KING'S College LONDON

Triennial Report
2020-2023

Cicely Saunders Institute
of Palliative Care, Policy and Rehabilitation

Cicely Saunders International
Better care at the end of life

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Welcome from the Institute Director

Palliative care puts the person before their disease, and supports them and those important to them wherever they are cared for. As people live longer due to better prevention and treatment of diseases for children and adults, the prevalence of long term health problems increases, and so does the need for palliative care. Adults and sometimes children can live with different and often multiple illnesses, which can result in symptoms and concerns that need detection, recognition, treatment, and care. There are gaps in knowledge and provision locally, nationally, and across the globe that the team at the Cicely Saunders Institute are addressing.

I am delighted to introduce the latest activities, outputs, and impact from the Cicely Saunders Insititute, reporting the period of 2020-2023. During the past three years our academic, research, clinical, and professional services colleagues have grown considerably. This expansion ranges from extending our clinical nursing palliative care service to a 7-day service, to expanding our academic team to include disciplines essential to address the current global challenges in palliative and end-of-life care. We have welcomed new academics working in epidemiology, health economics, paediatrics, and child health. This widens our existing team spanning medicine, nursing, rehabilitation, social work, sociolinguistics, and clinical trials.

We have also seen growth in our global education researchers and clinical academic pathways. Since its inception, the Institute has sought to identify and grow future leaders. The number of international students choosing to undertake their MSc and/or PhD in palliative care with us has continued to increase. The Covid-19 pandemic led to a redesign of our MSc delivery, which is now fully Hyflex, and has enabled busy clinicians around the world to study with us online and offline while continuing their clinical duties. We have also supported clinical and non-clinical fellows to grow their careers, ranging from pre-doctoral fellowships which have led to fully PhD fellowships, post-doctoral awards, advanced fellowship awards, and academic promotions.

Within this triennial report, we also describe our clinical and research response to Covid-19. We were able to meet the challenge by drawing on our unique clinical-academic integration and our global partnerships, rapidly responding to the needs of the health system with clinical expertise and global timely evidence.

We were delighted that in 2023 Her Royal Highness Princess Anne returned to see our progress and to hear our new aspirations, having opened the Institute 13 years earlier. As we reflect on the impact we have achieved in the past 13 years, we also consider how best to respond to present and future challenges. Therefore, we have co-developed a refreshed Cicely Saunders Institute Vision and Mission with our clinical and academic colleagues.

The number of children and adults who would benefit from palliative care is rapidly increasing; the multiprofessional clinical, academic, research, and professional services team at the Institute seeks to lead the response. We are enormously grateful to the funders, partners, patients, and families who have enabled the work we describe in this report.



Prof Richard Harding,
Vice Dean (International)
and Director and Global Lead,
Cicely Saunders Institute
of Palliative Care,
Policy & Rehabilitation

Vision and mission of the Cicely Saunders Institute

The Cicely Saunders Institute drives forward Dame Cicely's pioneering work to improve palliative and end-of-life care for all. The Institute opened in 2010, bringing together the clinical palliative care team established in 1994 and the original academic department that began in 1996.

Vision

Our Vision is to remain at the forefront of palliative care and rehabilitation research, education, and clinical care, developing knowledge and leaders in the field, and situating patients, families, and the public at the core of our efforts. We strive for excellence to improve care and reduce inequalities, ensuring that the changing needs of global populations are met across health and social care from childhood to the oldest old.

Mission

We maximise our impact by integrating:

- **Cutting-edge research** – world-leading discovery that improves care and outcomes through robust clinical, policy, and applied health research, driven by patients, families, and the public
- **Skilled multi-disciplinary clinical care** – delivering equitable, accessible, inclusive, and sustainable interventions in health and social care and support to people living and dying with serious illness and those close to them
- **Innovative education** – underpinned by evidence to develop tomorrow's leaders and drives national and international change in policy and practice.

Reflections from the Faculty Executive Dean

At King's we strive to make the world a better place through world-leading education, research, and service. The Cicely Saunders Institute stands as a beacon of this aspiration, epitomizing our commitment through its cutting-edge research, educational initiatives, collaborative partnerships, pioneering clinical services, and policy engagements.

The Institute confronts one of society's most daunting challenges: meeting the diverse needs of individuals grappling with serious illness, end-of-life care, unmanageable symptoms, or emotional distress, as well as the needs of those important to them. It continually innovates methods to bolster support for clinical and care teams across care settings, from community outreach to hospital, care home, or hospice care. The Institute's commitment to patient and public involvement, including the award-winning online forum, is ever improving.

King's, an internationally renowned university delivering exceptional education and world-leading research, with its diverse Faculties ranging from humanities to law and ethics, engineering, computing, medicine, or psychiatry, provides an outstanding home for the Institute. It benefits from unique clinical partners, including world leading hospitals and community services.

