Cicely Saunders International
Better care at the end of life

KING'S College LONDON

The case for a new Impact Centre for Palliative and End-of-Life Care

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EXECUTIVE SUMMARY

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This report, commissioned by King's College London, sets out the conclusions of a period of exploration which has sought to establish whether there is a case to be made for creating a new Impact Centre for palliative and end-of-life care, and if so, what should a new Centre do and how should it operate. During 2022 and 2023, we spoke with many different stakeholders and people with experience of palliative and end-of-life care, including patients, carers, practitioners, funders, charities, commissioners, parliamentarians and policymakers. We found widespread support for a Centre that would mobilise the knowledge we have and promote implementation to improve outcomes and experiences of end-of-life care. We also found consensus that the need for it is now, with rising demand and inequalities in access to care, and new legislation that mandates the provision of palliative care to meet population needs.

By 2040, there will be an extra **150,000** people dying each year in need of palliative care.

The urgent need for improving palliative and end-of-life care

The challenge of providing comprehensive palliative and end-of-life care is growing more acute as the population ages. It is estimated that up to 90 per cent of people in the UK will need palliative care at the end of their lives. Demographic changes mean that by 2040, there will be approximately an additional 150,000 people dying each year needing palliative care, which is likely to widen already existing inequalities in who has access to palliative and end-of-life care. Hospital attendances and admissions account for about 60 per cent of costs in the last year of life. Reducing ineffective and unnecessary interventions at the end of life would improve outcomes for patients and carers and improve value for the health and care system. There are increasing pressures on staff in key professions such as district nurses who spend a large proportion of their time on palliative and end-of-life care. Giving staff across health and social care tools to deliver high quality care would improve morale and enhance workforce retention.

While there is a growing evidence base for services and approaches that deliver positive outcomes for people approaching the end of life and their families, this evidence is often poorly understood and used by practitioners and policymakers. As a result, people are missing out on access to high quality end-of-life care and suffering unnecessarily.

The Impact Centre for Palliative and End-of-Life Care

The Impact Centre for palliative and end-of-life care will enable the delivery of high-quality and high-value palliative and end-of-life care across the UK by closing the gap between evidence and practice. This will ensure that individuals receive the highest standard of care during their final stages of life, regardless of who they are or where they come from. The Centre will be instrumental in addressing the following critical issues:

- Increasing annual numbers of deaths, with many people missing out on the high-quality palliative care that they need.
- Unacceptable variations in care quality, with nearly half of people dying in hospitals despite their preference to die at home or in hospices.
- Widespread inequalities in palliative care access based on factors such as age, ethnicity, socioeconomic status, sexuality, type of illness, and geography.
- Providing support to Integrated Care Systems (ICSs) to better plan and deliver efficient and effective palliative and end-of-life care.

Key objectives of the Impact Centre

The Impact Centre will address these challenges through the following activities:

- **Synthesise, translate, and communicate evidence:** delivering accessible, actionable insights to improve how palliative and end-of-life care is delivered.
- **Share evidence-based approaches:** equipping practitioners and providers with the necessary skills, knowledge, and confidence to deliver palliative and end-of-life care.
- **Influence national and local policymakers:** influencing changes in policy and guidance, shaping how palliative and end-of-life care is implemented at national and local levels.
- **Improve public understanding of dying, death, and bereavement:** empowering people and communities to advocate for and support themselves and their families to ensure they are receiving the care they need.

Outcomes and benefits

Through this work, the Impact Centre will:

- Reduce physical, psychological, and emotional distress experienced by people with life-limiting illnesses.
- Ensure that ethnicity, socio-economic status, sexuality, diagnosis, location and other characteristics are not barriers for access to good care.
- Reduce inappropriate and unwanted, costly interventions, and create a shift towards proactive palliative care, with services that have reliable evidence to support them.
- Ensure that health and care staff have the tools to provide high-quality, coordinated, and person-centered care, aligned with people's preferences and values.

This report makes clear that the Impact Centre for palliative and end-of-life care is not only desirable and timely, but it is also deliverable.

Through its work, the Impact Centre for palliative and end-of-life care could transform care for many people approaching the end of their lives and those close to them across the UK. By giving knowledge and confidence to health and care staff, ensuring providers and commissioners of care have a shared understanding of best practice, and policymakers feel confident to allocate resources to palliative and end-of-life care, the Centre will deliver both better outcomes for people approaching the end of life, and lower costs for the health and care system.

BY PETER KINDERSLEY VIA CENTRE FOR AGEING BETTER

FOREWORD

FOREWORD

As a clinical academic working in palliative care for over fifteen years, I am driven by the desire to improve how we care for people approaching the end of life. As a clinician, I see first-hand the benefits that high quality palliative care delivers for patients and their families. As a researcher, I know that many people are not getting the care which could benefit them, and that there are huge (and in some cases, growing) inequalities in accessing high quality care.

Part of the problem is the large gap between evidence and practice. A wealth of evidence has now been generated on ways to improve experiences and outcomes for people approaching the end of life. However, too often this evidence is simply not used to improve care. This means that dying people receive suboptimal care, health and care resources are wasted, and families and relatives are left to pick up the pieces, and subsequently suffer the impacts of difficult bereavement.

What Works Centres have been established to bridge the gap between research evidence and the everyday practice of those working to deliver public services. There are currently What Works Centres focusing on varied topics including ageing, homelessness and education. No What Works Centre exists for palliative and end-of-life care.

This report is the culmination of over two years of work exploring the idea of a What Works Centre for palliative and end-of-life care. We engaged with those who receive care and their carers and loved ones, those who deliver palliative and end-of-life care, charities who support and advocate for those with serious illness and/or who are approaching end of life, commissioners, clinicians, managers and senior policymakers. Early on, stakeholders told us they preferred the term ‘Impact Centre’ to ‘What Works Centre’, therefore we use this term throughout this report. I am grateful to everyone who has given time to engage with us in these conversations. King’s College London commissioned Anna Dixon, who helped to establish the Centre for Ageing Better, a What Works Centre and part of the government What Works Network, to support this work. This report summarises how we have established the case for an Impact Centre for palliative and end-of-life care, and outlines the vision, strategy, and guiding principles.

I hope the publication of this report will mark the shift from exploration to delivery. We are keen to speak to organisations and individuals who are interested in helping us turn the plan into a reality and who share our vision to create long-term systemic change in how palliative and end-of-life care is delivered, directly improving such care in the UK and ultimately establishing a framework for better palliative care globally.

Professor Katherine Sleeman
June 2024

About the report author

Dr Anna Dixon MBE

Anna Dixon has over 25 years' experience in health and social care. Anna's roles include Director of Strategy and Chief Analyst at the Department of Health, Director of Policy at the King's Fund and Chief Executive of the Centre for Ageing Better (a What Works Centre). Anna chaired the Archbishops' Commission on Reimagining Care (June 2021 – January 2023) and received an MBE for services to wellbeing in later life in 2021.

About the report sponsors

Professor Katherine Sleeman

Katherine Sleeman holds the Laing Galazka Chair in Palliative Care, based at the Cicely Saunders Institute at King's College London. She is joint Academic Impact Lead for the Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, Chair of the Palliative Care Clinical Academic Group on Reach and Impact, and leads the Integrated Academic Trainee (IAT) programme for palliative medicine at King's. She has recently become Director of the new NIHR Policy Research Unit in palliative and end-of-life care. She practises as an Honorary Consultant in palliative medicine at King's College Hospital NHS Trust.

Cicely Saunders International

Cicely Saunders International is a globally recognised international charity committed to advancing palliative care worldwide. It was established in 2002 by Dame Cicely Saunders, a pioneer in modern palliative care. The organisation's primary mission is to 'promote research to improve the care and treatment of all patients with progressive illness and to make high-quality palliative care available to everyone who needs it – be it in hospice, hospital or home.' In 2021, the charity launched 'You Matter Because You Are You: An Action Plan for Better Palliative Care'. This comprehensive plan addresses significant challenges within the palliative care system, offering evidence-based solutions derived from research conducted during the Covid-19 pandemic. With 24 achievable actions, the plan aims to enhance patient care and improve the capability of NHS services to meet escalating demand.

The Cicely Saunders Institute at King's College London

The Cicely Saunders Institute at King's College London is world renowned for its high quality and pioneering research in palliative and end-of-life care, delivering impact locally, nationally and globally. In Research Excellent Framework (REF) 2021, the Cicely Saunders Institute scored 100 per cent 4* for environment, and 84 per cent 4* for impact, and was ranked #1 overall. The Cicely Saunders Institute is a World Health Organisation collaborating partner and houses the Centre for Global Health Palliative Care and the NIHR Policy Research Unit in palliative and end-of-life care.

THE PURPOSE OF THE REPORT

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1. THE PURPOSE OF THE REPORT

This report, commissioned by King's College London, sets out the conclusions of a period of exploration which has sought to establish whether there is a case to be made for creating a new Impact Centre for palliative and end-of-life care, and if so, what should a new Centre do and how should it operate. During 2022 and 2023, we brought together and spoke with many different stakeholders and people with experience of palliative and end-of-life care. We heard many moving and powerful stories about what is wrong with the current approach from those who have experienced end-of-life care or who work in health and care. We benefitted from the experience and expertise of existing What Works Centres and those involved in evidence-based practice in other spheres, as well as earlier work undertaken by SCIE on behalf of Marie Curie.[1]

We found widespread support for a Centre that would mobilise the knowledge we have and promote implementation to improve outcomes and experiences of end-of-life care. We also found consensus that the need for it is now, with rising demand and inequalities in access to care, and new legislation that mandates provision of palliative care to meet population need.

This report makes clear that it is not only desirable and timely to address this issue, but it is also deliverable. The report summarises what we learned and then sets out a plan for how the Centre will operate.

Currently, over **100,000** people in the UK die every year without the high-quality palliative care that they need.

CENTRE FOR AGEING BETTER

What is a What Works Centre?

It is now more than 10 years since the then Cabinet Secretary and Prime Minister supported the establishment of a network of organisations to promote evidence-based policy and practice, known as the What Works Network (**gov.uk/guidance/what-works-network**). Supported by a small team in the Cabinet Office, the network currently has 9 independent What Works Centres, and 3 affiliate members. The model was loosely based on the example of NICE established in 1999.

