consensus that partnering with policy and service delivery as early as possible, including through co-design and co-production, should be a key priority to ensure such stakeholders remain engaged throughout the entirety of a project and increase the chances of implementation in the longer term.

Valuing research

Participants agreed on the need for increased awareness of the value of research across wider health and social care, as explored in a recent Academy of Medical Sciences report on enhancing the NHS-academia interface.[74]

It was noted that, despite the high proportion of research capable clinicians in end of life and palliative care, numbers of those who are research-active remains lower than that of other medical specialties. Further, delegates agreed that at times medical professionals, as with ethics committees, could also adopt a protectionist approach to involving patients nearing the end of life in research.

Participants felt that much could be learned from the realm of clinical trials, which has seen a transformation in research activity across sites after efforts, led by NIHR, to communicate the benefits of research on care outcomes. In future, more should be done to encourage healthcare settings across the end of life landscape to become research active.

Hospice UK's Research and Outcomes programme was a cited as a good example of efforts to connect with and promote the value of research in community care settings (Box 7). In future, greater efforts of this nature will be fundamental in communicating the message that patients and the public do wish to be involved in research, and stressing the benefits this can offer, to foster a health and social care system which truly values and prioritises patient-focused research and evidence-based practice.

Box 7: Hospice UK Research and Outcomes Community of Practice

Hospice UK launched a Research and Outcomes Community of Practice in November 2017, which supports hospice settings to become research active. Efforts aim to ensure hospices use the right evidence, in the right way, at the right time to plan, deliver and evaluate care, whilst also encouraging the development of new knowledge and research questions.

The Community of Practice consists of over 200 members from across sectors and covering multiple aspects of research and outcome measures. Available resources include monthly newsletters, special events and a Hospice IQ Forum, for the purposes of discussion, debate and sharing of ideas.[75]

Methodology and implementation

There was wide consensus amongst participants that the current methodology most commonly applied to end of life care research, double blinded Randomised Controlled Trials (RCTs), may not always be entirely fit for purpose, with many complex palliative care interventions struggling to fit well into the RCT framework. Moreover, delegates cited that running this type of trial can be very costly and difficult to conduct, often without achieving desired outcomes. It was noted that whilst lengthy RCTs are running, changes within the wider health and social care system can negatively impact likely future implementation of research findings.

Participants agreed that a paradigm shift was needed, with greater focus on implementation research and methodological development, so research can better mirror how services are implemented in the community. However, a lack of funding and resource acts as a major barrier to progress in this area. It was noted that whilst the NIHR provides some methodology resource for clinical research, such as its *Plan for impact* guidance,[76] basic translational research in this area is often overlooked, in part due to a lack of comprehensive guidelines from funding bodies.

Funding barriers

Delegates highlighted a lack of appropriate funding levels as major barrier, currently inhibiting the ability of palliative and end of life research to moving beyond RCTs more systematically. Whilst the landscape is seeing an overall rise in the amount of health services research – and funders such as The Health Foundation and NIHR's Health Technology Assessment (HTA) programme increasing the number of pragmatic, non-RCT calls in respective portfolios – opportunities to develop this area further were viewed as limited.

It was felt that funding gaps were arising in part due to the current outlook of funders, who may view health services research less favourably in comparison to RCTs, and concerns were raised over the competitiveness of palliative care research bids against other specialisms that can better justify conducting more 'attractive' RCTs. Going forwards, it will be important for funders and researchers to place emphasis on ensuring study designs are fit for purpose.

Participants also noted that whilst networks such as the Applied Research Collaborations (ARCs) are highly valuable for connecting research and healthcare, and could be a useful structure to support implementation and health services research, focus on palliative and end of life care is intermittent within such forums.

In future, researchers should look beyond funding calls specifically targeted to end of life care, to consider more generalist funding stream or those which may have applications to palliative and end of life care. For instance, the NIHR Funded Methodology Fellowships programme,[77] may provide opportunities for researchers to explore the best methodologies to apply to end of life care research.

Further support is needed for health services research to reach the world-leading standard of general science, clinical, and translational research across the UK. Participants called for greater activity at national and governmental level, to encourage and catalyse a paradigm shift towards a system which places greater value on differing types of research. Efforts of organisations such as Marie Curie to advocate for an increased focus on methodological development could be a useful starting point to build upon.

Digital opportunities for improving evidence–based practice

Delegates felt that digital and technological opportunities could be harnessed to support research and bridge some of the current gaps in end of life and palliative care.

For instance, the use of remote meetings and virtual recruitment could have benefits such as increased flexibility, reach and impact, by enabling researchers to foster better connections with key stakeholders - including PPI representatives, policymakers and commissioners - who often lack the time, capacity and/or the ability to travel offsite. Webinars could

also be a useful platform to exploit for their ability to draw a wide audience, and associated post-event playback features; such mechanisms could be particularly useful for drawing clinical audiences who have limited flexibility to engage in external meetings during clinical working hours.