Independent analysis underscores the Institute's global leadership, with its palliative care academics, clinicians, and students producing the highest number of highly cited papers in the world. In the UK's Research Excellence Framework, the Cicely Saunders Institute excelled, securing top spots for overall research, impact, and environment. These outcomes underscore the global pre-eminence of its work. Witnessing professional growth and strides in enhancing clinical care, building capacity, evidence, and understanding, and addressing societal challenges is truly gratifying. What is even more remarkable is the unwavering dedication, collaborative ethos, and sheer talent exhibited by every member of the Institute, its partners, and collaborators.

Amid the Covid-19 crisis, the Institute's teams showcased flexibility and solidarity, uniting across clinical, research, and educational domains to provide exceptional services and disseminate knowledge on symptom management across languages.

I extend heartfelt gratitude to our invaluable partners who have supported our mission. This includes esteemed supporters such as Cicely Saunders International, the National Institute for Health Research, the World Health Organisation, our collaborative hospital and community service partners, policy stakeholders, and the myriad individuals from within King's and beyond who contribute, advise, and inspire the Institute's transformative efforts in care.

I am delighted to commend this report to you, outlining the remarkable achievements and ongoing dedication of the Cicely Saunders Institute teams and their partners.



Prof Irene Higginson,
Founding Institute Director,
Executive Dean Florence Nightingale Faculty of Nursing Midwifery and Palliative Care

Partnerships and engagement

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."('Cicely Saunders International: What We Do' 2024)

Partnering with King's College London, the charity raised £10 million to create the Institute of Palliative Care in 2010. This Institute serves as a vital hub for research, education, clinical services, and patient support on an international level. Since its inception, Cicely Saunders International has continuously supported the Institute's work through direct funding of research programmes, peer review from its panel of international scientific experts, and collaborations with other funders.

The charity focuses on patient empowerment, care for older people, improving access to palliative care for marginalised groups, and addressing challenging symptoms like breathlessness. In a field that has historically received limited attention, the need for improved research methods and capacity is critical to discovering better treatments and cost-effective palliative care for individuals with serious illness.

Cicely Saunders International actively pursues its mission by:

- Supporting research: Backing research into effective, person-centred palliative care to set an international standard.
- Advocating inclusive care: Promoting high-quality care for patients with serious illness, particularly those underserved in palliative care.
- Empowering healthcare education: Supporting high quality education for healthcare professionals at all levels, from undergraduates to postgraduates.
- Public awareness and policy development: Educating the public about palliative care and contributing to national and international policy development for its improvement.

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 Action Plan takes a holistic approach, addressing challenges and solutions across the entire healthcare and social system. It calls for reforms in hospitals, hospices, care homes, patient



Figure 1.1. You Matter Because You Are You: An Action Plan for Better Palliative Care

homes, and communities, advocating for changes in education, healthcare professional training, and increased investment in research ('Cicely Saunders International: What We Do' 2024).

Since its launch, Cicely Saunders International has engaged with policy makers and stakeholders, collaborated with the Department of Health and parliamentary groups, and initiated a fundraising network – the Friends of Cicely Saunders International – for individual donors. Additionally, the charity has updated its research strategy to encompass emerging palliative care issues and is now fundraising for a new policy impact centre. Ongoing programmes at the Institute, such as BuildPall capacity building (see Training and Environment section), Cicely Saunders International Annual Lectures, and Michal Galazka Study Days continue to receive support from the charity.

The Institute also benefits from scientific review and critical guidance from the members of its International Scientific Expert Panel. We are grateful for the insights on our research programme and strategic direction provided by these world-leading scientists.

Palliative Care Clinical Academic Group, King's Health Partners

The Palliative Care Clinical Academic Group (CAG) is a multi-disciplinary partnership between our clinical academic teams and researchers. This is the 22nd CAG within King's Health Partners. The CAG was formed in 2018, with publication of the Palliative Care CAG Outcomes Book, demonstrating our vision for

Figure 1.2. The Palliative Care Clinical Academic Group (CAG) executive subgroups





Figure 1.3. Palliative Care CAG Outcomes Book

excellence in clinical care, research, education, and training ("King's Health Partners: Palliative Care Clinical Academic Group Outcomes Book" 2018). This built on the strong foundations of the Cicely Saunders Institute and the clinical services at all of our sites. The CAG builds on, and further supports the Institute and all partners, to pioneer the very best in palliative care and rehabilitation through the Cicely Saunders Institute's mission statement.

The CAG is an important strategic forum to continually strengthen the palliative care and rehabilitation evidence base through high-quality research, integration with clinical care, and education to maximise clinical effectiveness. The CAG's Executive Team brings together the senior clinical and academic leads to oversee delivery of the Institute's mission. This is achieved through nine reporting executive subgroups: Clinical Services; Research and Quality; Education; Mind and Body; Research and Impact; Patient and Public Involvement; Diversity and Inclusion, Global Health and Palliative Care; and Estates. Figure 1.2 details the aim for each sub-group.

Colleagues across the CAG have worked together on a number of clinical and academic developments over recent years. Their achievements are interwoven throughout the report. This includes for example, the response to the Covid-19 pandemic (Edmonds et al. 2021; Bajwah et al. 2020) and more recently in 2023, the implementation of Epic across KHP clinical services.