In 2018 a review of the first 5 years was published,[2] in which the centres were described as having in common a commitment 'to generating evidence, translating that evidence into relevant and actionable guidance, and helping decision makers act on that guidance.' The report went on to say one of the key contributions was 'developing new approaches to translating evidence into user-friendly formats and disseminating their findings to diverse audiences.'

The report set out the main functions as:

- **Generating and collating evidence:** including assessing the current evidence base, conducting rapid evidence reviews and systematic reviews, addressing gaps in the evidence either by influencing others or commissioning research directly and strengthening the research and evaluation capabilities of the sector.
- **Translation:** communicating evidence in innovative ways through comparison toolkits, advice and guidance, digital media and outreach programmes.
- **Adoption:** putting evidence into practice by supporting implementation, influencing regulators, establishing strategic partnerships to reach practitioners, and capacity building in the sector among the users of evidence.

The different What Works Centres have placed more emphasis on one or more of these functions depending on the area they are working in and their funding. As they have matured, the focus has shifted more towards adoption.

What do we mean by palliative and end-of-life care?

Palliative care is defined by the World Health Organisation as:

> **'Care that is given with the intention of improving the quality of life of people with a life-limiting illness and those close to them, including symptom management, psychological, social and spiritual support'**[3]

Palliative care prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems whether physical, psychosocial, or spiritual.

Palliative and end-of-life care may be delivered by professionals for whom this is only part of their role (called generalist palliative care in this context), or by professionals who specialise in palliative care (specialist palliative care). Specialist palliative care professionals have undergone additional, detailed palliative care training, and work in multi-disciplinary teams.

According to NHS England, the term end-of-life care refers to the last year of life; however, it is also commonly used to indicate the last months or weeks of life.

Palliative care can improve symptom burden and quality of life for people affected by serious illness.

Development work undertaken

Professor Katherine Sleeman, Laing Galazka Chair in Palliative Care at the Cicely Saunders Institute, King's College London, began discussions about the idea for a What Works Centre for palliative care in Spring 2021 with Dr Anna Dixon, then Chief Executive at the Centre for Ageing Better, Professor Baroness Ilora Finlay and others. At this stage, Katherine and team also had conversations with key stakeholders, including NICE and the Cabinet Office What Works team.

In parallel, the Social Care Institute for Excellence (SCIE) was commissioned by Marie Curie to carry out a short study into the feasibility of a new evidence centre for palliative

On average 80% of people who die in hospices have cancer (even though cancer accounts for only 25% of all deaths).

and end-of-life care. SCIE conducted a rapid review of relevant literature and interviews with stakeholders involved in palliative and end-of-life care research and evidence dissemination to explore the case for a new centre, its potential purpose and role.

As part of these early exploratory activities, SCIE, supported by Marie Curie and with input from Katherine Sleeman, facilitated a workshop with a wider group of stakeholders to discuss the proposed concept of an evidence centre in palliative and end-of-life care and emerging options for its development, including the purpose of such a centre, its potential position and impact within the wider sector, and possible form and funding models. The workshop was held in London in March 2022 and involved representatives from across the spectrum of evidence users, generators and facilitators, as well as from existing What Works Centres and potential supporters, to help shape and develop the concept at this formative stage. The findings were summarised in a briefing paper in September 2022.[1]

A second workshop was held in Leeds in September 2022, organised by King's College London and Marie Curie and co-hosted by the Department of Health and Social Care, to co-create a system-wide plan for how we can achieve better outcomes in palliative and end-of-life care. The workshop brought together people with lived experience and their carers, commissioners, providers and policymakers. Through the workshop, we sought to understand more broadly the actions that are needed to deliver good care, who is already doing what, and what the barriers and enablers to change are. The outputs of this workshop were written up and shared with participants. We draw on these in this report.

We held virtual Patient and Public Involvement (PPI) workshops in advance of and following the Leeds workshop to develop and refine a statement of the overall vision and outcomes for palliative and end-of-life care. This has informed the proposed issues that a Centre would focus on and is reflected in an organisational theory of change for the Centre.

Following the Leeds workshop, we have continued to engage and speak to key stakeholders and informants to develop the case and business plan for a Centre. We have drawn on the experience of the What Works Network through interviews and discussions with Directors and Chief Executives. The author was also able to draw on the experience of setting up and leading the Centre for Ageing Better, a What Works Centre. We have also drawn on the example of IMPACT (Improving Adult Care Together) Centre at the University of Birmingham, which, while not part of the What Works Network, is focused on the translation and adoption of evidence into practice in adult social care.

As part of these discussions, stakeholders told us they preferred the term 'Impact Centre' to 'What Works Centre'. Therefore, we use this term throughout the report. The next section of the report sets out the case for a new Impact Centre for palliative and end-of-life care and why this is timely.

BY PETER KINDERSLEY VIA CENTRE FOR AGEING BETTER

WHY DO WE NEED AN IMPACT CENTRE FOR PALLIATIVE AND END-OF-LIFE CARE?

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KING'S College LONDON

2. WHY DO WE NEED AN IMPACT CENTRE FOR PALLIATIVE AND END-OF-LIFE CARE?

While there is a growing evidence base for services and approaches that deliver positive outcomes for people and their families, this evidence is often poorly understood by those who could act on it and make changes in policy and practice. There is an opportunity to improve people's quality of life at the last stage of life if we close the implementation gap, putting into practice what we know works and making better decisions informed by evidence and data. Currently, increasing numbers of people are dying and there is rising demand for end-of-life services. Yet there is significant variability in the quality of care that people receive, and persistent inequalities in access to care.

'With dying, you only get one opportunity to get it right.' Family carer, stakeholder workshop

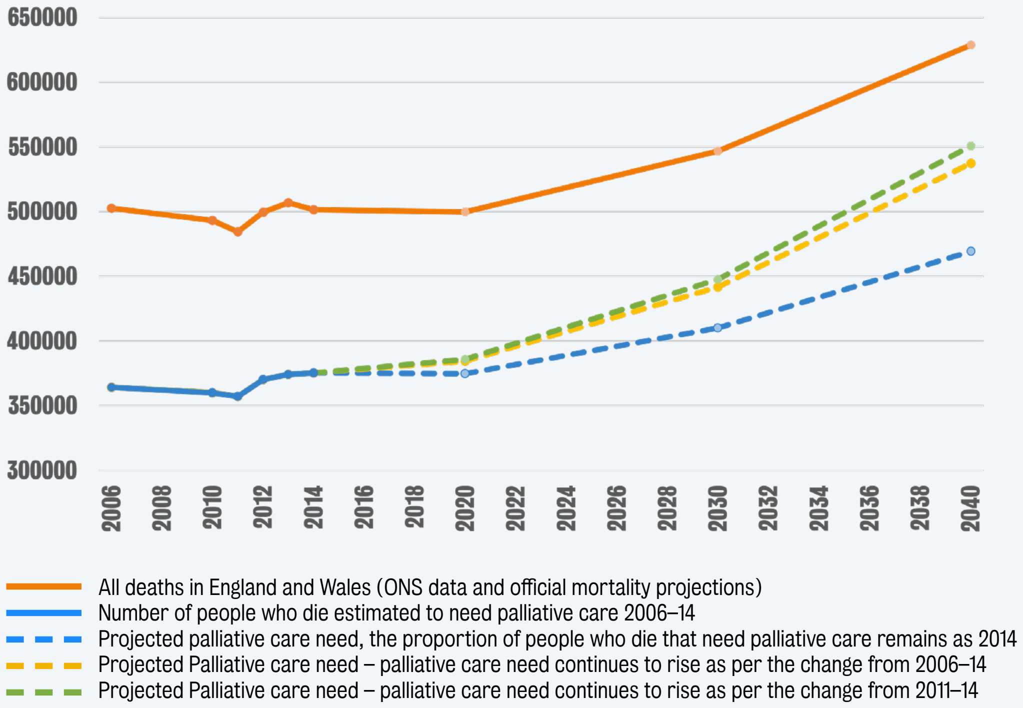
Need for services

More people are dying each year, many without access to palliative and end-of-life care

Between 2015 and 2019, on average 604,000 people died each year in the UK. In 2020, the absolute number of people who died was just over 695,000 – an increase of 15 per cent on the previous five-year average – much of the excess due to the Covid pandemic.[4]

Population ageing means that 160,000 more people annually are expected to need palliative care by 2040, up to a 43 per cent increase compared to 2020.[5]

Figure 1. Estimated number of people requiring palliative care from 2006 to 2040. Projections of overall population palliative care need according to International Classification of Disease-10 estimates. Solid lines indicate estimates based on actual mortality data. Dotted lines indicate projection models. Source: Etkind et al. 2017.[7]



Source: Etkind et al. BMC Medicine (2017) 15:102

Currently, over 100,000 people in the UK die every year without high-quality, effective palliative care.[6] This leaves many people dying in unnecessary pain and discomfort, with a feeling that their wishes have not been met or that their preferences have been ignored.

Demand for palliative and end-of-life care is set to increase rapidly, as more people live for longer with multiple and complex conditions (see Figure 1).[7]

Nearly half of people die in hospital, despite a stated preference to die at home or in a hospice and there are inequalities in place of death

Before the pandemic about half of all deaths in Great Britain took place in hospital (47 per cent). 24 per cent of deaths were at home and 22 per cent in a care home. Just 6 per cent of deaths took place in a hospice.[4]

The number and proportion of people who died at home in England from March to December 2020 increased in comparison to 2019, for both men and women. Deaths at home increased for all deprivation groups; however, this increase was greatest for people living in the least deprived areas and smallest for people living in the most deprived areas.[8]

Projections of place of death (see Figure 2) show rising deaths expected in the community, with care home deaths projected to be the most common place to die by 2040. This highlights the need to implement sustainable models of community care, to ensure people receive high-quality care that enables them to die in the place of their choosing.