Massive Open Online Courses (MOOCs) were also viewed as a key platform to utilise going forwards. Examples of successful implementation include Lancaster University International Observatory on Palliative Care's recent use of MOOCs to disseminate study outcomes in improving palliative care in care homes. Outputs reached over 9,500 people, including healthcare professionals, academics and lay audiences.[78]

Next steps

Participants proposed the following as important next steps:

- Better communicating the value of research to patients, the public, carers and health care settings – particularly that research with services improves care outcomes.
- More cross-sector and cross-speciality working – and efforts to move beyond the 'palliative care' box, to tackle the disconnect between research and health-care settings.
- Greater efforts to map stakeholders at the start of the research process – including policymakers, commissioners, GPs and social care, to enable early partnering with such groups and increase the likelihood of research implementation.
- Tapping into existing levers and policy drivers – such as the CQC and NHS RightCare, to support palliative care to become part of the wider health and social care agenda.
- Better provision of funding for implementation research and methodological development – with greater focus on study designs that are fit for purpose.

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Next steps

A number of barriers to furthering communication, improving support, service provision and delivery of end of life care, were identified at the meeting. These included: a fragmented health and social care landscape; poor utilisation of, and agency for, community efforts; an absence of appropriately evidence-based practice and true patient involvement; and a lack of funding on a systematic level. To overcome such challenges, an array of potential solutions for implementation in the shorter and longer term were proposed, as outlined in boxes at the end of the three previous chapters.

Next steps in the shorter-term included:

- An urgent need to better link health and social care to address medical and social aspects of end of life and palliative care, with encouragement for a culture shift towards patient-focused, holistic palliative care, and building supportive capacity within communities.

- A scoping/review of existing locally-led initiatives and how they link into national initiatives, including further scoping for roles such as Community Development Workers and how these are defined.

- Greater efforts to inform the public about what to expect from end of life care, and mechanisms to better communicate the types of support that are available. This includes efforts to improve accessibility of information – especially in high-level policy documents.

- Better communicating the value of research to patients, the public, carers and health care settings.

- A need to move beyond the 'palliative care' box and greater emphasis on cross-sector and cross-specialty working, to address the disconnect between research and healthcare settings and improve evidence-based practice.

- Further training health and social care professionals across the board in the broader implications and social aspects of death. This could help to achieve a more universal and consistent coverage of end of life support and tackle the disconnect with patients, families and carers.

Whilst these priorities were viewed as immediate actions for the field, the next steps identified in previous chapters within this report will also require careful attention in due course. Moreover, immediate and longer-term solutions should not be viewed as mutually exclusive, with many components needing to go hand-in-hand.

Professor Dame Jessica Corner, Vice Chancellor, Research and Knowledge Exchange at the University of Nottingham and workshop co-Chair, noted the need for an overarching step change in the operating model for palliative and end of life care, across policy, service delivery, care provision and research. Better conveying the message that research within healthcare settings can improve care outcomes, and creating a system where research is highly valued, will be crucial to inform and support the implementation of evidence-based end of life care.

There was widespread enthusiasm to take forwards the priorities identified at the meeting, with commitments to: facilitate conversations with the HRA around palliative and end of life care ethics and governance processes, and the oversight of research in non-NHS sites; facilitate training for researchers and ethics committees relating to end of life care ethics applications; share learning, ideas and resources for methods of public engagement on the topic; and ensure continued charity funding for research in this area. The workshop provided an important platform to explore cross-sector partnerships to address the challenges identified, using the networks formed at the meeting as a basis for closer working between research, the NHS and policy.

Annex 1: Academy of Medical Sciences' 'End of life and palliative care: Policy catalysis' workshop agenda

Thursday 30 January 2020, 10.00 – 15.00

Academy of Medical Sciences, 41 Portland Place, London W1B 1QH

09.30 – 10.00	**Registration and refreshments**
10.00 – 10.15	**Welcome and introduction** Professor Irene Higginson FMedSci, co-Chair *To provide a brief overview of the 'Death and dying' project, a recap of the February 2019 policy landscape workshop, and an introduction to the background and aims of the meeting.*
Session 1: 'The Departure Lounge' – findings and reflections	
10.15 – 10.25	**'The Departure Lounge': A summary of the public engagement installation** Nick Hillier, Director of Communications, Academy of Medical Sciences *To give a summary of 'The Departure Lounge' public engagement installation, its format and execution.*
10.25 – 10:40	**'The Departure Lounge: Public attitudes to death and dying' research report: findings and reflections** Sarah Castell, Head of Futures, Ipsos MORI *To provide an overview of the 'The Departure Lounge: Public attitudes to death and dying research' report and reflect upon the key findings and recommendations.*
10:40 – 11:00	**Q&A and plenary discussion** *Discussion topics:* • Feedback on findings from '*The Departure Lounge*' • What are the key focus areas to draw out of the Ipsos MORI report and take forward?
Breakout sessions – further discussion of key themes	