Held six-monthly, Knowledge Exchange seminars provide opportunity for clinicians and researchers to share and discuss their work, learn from each other, enjoy time to think and reflect on their work, and pursue opportunities to integrate clinical practice, research, and education. Knowledge Exchange seminars included:

- Palliative care for people with dementia, 5th March 2020.
- Patient and Public involvement in research on palliative care, co-produced by public members, clinicians and researchers, 12th November 2021.
- Palliative Care Clinical Academic Group: Mind, Body and Wellbeing, 23rd February 2023.
- Reach and Impact: the difference we make, showcasing research studies undertaken in the CAG and the impact on policy and clinical care, 12th October 2023.

Centre for Global Health and Palliative Care and partners

The Centre for Global Health Palliative Care is directed by Prof Richard Harding and leads major international programmes with competitive funding from the National Institute for Health and Care Research, UK Research and Innovation, the World Health Organization, and charitable bodies. It has a multidisciplinary team of staff who lead and coordinate its global health research, education, and capacity building activities. Our goal is to ensure that the Cicely Saunders Institute is global in its reach. The Centre is delivering a large global health programme with clinical and academic sites across the world, providing the scientific expertise to work together with partners to assist in finding answers to current challenges



Figure 1.4. NIHR Global Health Research Group on Global Health and Palliative Care (GHAP) consortium meeting in Cape Town

together. We partner with the King's Global Health Institute to optimise health systems as "fit for purpose" to meet the needs of populations with life limiting and life-threatening conditions through our palliative care research programme.

The Centre works with international partners from sub-Saharan Africa, including collaborators in Ghana, Ethiopia, Malawi, Nigeria, South Africa, Uganda, and Zimbabwe, the Middle East, including Jordan and Oman, and Asia, including China, India, Thailand, and Vietnam. Collaborative studies focus on strengthening integration of palliative care in primary care for adults with cancer and noncancer conditions, including HIV, chronic lung disease, and older adults with multiple conditions (see the Evaluating and Improving Care section for more details).

In sub-Saharan Africa, we are currently conducting a four-year (£2.7 million) Programme 'Global Health Research Group on Global Health and Palliative Care (GHAP): expanding access'. This work is being undertaken in Uganda, South Africa and Zimbabwe. We have university partners in each country: Makerere University in Uganda, University of Zimbabwe in Zimbabwe, and University of Cape Town in South Africa.

In Uganda, we aim to integrate a child-and family-centred outcome measures into children's palliative care at three Ugandan demonstration sites and develop data usage plans to ensure quality. In Zimbabwe, we aim to develop a model of integrated cancer palliative care that is appropriate and acceptable and determine its feasibility. In South Africa, we will develop and assess the acceptability and feasibility of implementing a symptom self-management intervention for people living with chronic organ failure focusing on the highly prevalent symptoms of pain, breathlessness, and fatigue.

A key component of the GHAP project is capacity building in palliative care at doctoral, early-career, and mid-career levels. The project includes four funded doctoral students, three registered with local universities in the respective sub-Saharan countries included in the GHAP project, and one is registered at King's College London. Additionally, we sub-contracted Africa Research Excellence Fund (AREF) to further our capacity building activities in research. AREF professional development programmes are designed to support the development of high quality non-technical research skills, such as grant and publication writing and leadership. A management consultancy firm called Imprint from Uganda

was also sub-contracted to provide training on leadership and management in health to all early-career researchers and managers working on the GHAP project.

The team recently won £30,000 additional funding from NIHR (Global Health Research Cohort Academic Development Award) to deliver a workshop in Harare, Zimbabwe on developing complex palliative care interventions using randomised controlled trials in Africa. The workshop was delivered from 7th to 10th November 2023 at Cresta Lodge in Harare and was attended by six PhD students and seven pre-doctoral researchers. Four GHAP PhD students attended a writing retreat prior to the workshop.

Policy engagement

Our priority is that our research findings are used to improve care and benefit patients, families and wider society. Engaging policy makers at local, national and international levels is an important aspect of this.

Engagement with UK policymakers

Evidence from our Marie Curie funded Better End of Life programme contributed to a successful amendment to the 2022 Health and Care Bill that means palliative care must now be provided by all Integrated Care Boards. The Better End of Life team have been invited to present their research findings at the Department of Health and Social Care and the Scottish Parliament.

In 2023, Dr Lesley Williamson, Prof Katherine Sleeman and colleagues held a Parliamentary reception to launch a Policy Brief on palliative dementia care. The reception, which was hosted by The Baroness Watkins of Tavistock, was attended by Parliamentarians as well as stakeholders from NHS England, the Department of Health and Social Care, Royal Colleges, and the voluntary sector. The Policy Brief included several CSI research studies and was subsequently cited in a House of Lords debate.

The CSI Reach and Impact Group have led submissions of evidence to several national



Figure 1.5. UK Houses of Parliament, the setting for the reception to launch a Policy Brief on palliative dementia care

inquiries and calls for evidence, ensuring that up to date, relevant, data-driven information is available to policy makers. These include the Health Select Committee Inquiry on Assisted Dying, the Inquiry on the Integration of Primary and Community Care, the Major Conditions Strategy call for evidence, and two Parliamentary Office for Science and Technology evidence notes.