The higher someone's socio-economic position the more likely they are to die at home/hospice rather than hospital compared to people of a lower socio-economic position.[9]

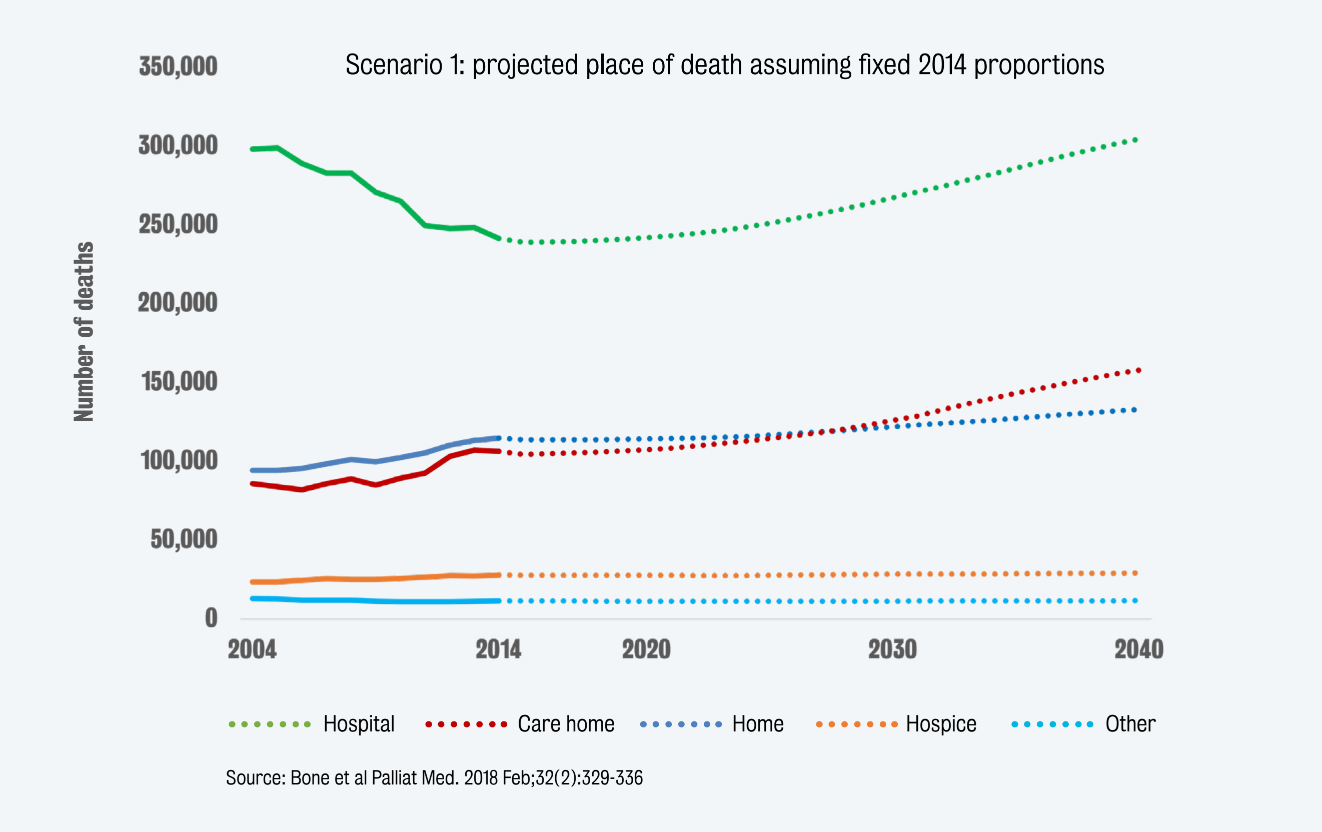
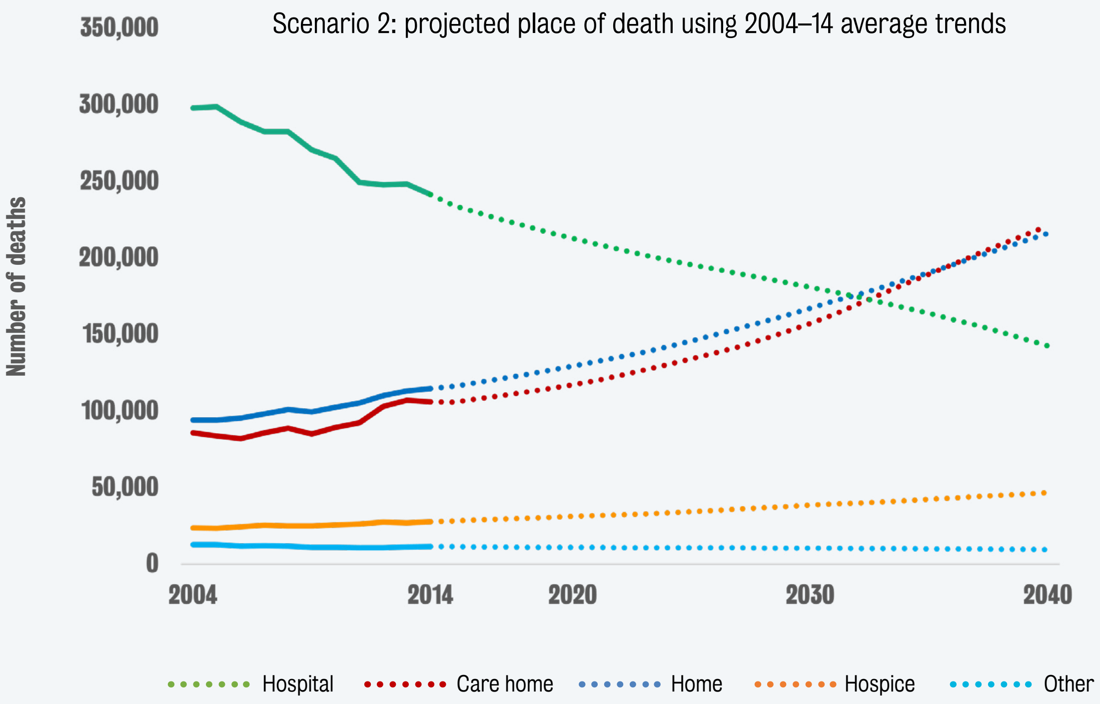
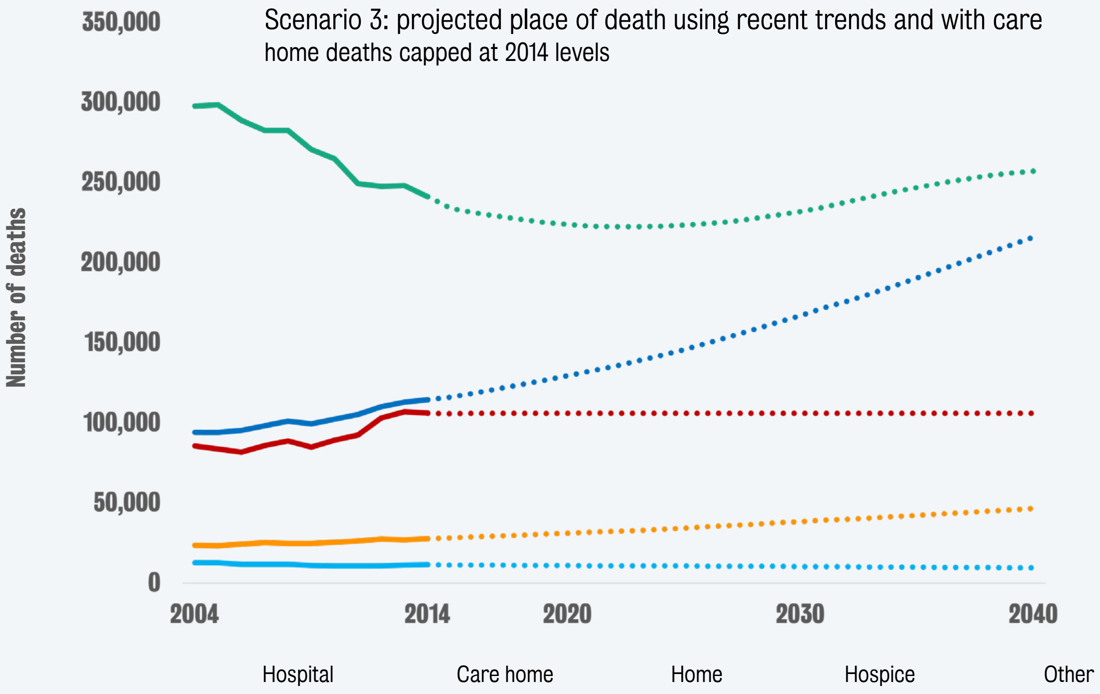


Figure 2: Scenario 1. Actual (2004–14) and projected (2015–40) numbers of deaths in each setting in England and Wales.
Source: Bone A et al 2018 [10]



Scenario 2: projected place of death using 2004–14 average trends

Source: Bone et al Palliat Med. 2018 Feb;32(2):329-336



Scenario 3: projected place of death using recent trends and with care home deaths capped at 2014 levels

Source: Bone et al Palliat Med. 2018 Feb;32(2):329-336

Figure 2: Scenarios 2 and 3. Actual (2004–2014) and projected (2015–2040) numbers of deaths in each setting in England and Wales.
Source: Bone A et al 2018 [10]

There are also inequalities in access to specialist palliative care and hospice care

People living in more deprived areas are less likely to get access to specialist palliative care and are more likely to report fair/poor experience. There is also less use of specialist palliative care services by minority ethnic groups.[11]

There are further inequalities in access to palliative care on the basis of age, ethnicity, socio-economic position, and among people who identify as LGBTQ+.

On average 80 per cent of people who die in hospices have cancer (even though cancer accounts for only 25 per cent of all deaths).

The quality of end-of-life care is mixed and staff shortages are set to get worse

Over half of respondents to Marie Curie's Public Attitudes to Death and Dying survey, did not agree or did not know whether there are adequate health and social care services available for people at the end of life, and the same proportion felt that way about whether cultural or religious/spiritual needs are adequately supported by these services.[12]

In the National Audit of Care at the End of life 's Quality Survey, performance on the measure of consideration of families' and others' needs has fallen since 2021. Around half of the cases audited found a need to improve documentation of discussions with families and others about the risks and benefits of hydration and nutrition options.[13]

There are increasing staff shortages in key professions such as district nurses who spend a large proportion of their time on palliative and end-of-life care. Giving staff knowledge, skills and confidence to deliver high quality care can increase job satisfaction as well as the quality and effectiveness of care.