11.00 – 12.45 (inc. coffee break)	**Breakout sessions**
	Building on the morning's talks and discussion, the breakout groups will provide an opportunity to further explore the following themes, which emerged from both the Ipsos MORI report and our earlier context-setting workshop:
	1. Overcoming fragmentation
	    a) Exploring the role of community groups/ non-traditional agencies at the end of life
	    b) Better connecting the work of locally-led initiatives with national efforts, to improve palliative and end of life care provision

	Facilitator: Professor Dame Lesley Fallowfield DBE FMedSci
	    2. **Increasing public, patient and community engagement**
	        a) Facilitating greater communication with the public, patients and carers
	        b) Increasing public awareness of available resources
	Facilitator: Toby Scott
	    3. **Improving evidence-based practice**
	        a) Increasing involvement in research at the end-of-life
	        b) Improving links between research and healthcare settings
	Facilitator: Dr Katherine Sleeman
	For each theme, groups are invited to discuss the following:
	• What are the immediate policy priorities or policy gaps?
	• What, if any, activity or initiatives exist in this area?
	• How may these initiatives be adapted to address the issues identified? If none, what activities are required?
	• What are the key challenges to and opportunities for addressing identified policy priorities?

11:00 – 11:10	**Introduction to breakout sessions**
11:10 – 11:50	**Breakout session 1** Groups to discuss sub-theme a)
11:50 – 12:00	**Refreshment break**
12:00 – 12:40	**Breakout session 2** Groups to discuss sub-theme b)
12:45 – 13:45	**Lunch and networking**
13:45 – 14:15	**Breakout session feedback** Facilitated by Professor Dame Jessica Corner DBE FMedSci, co-Chair *Brief feedback from each of the breakout sessions [8-10 mins per group]*
Session 2: Priority setting	
14:15 – 14:55	**Plenary group discussion and priority setting** *Facilitated by Professor Dame Jessica Corner DBE FMedSci, co-Chair* • Where do the immediate priorities lie for policy and practice? • Where are the key opportunities for and barriers to catalysing policy/healthcare activity? • How do we move forward? What can the Academy and other organisations do to facilitate these actions? This session could also explore: • Future trends and their implications for death and dying • Research priorities
14:55 – 15:00	**Summing up and next steps** *Professor Dame Jessica Corner DBE FMedSci, co-Chair*
15:00	**Close**

Annex 2: Participant list

Dr Julian Abel, Vice President, Public Health Palliative Care International; Director, Compassionate Communities UK

Professor Mike Bennett, St. Gemma's Professor of Palliative Medicine; Head of Academic Unit of Palliative Care, Leeds Institute of Health Sciences, University of Leeds

Dr Sabine Best, Head of Research, Marie Curie

Amy Brewerton, Publications & Website Editor, British Geriatric Society

Phil Brough, National Senior Programme Manager (Palliative and End of Life care), Personalised Care Group, NHS England and NHS Improvement

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Lesley Goodburn, Chair, People in Partnership (PiP) Forum, Hospice UK; Senior Improvement Manager Patient Experience, NHS England/ NHS Improvement

Esther Green, Senior Policy & Advocacy Officer, Hospice UK

Sam Grice, Chief Executive, Guardian Angel

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Simon Jones, Director of Policy & Public Affairs, Marie Curie

Rashmi Kumar, Patient and Public Involvement representative, Cicely Saunders Institute, King's College London

Andy Langford, Chief Operating Officer, Cruse Bereavement Care

Professor Karen Luker FMedSci, Queens Nursing Institute Professor of Community, University of Manchester

Philip Lumsden, Volunteer, Marie Curie Voice; Volunteer Guide, The Departure Lounge

Dr Kathryn Mannix, Palliative care Doctor and Author

James Norris, Founder/CEO, Digital Legacy Association

Maria Parry, Academic Manager, Bachelor of Nursing Programme, University of South Wales; Volunteer Guide, The Departure Lounge

Professor Nancy Preston, Professor of Supportive & Palliative care; Chair, International Observatory on End of Life Care, University of Lancaster

Dr Heather Richardson, Joint Chief Executive, St Christopher's Hospice

Ella Robinson, Senior Policy Officer, Alzheimer's Society

Sue Robinson, Community Matron (End of Life care), Central London Community Healthcare NHS Trust; End of Life Doula, Living Well Dying Well

Dr Libby Sallnow, Palliative Medicine Consultant, Central & North West London NHS Foundation Trust; Honorary Senior Clinical Lecturer, St Christopher's Hospice and University College London

Professor Elizabeth Sampson, Professor of Dementia and Palliative Care, University College London; Consultant in Liaison Psychiatry, North Middlesex University NHS Trust

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Emma Self, Community Nursing Lead, NHS England and NHS Improvement

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