Our qualitative work focussed on communication about sexual orientation and gender identity between clinicians, LGBTQ+ people facing serious illness and their significant others was selected as an NIHR Alert (Braybrook et al. 2023a and 2023b). NIHR Alerts are short, accessible summaries of research that NIHR reviewers believe should inform practice. They are shared by NIHR Evidence with audiences that are best placed to act on the new evidence.

Our programme of research and impact activities also influence international policy and action. Our REaCH team (Remote consulting in primary care in Nigeria and Tanzania) led by Prof Jackie Sturt in the Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care with Dr Kennedy Nkhoma and Prof Richard Harding held face to face meetings with national health policy makers in ten countries in Sub-Saharan Africa during February 2023 (Sturt et al. 2023). All policy makers endorsed the need for implementing the training developed by the REaCH team, which supports clinicians to safely consult with patients via mobile phones. Professional regulators in Kenya, Uganda, Tanzania, and Nigeria are now actively working with local universities to support continuing professional development accreditation for the training as an incentive for completion. The training is currently live and being disseminated to health workers in Nigeria with plans to extend delivery across Tanzania, Uganda, and Kenya.

Commissioned briefs for the World Health Organization

We have also worked closely with the World Health Organisation on commissioned policy briefs based on our research. These include:

- **Integrating Rehabilitation into Palliative Care Services:** This policy brief includes recommendations for, and examples of how, rehabilitation could be integrated into palliative care services. Informed by CSI research on rehabilitation needs and models of care, it highlights the potential role of relevant healthcare professionals such as physiotherapists and occupational therapist within palliative care teams and the importance of personalised and goal-based approaches to address the priorities of patients and their carers ("Policy brief on integrating rehabilitation into palliative care services" 2023).

- **Health and Social Care near the End of Life:** This policy brief is based on research about health and social care needs and expenditure towards the end of life, again including CSI research on key cost drivers and healthcare utilisation. It highlights anticipated higher needs and spending for an aging population, but also strategies to address these challenges through cost-effective public health and rehabilitation initiatives (Normand et al. 2021).

- **Guidelines on HIV prevention, testing, treatment, service delivery and monitoring:** These guidelines provide a detailed overview of HIV prevention, testing, treatment, service delivery and monitoring throughout the lifespan and across contexts. It includes a section on palliative care need, best practices, and essential medicines for this patient population ("Consolidated guidelines on HIV prevention, testing, treatment, service delivery and monitoring: recommendations for a public health approach" 2021).

- **WHO Technical Brief on the Economics of Palliative Care:** This forthcoming report will summarise key issues and present evidence-based examples to inform international efforts to expand palliative care. The main domains covered are frameworks for funding, the evidence base on different models of care, opportunities to alleviate financial burdens on systems and households, and opportunities to improve patient outcomes at no increased cost.

Public engagement

Public engagement with research can inform, inspire and educate members of the public, making the process of research more accessible, as well as disseminating key messages and learning about priorities. In July 2023, the Empowering Better End of Life Dementia Care (EMBED-Care) study team took part in a Science Museum Lates, as part of the NHS 75th birthday celebrations. The team developed a suite of activities, collectively called 'The D Words', to engage young adults with their research into palliative dementia care. Visitors were invited to take part in activities including a card game, a wishing tree and a myth-buster quiz, as well as chat with the research team about dying with dementia. Over 200 people attended.

As well as disseminating research to the academic community, CSI researchers use innovative methods to share findings with the wider public. In 2022, the CovPall Care Homes team launched an animated short film "Care Home Staff are Heroes Too". The film, which was based on research interviews and surveys, highlights that the essential role of care home staff was often overlooked during the Covid-19 pandemic.

In March 2022, the CSI's Patient and Public Involvement group held a community outreach event. This was a drop-in, café style event with light refreshments and resources promoting the research undertaken at CSI. Researchers were available to discuss their work with attendees and listen to how we might better involve and engage the local community. The event enabled nine attendees to join our public involvement group, and we learned invaluable lessons about how to involve and engage with the local community better in the future.



Top left: Figure 1.6. A young person hanging their response to "What would be important to you at the end of their life?" written on a leaf on the wishing tree

Bottom left: Figure 1.7. Two visitors playing 'Knowing me, knowing you', a card game which explored how well people know what would matter to their friends or families at the end of life

Top right: Figure 1.8. "Care home staff are heroes too" video

Bottom right: Figure 1.9.South London residents hear about research at the Cicely Saunders Institute at community event

Welcoming the Princess Royal to the Institute

Our team welcomed Her Royal Highness The Princess Royal to the Cicely Saunders Institute on Wednesday 22nd February 2023. During the visit, The Princess Royal, in her role as Chancellor of the University of London, met researchers, clinicians and patients at the CSI to understand how our research is improving people's experience with life-limiting conditions, death and dying. The Princess Royal opened the CSI in May 2010 as the world's first purpose-built Institute for palliative care integrating research with clinical care and education. The visit was due to mark the 10-year anniversary of the CSI in 2020 but was postponed due to the pandemic.