State of the evidence

There is a growing body of evidence showing the benefits of good palliative and end-of-life care

Evidence shows palliative care has benefits for people of all ages including children, and for a wide range of conditions including dementia, and is most effective when provided early in a patient's journey rather than close to the end of life. There have been several systematic reviews demonstrating the effectiveness of hospital-based specialist palliative care,[14] effectiveness of home-based care[15] and experience of home-based palliative care.[16]

Palliative care can improve symptom burden and quality of life for people affected by serious illness. It can enhance their experiences of security, increase the likelihood of dying at home, and reduce hospitalisation towards the end of life. Importantly, palliative care can be provided at the same or lower overall cost.[5]

20% of people reported that quality of care for their loved ones towards the end of life was quite poor or very poor. **King's YouGov survey**

...but there remain aspects of care with little or no evidence base

While there is increasing research evidence for palliative care, there remain areas of practice for which there is little or no evidence and many unanswered questions. The James Lind Alliance carried out a prioritisation exercise which identified the top 10 priorities for research in palliative and end-of-life care.[17] This was published in 2015 and the state of the evidence will have moved on. Marie Curie has announced it is launching a new project to refresh the James Lind Alliance prioritisation. More recently, the What Works Wellbeing project on end-of-life care identified areas of research interest through conversations with practitioners.[18] An important task for the new Centre will be to systematically map the available evidence and identify priorities for further research to meet the questions of its key audiences as identified through a process of engagement and co-production (see below).

State of practice

There is currently a large gap between what we know about good care and what is implemented and available.

To illustrate the gap between evidence and practice we can consider some examples.

NICE recommendations made over a decade ago have not been followed through and implementation remains patchy. For example, the 2022/23 National Audit of Care at the End of Life (NACEL) in hospitals found access to specialist palliative care, in particular face-to-face access 8 hours a day, 7 days a week, is available in just 60 per cent of hospitals/sites. Similar variability exists in the out of hours services to support people in their own homes. Only 1 in 3 UK areas provides access to designated palliative care phone lines, even though this has been a NICE recommendation since 2011.[19]

Electronic Palliative Care Coordination Systems (EPaCCS) are a means to capture and share information electronically from people's discussions about their care. There was a commitment to implement these fully by 2020, and yet in 2022, only two out of three clinical commissioning groups (CCGs) have these systems in operation.[20]

The Marie Curie Better End-of-life report 2022 highlighted the gaps in out of hours care for those dying at home with significant geographical variation.[8]

Finally, despite good evidence of the benefits of Enhanced Health in Care Homes and a commitment in the NHS Long Term Plan to roll out across England by 2024, workforce challenges mean this may not be met.

Demand for palliative and end-of-life care is set to increase rapidly, as more people live longer with multiple and complex conditions.

The majority of Integrated Care Systems do not have a strategy to deliver on their duty to provide palliative and end-of-life care.

The Health and Care Act 2022 includes a requirement for Integrated Care Boards (ICBs) to provide palliative care services. Documentary analysis of Integrated Care System strategies found only a quarter framed palliative and end-of-life care as a priority; few mentioned the need for equal access to care and outcomes at the end of life, or how strategies would lead to better patient outcomes.[5]

There are a wide range of professionals involved in the delivery of palliative and end-of-life care who are often poorly served in terms of their research and evidence needs

While there are about 700 specialist palliative care doctors working in the UK, most end-of-life care is delivered in primary care and is spread across a large range of professionals and organisations.

Specialist palliative care teams are usually multi-disciplinary and may involve dieticians, speech and language therapy, pharmacists, physiotherapists, occupational therapists, spiritual and psychological services as well as physicians and nurses.

There are over 200 hospices in the UK, a quarter of which provide 'outstanding' care according to the Care Quality Commission.

There are 17,000 care homes, of which over 5,000 provide nursing care, in the UK.[21]

Community professionals including GPs, district nurses and community nurses, social workers and home carers provide a large amount of palliative and end-of-life care, as do hospital staff.

None of the existing Royal Colleges takes a lead on producing professional guidelines on palliative and end-of-life care.

Palliative and end-of-life care is delivered by a wide range of statutory, voluntary and charitable organisations.

The main charities involved in the provision of care and support for people with terminal illness are:

- Independent charitable hospices
- Charities supporting NHS hospices
- Marie Curie

- Sue Ryder
- Hospice UK
- Disease specific charities including Macmillan Cancer Support, Alzheimer's Society, Motor Neurone Disease Association.
- Grant giving charities, Trusts and Foundations
- NHS Charities Together

In addition to hospices, care homes, hospitals, community health services, general practice, housing associations and many other organisations are directly or indirectly involved in the care and support of people who are approaching end of life and their carers.

Our engagement with organisations across sectors suggests that they would value a source of reliable evidence to support them in delivering evidence-based care and services, as well as the opportunity to work with the Centre to test and evaluate the innovative services that they deliver as providers.

Before the pandemic, about half (47%) of all deaths in Great Britain took place in hospitals.

What others are doing in this space

While there are organisations producing research, there is not an organisation responsible for promoting evidence-informed action

The UK is world-leading in its research on palliative and end-of-life care. This is mainly delivered by research centres located in universities. Leading among these is the **Cicely Saunders Institute at King's College London**. Marie Curie funds two research centres at Cardiff and University College London. Other centres include the **Hull York Medical School Wolfson Palliative Care Research Centre**, the **University of Cambridge Palliative & End of Life Care Group in Cambridge (PELiCam)**, and the **Lancaster University International Observatory on End-of-life care**.

The NIHR has recently funded a new Policy Research Unit in palliative and end-of-life care which is led by Katherine Sleeman at King's (with co-leadership at the University of Hull, and partners at the Universities of Lancaster, Leeds and Cambridge). Following the model of other NIHR Policy Research Units, this is focused on national policy questions and will be responsive to the Department of Health and Social Care as the main audience. It is complementary to the proposal for an Impact Centre which would primarily serve those involved in the planning and provision of care as well as health and care professionals as the key audiences. Whereas the Policy Research Unit's primary focus is research, the Impact Centre's primary focus will be to synthesise existing research and evidence, and facilitate its application in practice.

While NICE produces guidance on palliative and end-of-life care it does not support implementation and has limited capacity to update this regularly. There is a range of palliative and end-of-life care guidance, clinical guidelines and quality standards currently available. These include:

- End-of-life care for Adults [QS13] (updated September 2021)
- Supporting Adult Carers [NG150] (published January 2020)
- Care of dying adults in the last days of life [QS144] (published March 2017)
- End-of-life care for adults: service delivery [NG142] (published October 2019)
- Care of dying adults in the last days of life [NG31] (published December 2015)
- End-of-life care for infants, children and young people with life-limiting conditions: planning and management [NG 61] (update July 2019)
- Palliative care for adults: strong opioids for pain relief [CG140] (updated in August 2016)

There are a few evidence-into-practice organisations that have done work on end-of-life care. However, they generally have a wider focus and their work on end-of-life care is limited:

- IMPACT at University of Birmingham is funded by the Economic and Social Research Council (ESRC) and the Health Foundation **more.bham.ac.uk/impact** – IMPACT's focus is on adult social care and so key elements of end-of-life care are out of scope such as children's palliative care or the more clinical aspects such as pain relief. They currently have one project with a hospice.

- The Social Care Institute for Excellence (SCIE) is a charity which supports sector led improvement for social care professionals and organisations and produces evidence-based resources. Those for end-of-life care have not been updated since 2016 **scie.org.uk/adults/endoflifecare**
- What Works Wellbeing had a project on Dying Well which looked at wellbeing for those with terminal illness and brought together practitioners to share learning and ideas and highlighted existing research **whatworkswellbeing.org/projects/dying-well**

There is no single organisation that has a focus on ensuring that existing research and evidence on palliative and end-of-life care is put into practice and used to inform decision makers.

Why now?

> **'I think the Covid pandemic has made people more aware of their own mortality. Whether that makes them want to discuss their own deaths is another matter but it could be viewed as a step along the road.'** Patient and Public Involvement workshop participant

There is a sense of urgency – that now is the time to do this.

- Integrated Care Boards have new statutory duties to ensure palliative and end-of-life care is commissioned but there is uncertainty about what or how to commission this. As the Covid Inquiry gets under way, questions will be asked about the experience of those who died and how care can be improved in future.
- Demographic changes mean that by 2040 there will be an additional 150,000 people dying each year needing palliative care, which is likely to widen already existing inequalities in who has access to palliative and end-of-life care.
- Resources (funding and workforce) are tight in both health and social care and there is growing pressure to use resources wisely. Hospital admissions account for the majority of costs in the last year of life.[22] Reducing ineffective and unnecessary interventions at the end of life would improve outcomes for patients and carers, and improve value for the health and care system.
- Waiting times for admission to hospital are long and growing, and a range of factors can result in discharge from hospital being delayed. Timely discharge of dying patients from hospital would free up acute beds for others.
- Staff retention is a problem due to burnout and staff reporting a lack of support. Staff shortages across health and social care as well as the opportunities of technology and routine data, mean existing models of care need to change, and change quickly.
- As more people's wishes to die at home are met, increasingly it is community-based staff and family members providing the care, and the workforce in this area needs to grow in line with future needs.

65% of adults are worried about access to palliative and end-of-life care. **King's YouGov survey**

Conclusion

This analysis has shown clearly that there is a gap between the evidence being generated through research and implementation of this evidence in practice. As a result, people are missing out on access to high quality end-of-life care and suffering unnecessarily.

> **'It is not a lack of knowledge that is inhibiting our collective efforts; it is about the will and priority that must be given to applying that knowledge in a focused and purposeful way.'** From Ambitions for Palliative and End-of-life care: A national framework for local action 2021–26

The need for an Impact Centre for palliative and end-of-life care is made even more urgent by the wider trends in demographics, public and charitable funding, and the pressures on health and social care. Furthermore, the wide range of practitioners and providers involved in delivering end-of-life care, and the Integrated Care Boards now legally responsible for securing this, lack a single source of reliable information on what to do and how to do it.

While more research is needed, simply producing more research will not deliver results. The Impact Centre will ensure that evidence translates into practice, transforming palliative care in the UK.

The next section sets out the vision and strategy for the Centre.

GEORGE TORODE

WHAT WOULD A NEW IMPACT CENTRE AIM TO ACHIEVE?

3

3. WHAT WOULD A NEW IMPACT CENTRE AIM TO ACHIEVE?

Vision and strategy

The Impact Centre would adopt the following vision, mission and objectives:

Vision

Everyone in the UK is supported to have the best quality of life in the final stages of life regardless of who they are or where they come from. Carers and relatives of those who are dying feel supported.

Mission

The Centre will enable the delivery of high quality and high value palliative and end-of-life care across the UK by closing the implementation gap between evidence and practice.

Key objectives

- **Synthesise, translate, and communicate evidence:** delivering accessible, actionable insights to improve how palliative and end-of-life care is delivered.
- **Share evidence-based approaches:** equipping practitioners and providers with the necessary skills, knowledge, and confidence to deliver palliative and end-of-life care.
- **Influence national and local policymakers:** influencing changes in policy and guidance, shaping how palliative and end-of-life care is implemented at national and local levels.
- **Improve public understanding of dying, death, and bereavement:** empowering people and communities to advocate for and support themselves and their families to ensure they are receiving the care they need.

12% of the public reported their loved ones were 'not very much' or 'not at all' treated with dignity and respect towards the end of life. **King's YouGov survey**

To ensure that everyone is receiving the best care when they need it, it is vital that research and evidence is co-produced by and effectively communicated to the people delivering care every day, informing their practice and developing their skills and confidence. Evidence also needs to be shared with decision makers at all levels, influencing policy and creating a context in which health and care organisations are more likely to deliver the high-quality care people need. The wider public also needs to be supported to understand and influence the health and care system, to change the public conversation about end-of-life care and ensure there are long-lasting, widespread and sustainable impacts.

Who are the main audiences?

There are many organisations working on end-of-life care and related issues, all of whom contribute to the achievement of better outcomes for people and those close to them. The Centre will need to influence the actions of a wide range of individuals and organisations. From our stakeholder mapping (see Figure 3) we identified priority audiences including leadership and delivery staff working in health and social care, provider organisations (including local authorities, NHS organisations, general practice, care homes and home care providers, hospices and other voluntary service providers), system structures involved in the planning and purchasing of care and support, and patients, those close to them and communities. There are also secondary audiences who will be influenced by and benefit from the information provided by the Centre including professional bodies, sector-wide bodies, regulators, education institutions, national and local government, politicians, and policymakers. It is key that the Centre is clear about its audiences, and prioritises which of these it is primarily seeking to influence the actions and behaviours of. Given the diversity of audiences, it is critical to engage representatives of these audiences in the development and governance of the Centre and tailor outputs to meet their different needs.

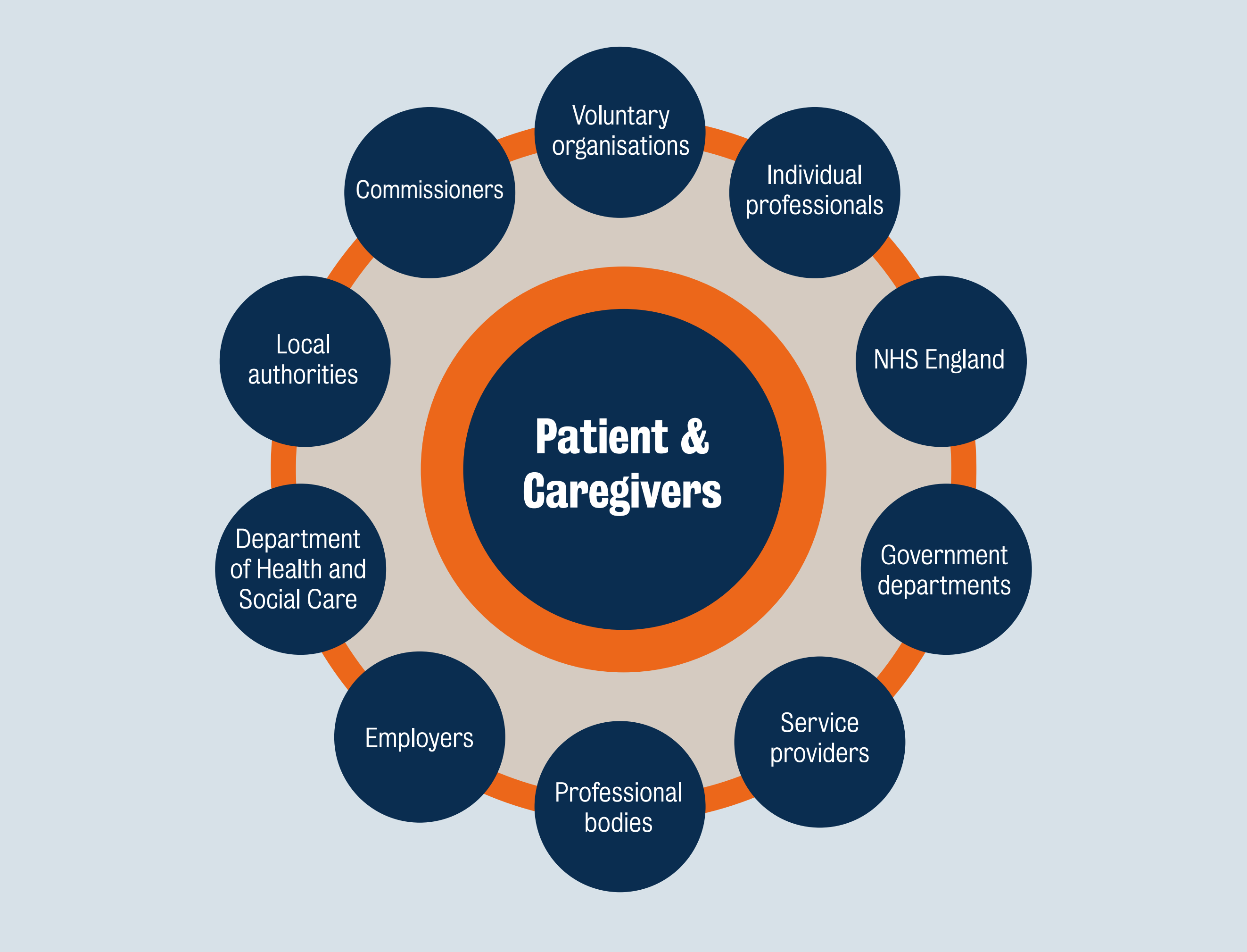


Figure 3: The different stakeholders who might be involved in the Impact Centre

Framework for creating change

The framework which has guided the theory of change for the Centre draws on theories of behaviour change such as the COM-B model by Susan Michie et al[23] as well as the approach and experiences of the What Works Network.[24] To implement evidence-based practice, people need to know what to do, how to do it and have the capacity, motivation and resources to act.

Knowing what to do: critical to change is that those who can take action know what to do. This means identifying the questions/knowledge needs of influencers/key audiences; whether the knowledge already exists; if it does, make this available in a way that is easy for them to understand and act upon; if it does not exist, either directly generate the knowledge (through evaluation or commissioning research) or influence research funders/researchers to answer these questions. The focus here is on what is effective and cost-effective.

Knowing how to do it: this is about implementation and is often a different knowledge base than formal research. It is often generated as knowledge from practice and focuses on the practical application of knowledge for example in service designs or specifications, project plans or tools. The focus here is on change management and deliverability.

Capacity, motivation and resources: even when we know what to do and how to do it, there are barriers to doing the right thing. This could be due to lack of:

1. Capacity and capabilities of those tasked with implementation – either finding it difficult to identify capacity within the organisation to lead the change process, having a lack of experience and skills in how to make change. The focus here is on capacity building, training and skills development.
2. Resources — the funding, equipment, or staff may not be available to support the change or delivery of effective models/services. This could be at the level of the team, organisation or place. The focus here is on contract specifications, business cases or return on investment.
3. Motivation — the incentives to make the change may not exist, either for the individual (pay or personal effort), organisation (contract and financial incentives) or policymaker (not seen as a priority or too much political capital). The focus here is on making clear the case for change, the benefits it will bring, and ensuring there are no financial penalties or reputational risks for the organisation if they change.

How will the Impact Centre deliver change?

The high-level organisational theory of change for the Impact Centre (See Annex 1) sets out how its activities will deliver the outcomes and impact needed to improve end-of-life care.

- Contextual factors – the environment in which the Centre would operate
- Inputs – the activities and resources currently available for the Centre to draw on
- Activities – the main activities the Centre would deliver
- Outputs –the deliverables from the Centre's activities
- Outcomes –the changes that would result from the Centre's outputs
- Impact – the ultimate impact the Centre would have

22% of people from minoritised ethnic groups have not heard of palliative care, compared to 4% of White people. **King's YouGov survey**

Contextual factors and inputs

The current variability in access to palliative and end-of-life care, inequalities in outcomes, growing demand and unmet need for palliative and end-of-life care present challenges as well as an impetus for action. Death and dying became more visible during the pandemic and the need to address the quality of and access to end-of-life care is seen as a priority across the UK by policymakers. Closer integration of health and social care provides an opportunity for developing more holistic care models.

There is a large university research base and a body of existing evidence. There is innovation taking place in the sector, enthusiasm from providers and interest from the NHS and government. The development of compassionate communities and community action as well as the presence of charities who have a strong user voice is useful in understanding priorities and driving change. There are also a wealth of practitioners who have practical know-how. The work of the Centre can draw on experience of other What Works Centres and international experiences of innovating in palliative and end-of-life care.

Activities

The Centre will deliver the following activities:

- **Evidence maps** – an interactive web-based tool for exploring existing research, designed for researchers and active users of research based on scoping reviews.
- **Evidence Digests** – short accessible briefing notes summarising the key actionable knowledge primarily for practitioners, but also depending on the topic suited to the public and policymakers based on evidence reviews.
- **Learning Network** – a learning network for sharing information and experiences from practice via webinars and online training sessions, particularly relevant to those involved in planning and delivering care.
- **Practice Demonstrators** – local service delivery projects which are applying existing evidence in practice and/or are able to demonstrate effectiveness of a new model through evaluation and document these for adoption by others.
- **Events & Debates** – a series of public events and other engagement events with key decisionmakers to shape the wider attitudes and understanding of end-of-life care.

BOX 1 | Impact Centre activities

Evidence maps

Existing research will be scoped and mapped, and presented in an interactive format to enable users of research as well as researchers and funders to explore the knowledge available on topics of interest.

Evidence digests

Evidence syntheses of priority topics (identified through a co-production process) will be communicated in the form of briefings or digests. The audience for these would primarily be practitioners but selected topics would also be written for a public/lay audience and for politicians/decision makers.