The Princess Royal paid tribute to clinicians who provided vital care during the Covid-19 pandemic and saw examples of our research about supporting older people to live in the community and improving care for people with life-limiting illness. She also saw how the CSI is supporting capacity building and knowledge generation across the globe so more people can benefit from palliative care.

> "We were delighted to welcome HRH Princess Royal to The Cicely Saunders Institute to showcase our research achievements in palliative care. In the twelve years since Her Royal Highness opened the CSI, King's researchers have made a tangible difference to the lives of patients and families."– Prof Shitij Kapur, President & Principal of King's



Figure 1.10. Her Royal Highness The Princess Royal visits the Cicely Saunders Institute, February 2023

Public and community involvement

Public and community involvement is the process of working together with people and communities who may be affected by our work. This includes, but is not limited to, service users, patients, families, unpaid carers, residents and clients. This is an essential part of ensuring the quality, relevance, and impact of our research and practice.

Our Public Involvement Strategy

Involvement practices at the Cicely Saunders Institute are guided by our Public Involvement Strategy (2021-2023), which we co-developed with our local professional teams and public members. The strategy builds on our previous research about public involvement in palliative care research (Johnson et al. 2021) and aligns with our aim to innovate public involvement in palliative care and rehabilitation to ensure our research, education, and practice address the priorities of people affected by life-limiting illness. An overview of our five goals is shown in Figure 1.11, underpinned by core values of inclusivity, flexibility, and respect.

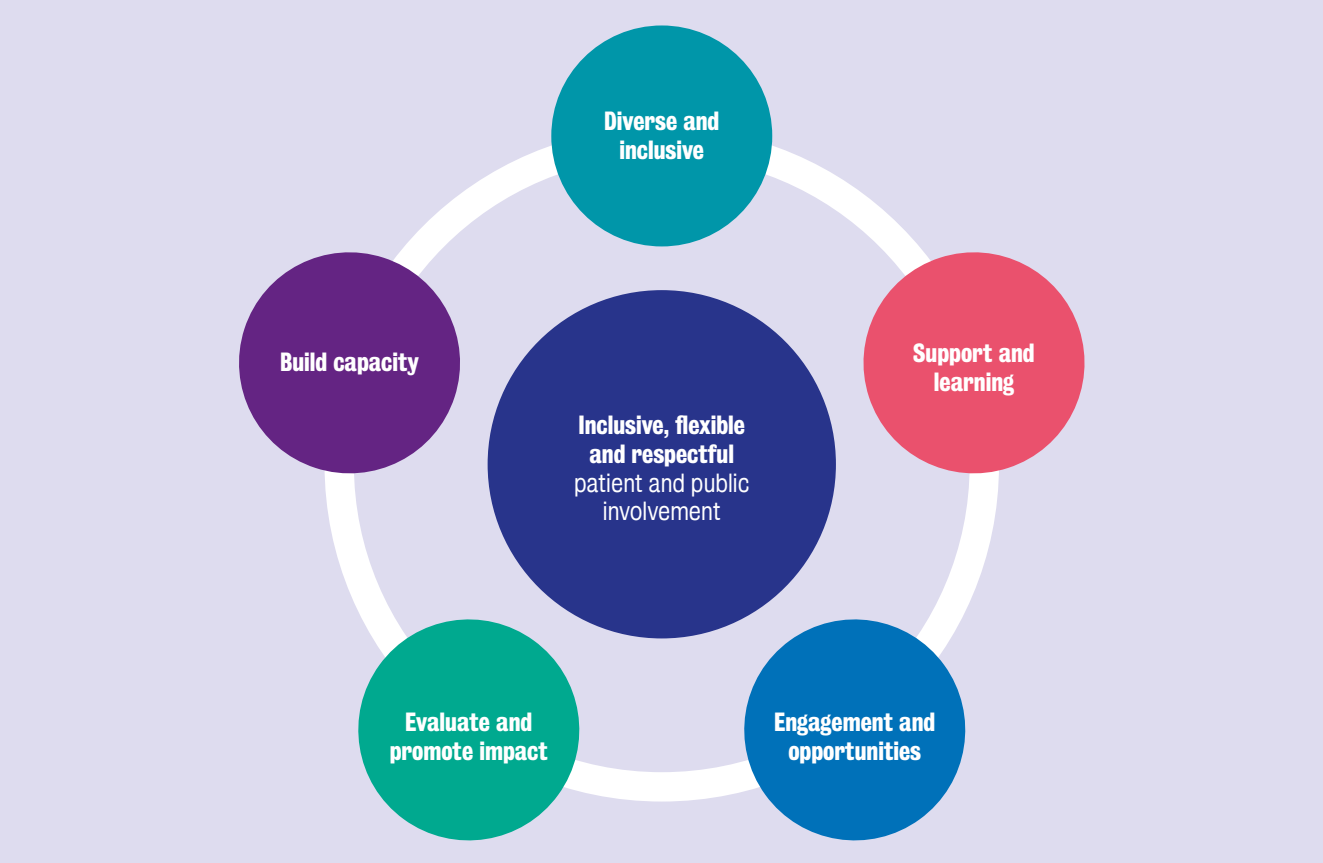
Our goals and achievements

Our strategy acted as a springboard to secure over £48,000 in involvement/engagement grants, which enabled us to pursue our five goals. Some examples of our activities and progress over the last three years include:

- **A diverse and inclusive public involvement group, with equality of opportunity**: Through continued relationship-building and staff training relating to diversity and accessibility, the diversity of our public involvement membership has increased. For example, our annual audit showed an increase in Black and Asian members and members reporting disability. We have also used innovative methods to engage specific populations, like people living with dementia, through our Dementia Community Research Network.