Learning network

The Impact Centre will establish a learning network, running webinars for members of the network on topics identified by members. This will increase awareness and understanding of the evidence base, share insights on the challenges of implementation, and develop the capabilities of those working in the sector to implement effective care.

Practice demonstrators

The Centre would put out a call for expressions of interest from delivery organisations who are implementing innovative practice and wish to evaluate these. The Centre would provide methodological support, and commission evaluations and directly disseminate the findings.

Events & Debates

The Centre would organise public events and debates with key policymakers and the wider public to promote an informed discussion of the evidence and issues surrounding palliative and end-of-life care. The Centre would also use these to draw international insights on palliative and end-of-life care.

Outputs and outcomes

Through its activities the Centre will deliver the following outputs and outcomes for people approaching the end of life.

- By mapping the existing evidence, identifying where evidence is missing and sharing this in accessible ways, the Centre will **increase the impact of research in end-of-life care** as well as highlight where new research would add most value.
- By synthesising, translating and communicating evidence that addresses the issues and questions practitioners have, the Centre will **improve knowledge among health and care staff**, supporting them to deliver effective care with confidence.
- By supporting Integrated Care Systems to become more informed, the Centre will support the commissioning of **the right services for local populations** and improve integration across health and social care. The Centre will support providers to enhance staff development, leading to greater job satisfaction and improvements in end-of-life care.
- By creating a supportive network of changemakers, the Centre will **increase confidence among those tasked with leading change** and give them a better understanding of the barriers and enablers to change and **increase know-how of implementing effective care models**.
- By promoting more **rigorous testing of new approaches** and sharing proven approaches widely, the Centre will provide strong, demonstrable examples of putting research into practice.
- By facilitating more informed policy debates about death and dying, the Centre will **make improvements in care for people approaching end of life a higher priority among national policymakers and listen to and shape public perceptions of dying, death and bereavement** to ensure it is seen as a normal part of life which can be freely discussed, leading to earlier and more open conversations, realistic expectations of death and dying, and more empowered communities.

Only 2 in 5 people are aware that hospice care is free of cost for the patient. **King's YouGov survey**

There are inequalities in access to palliative care with respect to age, ethnicity, socio-economic position, sexuality and gender identity.

What impact will the Centre deliver?

Health and care professionals, policymakers, and other stakeholders will use the evidence and guidance provided by the Centre to improve care, experiences, and outcomes for people approaching the end of life, and their families. Through its work, the Centre will:

- Reduce physical, psychological, and emotional distress experienced by people with life-limiting illnesses.
- Ensure that ethnicity, socio-economic status, sexuality, diagnosis, location and other characteristics are not barriers for access to good care.
- Reduce inappropriate and unwanted, costly interventions, and create a shift towards proactive palliative care, with services that have reliable evidence to support them.
- Ensure that health and care staff have the tools to provide high-quality, coordinated, and person-centred care, aligned with people's preferences and values.

The Centre will measure progress against a baseline, which will be established using current data trends, as well as surveys administered by the Centre. It will share this progress through an annual report.

What issues would a new Impact Centre work on?

The scope of the Centre is broad, not only relating to health and social care but to wider factors such as finance, housing and employment that directly impact on people's wellbeing at the end of life. The scope of the Centre will therefore encompass the social and practical aspects of palliative and end-of-life care as well as the clinical aspects. The outcomes for carers, relatives and other people close to the dying person are important and within scope for the Centre.

Our stakeholder engagement and workshops identified the following five overarching outcomes (see Annex 2) which define the broad scope of the Centre's work. The Centre will undertake further engagement to shape its programme of work.

Physical health and wellbeing

Physical health and wellbeing encompasses a person's wider physical health such as nutrition and hydration, as well as their living environment. This could include issues such as:

- Access to medicines and equipment, and relief of symptoms
- Rehabilitation techniques
- Out of hours access to community care
- Escalation processes and pathways Education for patients and those important to them about conditions and symptom management
- Staff training and education on symptom management
- Disease-specific care

> **'…if you're in pain and discomfort, everything else goes out the window. You could be the most luxurious place to live in, but if you're in pain, your life is a misery….'** Patient and public involvement workshop participant

Emotional Health and Wellbeing

Emotional Health and Wellbeing covers emotional and spiritual support, as well as bereavement support and help with anticipatory grief. Areas covered could include:

- Better public awareness of and conversations about death and dying
- Information and advice about death and bereavement
- Access to psychological support Access to spiritual support eg chaplaincy
- Companionship roles supporting the person dying eg Compassionate Neighbours, death doulas.

> **'[My son] died a horrendous death, crying out in agony till he took his last breath. As his mum [his] death will live with me forever – I will never get over how he suffered.'** Marie Curie Better End of Life survey 2024[25]

Social and financial security

Social and financial security covers caring needs and financial matters. It also recognises carers' needs in their own right, for social connections, respite, and financial security. It would look at aspects such as:

- Information and advice on claiming available benefits
- Access to employment support and/or adjustments by employers
- Assessment and provision of (social) care and support both for individuals with a life-limiting illness, and carers
- Availability of financial support
- Debt advice
- Guardianship, housing and financial planning for dependents
- Immigration matters
- Issues relating to people in custody, eg release on compassionate grounds
- Access to safe, warm and adapted living environments.

Person-centred care

Person-centred care looks at the whole person and their situation, including thinking about the people and community around them. This could include issues such as:

- Good communication with patients and those important to them
- Staff training on communication skills
- Honest conversations about diagnosis and prognosis
- Early and timely conversations, including conversations with children
- Understanding a person's communication needs
- Planning ahead, including advance care planning
- Redesigning systems to allow staff time to have conversations with the patient and those important to them and being able to follow them on their journey
- Different models of care based on understanding the person's situation, beliefs and preferences.

Coordinated care

Coordinated care requires good communication between teams looking after the person and someone to lead coordination. This could include issues such as:

- Shared health records and interoperability between systems
- Signposting of networks
- Design of services allowing single point of access
- Development of a shared language between professionals
- Streamlining of eligibility and finances
- Referral processes including access to Continuing Health Care

> **'[I] felt left on [my] own, all responsibility on myself for food, medication, appointments, care, liaising with many different people and services. No single point of contact – many different people dipped in and out but not one person coordinating assistance.'** Marie Curie Better End of Life survey 2024[25]

Process for establishing priorities

It is proposed that further prioritisation takes place during Year 1 of the Centre's operation through a wider consultation process to shape a work programme. Through this process the Centre will identify the questions and evidence needs of key stakeholders.

People with higher socio-economic position are more likely to die at home or in hospice rather than hospital compared to people with lower socio-economic position.

A Co-production Advisory Group will be set up as part of the early preparation and planning. This group will agree an engagement strategy and set principles to guide the prioritisation process. The engagement process could include:

- A survey – distributed and promoted widely through intermediary organisations including community organisations
- A series of stakeholder engagement meetings with a range of organisations and individuals including people with lived experience of terminal illness, unpaid family carers for people at the end of life, or bereaved family and loved ones
- A deliberative or Delphi-style process to identify priority issues and questions for different groups
- Expressions of interest for innovative models to be tested through the demonstrators

This exercise will build interest in and commitment to the work of the Centre in its pre-establishment phase and connect the team with others who could continue to be informed about and engaged in the Centre's work during the delivery phase.

There are other evidence sources which could be used to triangulate this. For example, being free of pain and being with loved ones were most frequently reported as people's top priorities for their end of life experience in Marie Curie's Public attitudes to death and dying report.[12]

30% of people from minoritised ethnic groups do not trust healthcare providers to provide high quality care towards the end of life, compared to 17% of White people. **King's YouGov survey**

What will success look like?

As the Centre's business plan is refined, SMART objectives and/or Key Performance Indicators with timescales and output targets will be developed. Some indicative outputs have been suggested but the scale could be more ambitious depending on the level of funding, and the range of partners and collaborators.

During its first year, the Centre will:

- Create a Centre name and brand identity, following language testing with stakeholders
- Set up a Co-production Advisory Group who will identify priorities through extensive consultation and engagement
- Carry out rapid scoping reviews to map existing formal research evidence
- Launch an interactive website with tools such as maps to explore existing evidence
- Establish baseline data for tracking outcomes and measuring impact
- Establish a methodology for collecting and sharing practice knowledge and knowledge from people with lived experience

After 5 years, the Centre will have:

- Created high levels of awareness among key audiences of the Centre and its work
- Created an online and interactive website with *Evidence Maps* to explore existing research
- Developed a collection of *Digests* of evidence for practitioners, public and policymakers
- Held regular *Network* webinars and events, and increased membership of the network
- Created a number of *Demonstrators* to evaluate models of care and published findings
- Held a series of *Debates* as part of efforts to shift attitudes
- Published an annual report looking at the outcomes, quality, and access of end-of-life care in the UK

After 10 years, the team will have achieved the following outcomes:

- The Centre will be established as the place that people turn to for answers, evidence or advice on issues relating to end-of-life care
- Organisations and individuals will be regularly accessing the *Evidence Maps* and, *Digests,* and report using them to inform practice
- People who attended the *Network* will report changes to their practice as a result
- Findings of *Demonstrators* will be used by other organisations to replicate the model
- The public will be more confident in talking about death and dying compared to baseline
- The majority of outcomes being tracked will be moving in a positive direction and some will have made significant improvements compared to baseline

MAKING THE IMPACT CENTRE A REALITY

4

4. MAKING THE IMPACT CENTRE A REALITY

People living in more deprived areas are less likely to access specialist palliative care.

Guiding principles

To ensure the Centre is credible and respected, it will adopt a set of principles to guide its work. The Centre will adopt the IMPACT values set out by the What Works Network (see Box 1) that all centres have to sign up to. In addition the Centre will consult on principles that are specific to work on end-of-life care, for example:

- Involving: focus on the priorities of those who have direct lived experience (people with experience of palliative and end-of-life care) and the key users of the work (health and care staff), with particular attention to power and equity.
- Interdisciplinary: draw on a wide range of expertise, value practice knowledge alongside research knowledge, and go beyond the clinical to address the social, emotional and spiritual dimensions of care.
- Collaborative: recognise that success will come from partnership and collaboration between organisations.
- Impact focused: set and track progress in making improvements to end-of-life care, and address the barriers to change.