- **Support and learning for our public members and staff, including sharing good practice**: We co-developed two new

Figure 1.11: Overview of Public Involvement Strategy values and goals 2021–2023



support systems for our public members: a buddy scheme and training in the research cycle. We also provided staff with additional training (e.g. writing in plain language, participatory research practices). Along with our public members, we continue to co-teach a session on public involvement within our MSc Palliative Care, which students particularly value.

- **Support for public members and staff to engage with each other in a range of public involvement opportunities**: Our twice-yearly virtual 'Dragons' Den' involvement workshops have supported over 17 new projects during this period, and activity on our online forum continues to grow (www.publicinvolvement.co.uk; ~150 members). We ran a collaborative workshop with colleagues in Public Health & Social Care about optimal involvement of people with multiple long-term conditions in research and shared the findings at a national National Institute for Health and Care Research event. We have also published key lessons for public involvement in 'big data' research in palliative care (Johnson et al. 2021).

- **Evaluation and promotion of the impact of public involvement in our research, education and practice**: To illustrate the impact of public involvement on our work, we have hosted a Knowledge Exchange seminar to share our experiences (e.g. involvement of LGBTQ+ communities) and supported our public members to write blogs about their experience with involvement (e.g. in dementia,

Innovating involvement of people affected by dementia

The Dementia Community Research Network aims to create a network with community partners providing a safe and engaging space for people affected by dementia to be involved in research. The new initiative, funded by Applied Research Collaboration South London, intends to better support and represent people affected by dementia from minority ethnic backgrounds. So far, the growing network has provided training and knowledge exchange between eight community partners, two people affected by dementia, and eight dementia researchers.

children's palliative care, and rehabilitation research). We are now evaluating the impact of our most recent public involvement strategy to inform next steps.

- **Partnership with other organisations to build local, national and international capacity in public involvement in palliative care**: Locally, we are setting up a group of 'public involvement champions' to help build skills and share learning across our faculty. To build capacity beyond our Institute, we have hosted National knowledge exchange events and facilitated involvement opportunities for research groups with fewer resources. Internationally, the Centre for Global Health and Palliative care has supported the development of the first patient and public involvement group for palliative care in Sub-Saharan Africa. This is working with the African Palliative Care Association who have developed guidance on involvement of lived experts in palliative care research. These activities have continued in the global research studies, with for example the study Multimorbid Ageing Primary Palliative Care (MAP-Care) establishing an African patient and public involvement palliative care network to inform research procedures and dissemination throughout the study. We contribute to public involvement in national palliative care research partnerships and are often invited to present about our approach to public involvement at national and international events. Our PhD students are also innovating new ways of involving public members across the globe.

Award for innovation

In January 2023, researchers, health and social care practitioners, and members of the public from across South London gathered to celebrate the 'Know Your Applied Research Collaborative' awards. Our Public Involvement Strategy Group received the award for 'Most innovative patient, public involvement and engagement activity', for co-developing a public involvement strategy strengthening our collaboration with diverse communities. The judges commented: "This was a well thought out implementation to include, innovate, involve and engage local community through mental health and major disease".



Figure 1.12. Marion Sumerfield [left] and Lisa Brighton [right] collect the Know Your ARC 2022 award for Most innovative patient, public involvement and engagement activity, on behalf of the Institute's public involvement team

Clinical services

Palliative care services

The clinical palliative care services affiliated with the Institute and our Clinical Academic Group are delivered in King's College Hospital (Denmark Hill and Princess Royal hospitals), Guy's and St Thomas' hospitals, in the communities of Lambeth and Southwark through our community palliative care teams and Pal@Home, and at Brompton and Harefield hospitals. Our clinical teams operate 24/7 and receive over 9,000 referrals a year, of which approximately 70% have a cancer and 30% a non-cancer primary diagnosis. Across our services we pride ourselves on our responsiveness, with urgent/emergency referrals seen within 24 hours in the inpatient and community setting. We measure our impact in several ways. Our patients have outcome measures routinely collected, and all are screened for recruitment into ongoing palliative care research studies. We are the top recruiter in the UK to research studies in palliative care, as well as the top recruiter worldwide to the CovPall study.

We continue to have close working relationships with all our neighbouring providers, including our local hospices and other hospitals. As well as providing day to day clinical services, the clinical teams are involved in service development, innovation, and translational research and lead the provision of relevant undergraduate and postgraduate education and training. The teams also regularly host a number of local, national, and international visitors and contribute to the highly successful MSc programme run by the Institute.

Bereavement follow-up is provided to friends and relatives of all patients known to King's and Guys and St Thomas's; all are invited to the annual Palliative Care Memorial Services held at Southwark Cathedral or in the chapel at King's College Hospital. This includes invitations to healthcare professionals involved in the care of our patients.

In October 2023, Epic (the new electronic patient record system) was rolled out across King's, Guys and St Thomas' hospitals and community, as well as the Brompton and Harefield. This is the largest single implementation of the system in the world. In the two years prior to this the palliative care services have worked collaboratively to develop shared core documentation and outcome measures for use across the whole sector. This brings with it enormous potential for further collaboration, benchmarking and potential research opportunities to improve the care of our patients.



Figure 2.1. St. Thomas' Hospital in-patient palliative care team



Figure 2.2. Guy's Hospital palliative care team

Equality, diversity, and inclusion in palliative care delivery

Recognising that more could be done to measure and reduce health inequalities for those from ethnically diverse groups, our clinical palliative care team has launched several initiatives. These initiatives include leading a UK audit on the validity of ethnicity documentation and mobilising a Trust-wide 'Racial Bias of Pulse Oximetry' group to reduce the risk associated with pulse oximetry, which measures the oxygen level in blood, for patients of colour. The team also developed Covid-19 factsheets at the height of the first wave of the pandemic and engaged translation companies to translate information into 25 languages (including the top 10 non-English languages spoken in the UK). Initiatives such as these, alongside the team's "one size does not fit all" approach to patient care, have helped to improve end-of-life care for patients from ethnically diverse groups locally and nationally.

In 2022, the KCH clinical team were recognised at the prestigious Health Service Journal Awards. The team were shortlisted in the NHS Race Equality Award category for their 'Equitable Care for All Ethnicities at the end-of-life' project.

Dr Sabrina Bajwah, Consultant in Palliative Medicine and Equality, Diversity, and Inclusion lead for the team, said: "We have fostered an environment where the ethos of delivering equitable care to all is at the core of everything we do. We are delighted that the importance of our racial equality work and its meaningful impact has been acknowledged through shortlisting for this competitive and prestigious award."



Figure 2.3. The KHC clinical team at the Health Service Journal Awards, 2022

Collaboration within the Cicely Saunders Institute Building

Clinical and academic integration is strong within the Cicely Saunders Institute and is focused through the Palliative Care Clinical Academic Group (CAG) within King's Health Partners. Prof Irene Higginson, Dr Shaheen Khan, and Dr Wendy Prentice continue as co-CAG leads supported by nine executive subgroups (Clinical services, Research, Education, Mind and Body, Reach and Impact, Patient and Public Involvement, Diversity and Inclusion, Estates and Global Health). A programme of joint journal clubs, clinical academic division and forum meetings, and clinical evidence updates allows regular exchange of information and ideas between clinical and academic staff.

Additionally, the Macmillan Information and Support Centre is housed on the ground floor of the Institute and provides a welcoming and relaxing environment for anyone affected by cancer or another long-term condition. Unfortunately, the centre was closed throughout much of the Covid-19 pandemic but is now back open and welcoming staff and patients once again. In 2023, the Centre has undergone a review of its services to ensure continued alignment with the vision of the Institute.

Palliative care delivery during the Covid-19 pandemic

The strength of the clinical services and the collaboration with the academic staff within the Cicely Saunders Institute was exemplified throughout the Covid-19 pandemic during which we led the delivery of high-quality palliative care based on the best available current evidence, supported staff through education



Figure 2.4. The Palliative Care Clinical Team at the Cicely Saunders Institute, King's College Hospital

in clinical areas in hospitals and the community, and continued to recruit patients to ongoing research studies to improve the understanding of Covid-19 and the care patients required. We have subsequently managed second and third waves of Covid-19 and re-established standard services, alongside continuing to manage Covid-19 as a new 'normal'. New services have also been established including increased use of the 'Urgent Care Plan' across London, the development of the 'Let's Talk' advance care planning resources, and increasing the profile and importance of Diversity and Inclusion within all of our work. The clinical services have also all participated in National Care of the Dying Audits thus benchmarking our services locally as well as nationally.

We have learnt much from the pandemic and celebrate our strengths in responding to the situation and ensuring high-quality palliative care support was available to all those patients and families who required it. Recovery post pandemic and staff well-being has been a prime focus for all our teams who continue to work across hospitals and communities in a pressurised health and social care environment.

Rehabilitation services

Specialised neurorehabilitation following trauma and complex neurological illness/injury is provided across London by a network of eight Level 1 provider units. The Regional Hyper-acute Rehabilitation Unit (RHRU) of Northwick Park Hospital, directed by Prof Lynne Turner-Stokes, is an affiliated unit of King's College London. It provides in-patient and outreach neurorehabilitation for a catchment population of over 15 million, spanning London and the Home Counties. The consultant-led (rehabilitation medicine and therapy) rehabilitation team provide fully coordinated inter-disciplinary rehabilitation in a range of different service models, including in-patient and outreach rehabilitation led by Dr Stephen Ashford. They support a range of district specialist rehabilitation services and community-based teams, as well as link with a number of specialist nursing homes who provide life-long residential care for patients with long term conditions resulting in complex neurological disability.