BOX 2 | What Works Network IMPACT values

Independent Providing independent, unbiased advice to users, retaining editorial control over all research and products.

Methodologically rigorous Using a clear and consistent process for evidence generation and synthesis; engaging with the wider academic and policy community to assure the quality of evidence products (for instance, through peer reviews), and giving primacy to findings from high-quality impact evaluations through a robust system for ranking evidence.

Practical Playing a leading role in driving the use and generation of evidence in a specific, pre-defined policy area across the United Kingdom, committing to the principle that it is both possible and useful to compare the effectiveness of different types of intervention and practice, and taking practical steps towards evaluating and improving the centre’s own impact.

Accessible Putting the centre’s target user group at the heart of all activities. Sharing evidence with users, at no cost, in formats that are easy to understand and that enable them to make practical decisions based on ‘what works’.

Capacity building Mobilising evidence and working to ensure that it is put into practice by decision makers, building user groups’ understanding of how and when to use and generate evidence, so that they can make better use of the centre’s evidence products and add to the international evidence base.

Transparent Providing comprehensive, easy-to-understand information about the methods and limitations behind the centre’s output, publishing both the research generated and the evidence around the impact of the centre’s work.

Source: What Works Network Membership Criteria 2018

Outline proposal for establishing the Impact Centre

King's College London has a track record and expertise for successful delivery of research and impact globally. The Cicely Saunders Institute is renowned for its world-leading palliative care research including the NIHR Policy Research Unit in palliative and end-of-life care. This provides strong links to national policymakers and will enable the Institute to further build up its expertise in policy-related research.

Within King's there are other centres with complementary expertise in methods and policy influencing. For example, The Policy Institute which specialises in evaluation methods and evidence-based policymaking as well as holding a successful programme of external events to engage the public and policymakers.

King's is also a member of King's Health Partners, an Academic Health Sciences Centre through which it has close links to the NHS, practitioners and the Health Innovation Network. These institutional links will ensure the Centre is grounded in service delivery and practice and give it access to a range of skills and expertise in informatics, education and training, service delivery and improvement methods.

King's College London has a strong and long-lasting relationship with Cicely Saunders International – a charity that promotes research to improve the care and treatment of all patients with progressive illness and to make high-quality palliative care available to everyone who needs it. The objectives of the charity are fully aligned to those of the Centre – to identify and promote best practice in palliative care – and could therefore assist with fundraising, global dissemination, and links to other foundations and charities.

Notwithstanding the organisational fit and strengths, it will be essential for the Centre to build wider links across the NHS, academia and with the sector and to have embedded within it a strong voice for people with lived experience (see below). To this end, the Centre will have to establish a clear identity and brand independent of the university, whilst ensuring there is good alignment in terms of objectives and values. There needs to be a sufficient degree of independence so it can respond to the priorities of users and stakeholders.

Projections of place of death show rising deaths expected in the community, and care homes may be the most common place to die by 2040.

Advisory and co-production arrangements

The Centre will be co-produced regardless of the form and host, and have strong stakeholder/sector engagement without being captured by any particular interest.

Given that the Centre's aims are to deliver improved outcomes and experiences for those with serious illness who are approaching the end of life and their loved ones, it is critical to ensure that the work of the Centre is co-produced with those most directly affected. This will build on the online public and patient involvement forum that King's has in place and ensure that a diversity of voices and views from a wide range of communities directly inform the work of the Centre.

We have been impressed with the approach taken by the IMPACT Centre hosted by the University of Birmingham to co-production and engagement and suggest the Centre model its approach on this. The Centre should establish a Co-production Advisory Group whose role will be to shape the priorities and guide the work of the Centre. The Advisory Group will include people with lived experience of palliative and end-of-life care, bereaved family members or those currently caring for someone with a terminal diagnosis.

Thought needs to be given as to whether the Co-production Advisory Group sits alongside a separate stakeholder group or combines these perspectives. If the latter, it is important to ensure that the people with lived experience are supported to have an equal voice at the table. This requires them to be in the majority rather than a lone/token voice and to be financially supported to participate.

In developing this report, we ran a series of workshops with experts, stakeholders, and people with lived experience. The Centre will build on this engagement and run further formal consultation and engagement in the set-up year to establish the Centre's priorities and shape the programme of work.

Collaboration and partnerships

It is proposed the Centre operates as a **hub and spoke model** working closely with collaborators and partners including service providers, other universities and third sector organisations. It will be essential for the Centre to have close collaboration with:

- Organisations that represent and bring together patients and carers to ensure the priorities are grounded in the lived experience.
- Specialist providers of end-of-life care services including hospices as well as ‘generalist’ health and social care providers including general practice, community trusts, hospitals and care homes to understand which questions and issues are most important to those that deliver care.
- Professional associations and other professional bodies that support the training and education of professionals and practitioners, to ensure the knowledge generated is shared effectively and accessible to those who can act on it as well as to ensure the Centre draws on practice knowledge.
- Integrated care systems and other key players in health and social care to ensure the commissioning and contracting of services reflects the evidence.
- Parliamentarians, government ministers, civil servants, regulators and key national bodies that are involved in national decision-making to ensure policy decisions are informed by evidence.
- Universities and research centres in the UK and internationally to ensure there is expert input into different topics and projects as needed.

The Cicely Saunders Institute already collaborates with a wide range of other organisations which can be built upon. For example, King’s has an established partnership with Marie Curie, producing the Marie Curie Better End of Life report series. The Centre could benefit from their established influencing and advocacy and that of other charities working in the sector, work with them to learn from service delivery, in particular testing out innovative approaches, and gain insights from families and users with whom the charities have contact.

Another example would be that the Centre could strengthen links to the National Clinical Director for End-of-life care at NHS England and support the ongoing work of the clinical network in end-of-life care to ensure guidance and support to Integrated Care Systems and commissioners is based in evidence.

Fewer than half of the public know where their nearest hospice is. Only 1 in 4 people from minoritised ethnic groups know where their nearest hospice is. **King’s YouGov survey**

Geographical coverage

It is envisaged that the Impact Centre will be UK-wide given that the experiences and practice of delivering palliative and end-of-life care are not systematically different in each nation although the policy context and organisational and governance of health and care are. However, this may also depend on funding.

The Centre will need to establish strong links to each of the 4 nations to give it credibility and influence across the UK. This could be achieved by having senior staff on the leadership team who have joint responsibility for functions/themes and nations or who are based in universities in all UK nations. Alternatively, a Co-production Advisory Group could be set up in each country to ensure a diversity of perspectives inform the work. IMPACT held Assemblies in each country and some regions of England, for example.

What skills and capacity will the Centre need?

Looking at other What Works Centres we see that skills are needed in a range of areas. There will be choices to make about how much these skills are located in-house and how much the Centre commissions external delivery partners. The core staff need the following skills:

- Evidence mapping and synthesis
- Communication of research and science and digital asset management
- Relationship and partnership building
- Running networks/webinars and online training modules
- Project management
- Secondary data analysis
- Patient and Public Involvement (PPI) and engagement and coproduction

Other skills and knowledge needed but not necessarily in the core team include:

- Designing and running trials and evaluation
- Policy influencing and advocacy
- Events and public engagement
- Change management/behaviour change
- Economic modelling
- Big data analysis
- Innovative and effective approaches to knowledge mobilisation/translation

Staffing will be focused on four key areas, which will ensure the Centre meets its goals:

1. **Leadership:** To harness global reputation and extensive expertise across research, evaluation and policy to make a tangible impact.
2. **Evidence and capacity building:** To build up the evidence base on what makes good, effective palliative care.
3. **Implementation and adoption:** To support the implementation of evidence-based care.
4. **Communication and co-production:** To support knowledge sharing and dissemination.

In addition to staff, there will need to be funds to cover all areas of activity at the Centre, including, marketing, website and digital assets, publications and design, coproduction and participation costs, translation and transcription, events and conferences, and equipment.

Only 1 in 3 UK areas provides access to designated palliative care telephone advice lines, even though this has been a NICE recommendation since 2011.

GEORGE TORODE

CONCLUSIONS & NEXT STEPS

5

5. CONCLUSIONS AND NEXT STEPS

There is widespread support for the establishment of a Centre whose primary focus will be on palliative and end-of-life care and which will mobilise the knowledge and research already produced and ensure that this is put into practice. With a growing number of people dying each year, and greater awareness of the inequalities in access to end-of-life care that exist, there is an urgency to address this. Through its work, the Centre could transform the care for many people approaching the end of their lives and their families across the UK. By giving knowledge and confidence to professionals, and ensuring providers, commissioners of care and policymakers have a shared understanding of best practice and feel confident to allocate resources to palliative and end-of-life care, the Centre will deliver both better outcomes for people and lower costs for health and care.

BY ELLIOT MANCHES VIA CENTRE FOR AGEING BETTER

Contact Information

For more information on the Impact Centre for palliative and end-of-life care, contact Professor Katherine Sleeman, Laing Galazka Chair in Palliative Care, Cicely Saunders Institute: **Katherine.Sleeman@kcl.ac.uk**.

Further reading

The What Works Centres: Lessons and Insights from an Evidence movement by Michael Sanders and Jonathan Breckon (eds) Policy Press: 2023
https://policy.bristoluniversitypress.co.uk/the-what-works-centres

Creating an Evidence Centre for Palliative and End-of-life care: Report from stakeholder workshop 21 March 2022 (Sept 2022) SCIE in collaboration with Marie Curie and King's College London.

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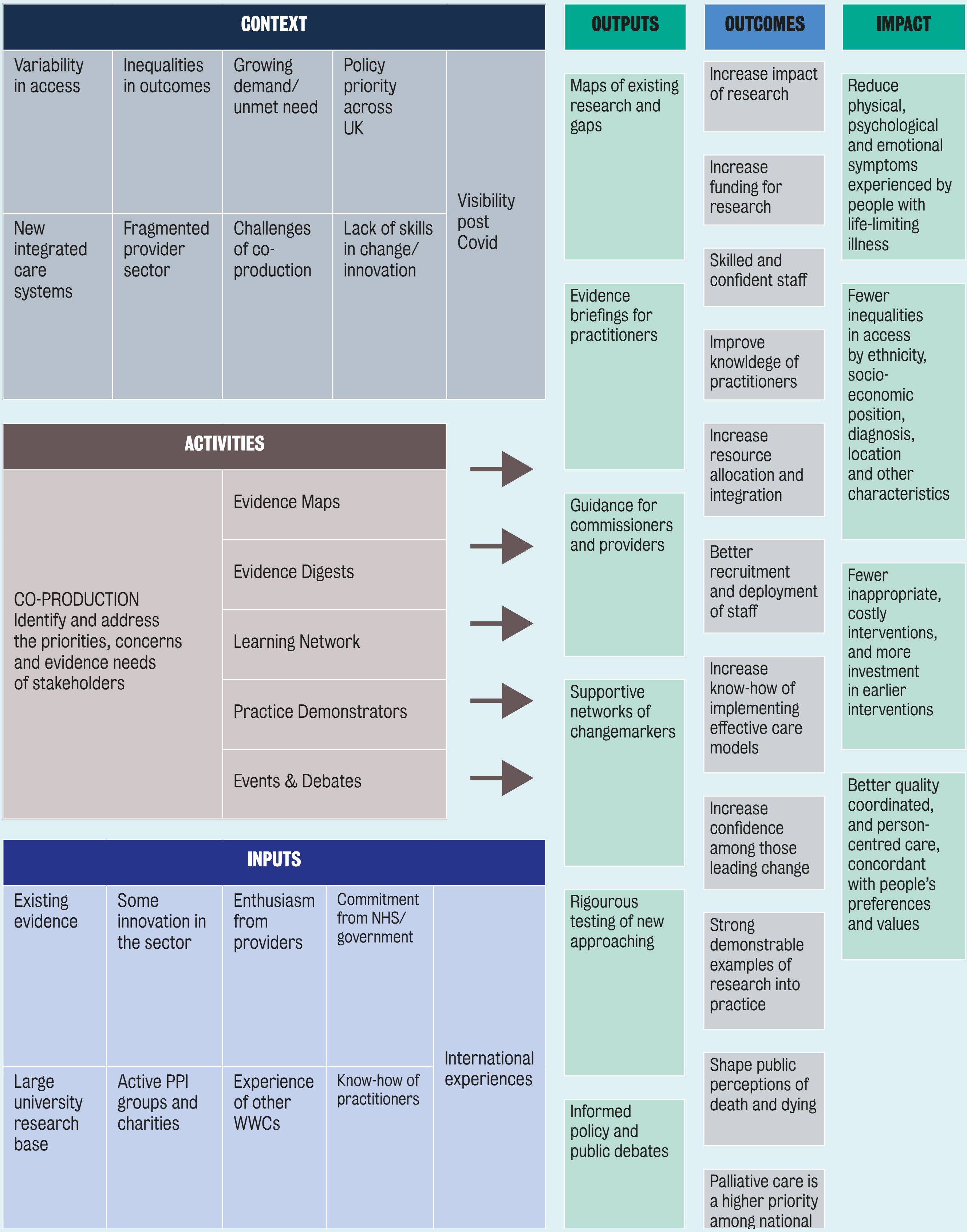
ANNEX 1 Organisational theory of change

This diagram presents a structured approach outlining how the Centre aims to improve care for people with life-limiting illnesses. The chart is divided into five sections: context, inputs, activities, outputs, outcomes and impact.



CONTEXT

Variability in access	Inequalities in outcomes	Growing demand/ unmet need	Policy priority across UK	Visibility post Covid
New integrated care systems	Fragmented provider sector	Challenges of co-production	Lack of skills in change/ innovation	

ACTIVITIES

CO-PRODUCTION
Identify and address the priorities, concerns and evidence needs of stakeholders

- Evidence Maps
- Evidence Digests
- Learning Network
- Practice Demonstrators
- Events & Debates

INPUTS

Existing evidence	Some innovation in the sector	Enthusiasm from providers	Commitment from NHS/ government	International experiences
Large university research base	Active PPI groups and charities	Experience of other WWCs	Know-how of practitioners	

OUTPUTS

- Maps of existing research and gaps
- Evidence briefings for practitioners
- Guidance for commissioners and providers
- Supportive networks of changemarkers
- Rigourous testing of new approaching
- Informed policy and public debates

OUTCOMES

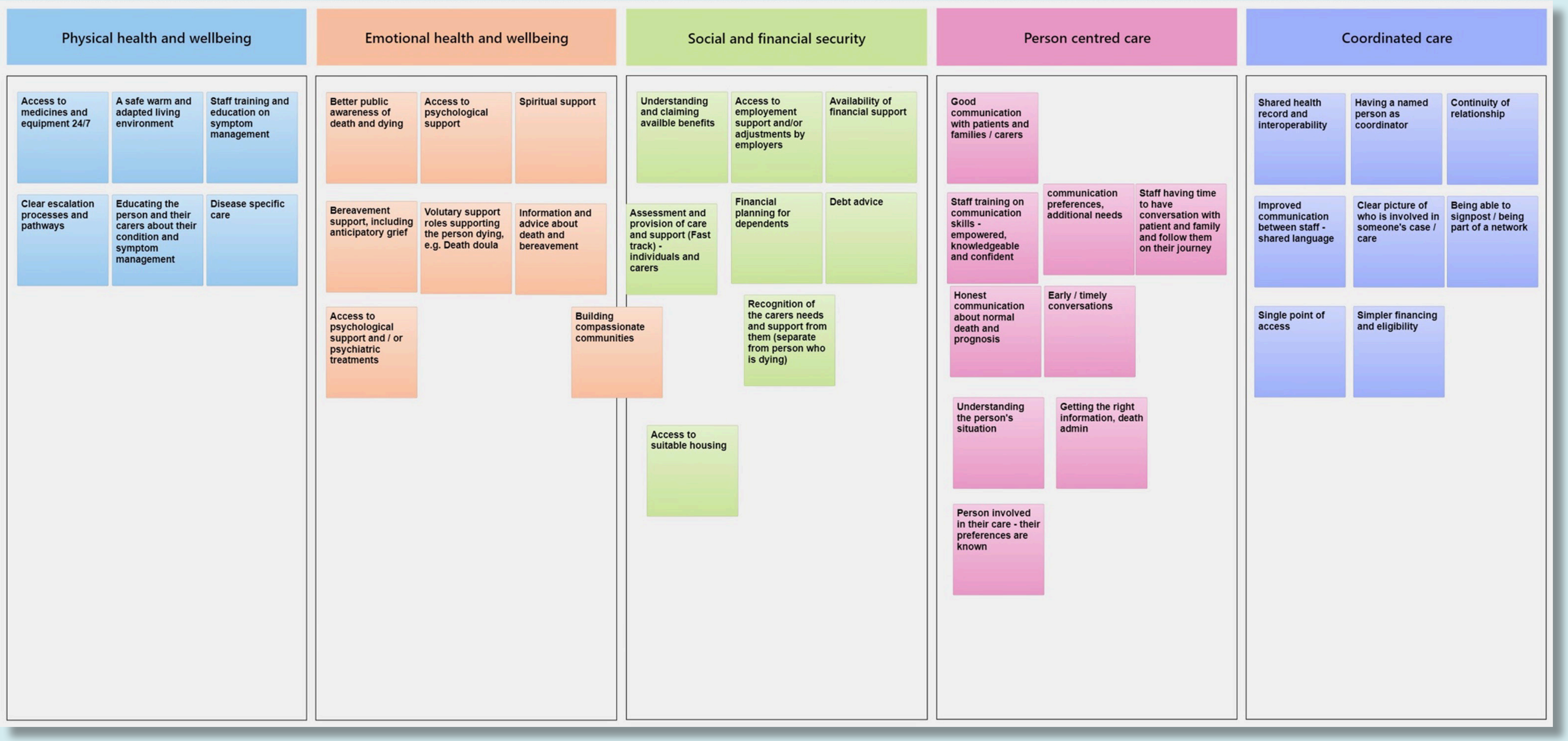
- Increase impact of research
- Increase funding for research
- Skilled and confident staff
- Improve knowldege of practitioners
- Increase resource allocation and integration
- Better recruitment and deployment of staff
- Increase know-how of implementing effective care models
- Increase confidence among those leading change
- Strong demonstrable examples of research into practice
- Shape public perceptions of death and dying
- Palliative care is a higher priority among national

IMPACT

- Reduce physical, psychological and emotional symptoms experienced by people with life-limiting illness
- Fewer inequalities in access by ethnicity, socio-economic position, diagnosis, location and other characteristics
- Fewer inappropriate, costly interventions, and more investment in earlier interventions
- Better quality coordinated, and person-centred care, concordant with people's preferences and values

ANNEX 2 Outcomes framework: co-designed with patients and the public

I and the people important to me are supported so that I can have the best quality of life in the last stage of my life regardless of my identity and circumstances and our wellbeing is protected.



Physical health and wellbeing

- Access to medicines and equipment 24/7
- A safe warm and adapted living environment
- Staff training and education on symptom management
- Clear escalation processes and pathways
- Educating the person and their carers about their condition and symptom management
- Disease specific care

Emotional health and wellbeing

- Better public awareness of death and dying
- Access to psychological support
- Spiritual support
- Bereavement support, including anticipatory grief
- Volutary support roles supporting the person dying, e.g. Death doula
- Information and advice about death and bereavement
- Access to psychological support and / or psychiatric treatments
- Building compassionate communities

Social and financial security

- Understanding and claiming availble benefits
- Access to employment support and/or adjustments by employers
- Availability of financial support
- Assessment and provision of care and support (Fast track) - individuals and carers
- Financial planning for dependents
- Debt advice
- Recognition of the carers needs and support from them (separate from person who is dying)
- Access to suitable housing

Person centred care

- Good communication with patients and families / carers
- Staff training on communication skills - empowered, knowledgeable and confident
- communication preferences, additional needs
- Staff having time to have conversation with patient and family and follow them on their journey
- Honest communication about normal death and prognosis
- Early / timely conversations
- Understanding the person's situation
- Getting the right information, death admin
- Person involved in their care - their preferences are known

Coordinated care

- Shared health record and interoperability
- Having a named person as coordinator
- Continuity of relationship
- Improved communication between staff - shared language
- Clear picture of who is involved in someone's case / care
- Being able to signpost / being part of a network
- Single point of access
- Simpler financing and eligibility

Source: developed as part of the workshop in Leeds with stakeholders

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Endnotes

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