Service innovation

- Our 24-bed inpatient Level 1 hyperacute rehabilitation unit takes patients mainly with catastrophic brain injury from acute and intensive care units all over London and southeast England.
- Our specialist community outreach team provide advice, support, and spasticity intervention for people with complex neurodisability and their carers.
- We provide advice to rehabilitation units and community rehabilitation services on complex physical disability management, from acute management post injury to long term disability management and palliative end-of-life care when required.
- The UK Rehabilitation Outcomes Collaborative (UK ROC) was established in September 2008 to develop a national database for collating case episodes nationally for in-patient specialist rehabilitation and is co-located with the Regional Hyper-acute Rehabilitation Unit at Northwick Park Hospital.
- The rehabilitation team helped develop the Royal College of Physicians' guidelines for review and re-evaluation of patients with prolonged disorders of consciousness.
- Furthermore, this team helped develop national guidelines for spasticity management with a systematic method of recording the process and outcome of intervention. This care is led by a consultant physiotherapist and supported by rehabilitation medicine consultants.
- We've developed and refined integrated care pathways for:
  - Hemiplegic shoulder pain
  - Spasticity management
  - Management of depression following brain injury
  - Prolonged disorders of consciousness

Education and capacity building

PhDs in palliative care

The Institute has a vibrant and enthusiastic group of UK and international PhD students who are an integral part of our research and benefit from our internal researcher and academic development programmes. Our PhD student body, typically around 25 students registered either part- or full-time, spans a wide range of professional backgrounds – currently medicine, nursing, allied health, social science, and psychology graduates are represented. Each student is allocated 2–3 supervisors, with whom they have regular meetings to receive feedback, who direct their research activities and help them identify training and development needs.

Our comprehensive programme of training includes monthly journal clubs, researchers' meetings, skills development workshops, evidence update sessions, and an Open Seminar series with national and international speakers. Our PhD students benefit from the extensive range of training and support provided throughout King's College London and the London Interdisciplinary Social Sciences Doctoral Training Partnership. Each student develops a bespoke programme in agreement with their supervisors according to their training and development needs. There is also a PhD peer-support group to provide mutual support, exchange experiences, and foster rapid learning.

Doctoral students who choose the Cicely Saunders Institute to undertake PhD research studies are at the heart of the latest developments in the field. Testament to our high levels of support, training, and career development opportunities, our student satisfaction in the 2021 national Postgraduate Research Experience Surveys is highest in the sector. The vast majority of our students (92%) were satisfied with the experience of their research degree programme and were confident that they would complete their research degree programme within the College's expected timescale.



Figure 3.1. 2022 PhD graduation ceremony



Figure 3.2. 2023 PhD graduation ceremony

PhDs completed in during this report period include:

- **Dr Cheng-Pei Lin** – Developing an intervention of advance care planning for people living with cancer and evaluating the cultural adaptation in Taiwan.
- **Dr Natasha Lovell** – Improving the management of refractory breathlessness: a feasibility double blind randomised controlled trial of mirtazapine.
- **Dr Lisa Brighton** – Improving lung rehabilitation for people living with COPD and frailty.
- **Dr Lucy Fettes** – Developing rehabilitation to prevent disability in activities of daily living (ADLs) among adults with advanced progressive illness.
- **Dr Alessandra Giusti** – What is the meaning, feasibility and acceptability of person-centredness in the global policy drive to improve care quality? A cross-national comparative study.
- **Dr Oladayo Afolabi** – Developing and preliminary feasibility testing of an integrated primary palliative care intervention for people with a serious illness and their families in Nigeria.
- **Dr Fei Fei** – Symptom Clusters in Patients with Chronic Obstructive Pulmonary Disease in China: A Mixed Methods Study.
- **Dr Javiera Martelli** – Understanding the impact of community health and social care services on hospitalisation in the last months of life for individuals with chronic conditions and multimorbidity.
- **Dr Joanna Davies** – Patterns and determinants of socioeconomic inequality in palliative and end-of-life care for older adults.
- **Dr Lesley Williamson** – Understanding Emergency Department attendance among people with dementia approaching the end of life.
- **Dr Lucy Coombes** – The development and initial validation of an outcome measure for children and young people with life-limiting and life-threatening conditions.
- **Dr Sameera Helal** – Exploring the assessment and psychological management of depression and anxiety for patients with heart failure in the community: a mixed methods study on the acceptability and feasibility of an online Cognitive Behavioural Therapy programme.

MSc, Postgraduate Diploma and Postgraduate Certificate in Palliative Care

With over 600 graduates to date, our Master of Science (MSc) in Palliative Care is the longest-running and one of the most highly acclaimed programmes in palliative care in the world. The underpinning philosophy of the MSc and the integrated Postgraduate Diploma and Postgraduate Certificate is to develop students to become international leaders in the field. To do this, we provide students with the essential skills required to appraise research and evidence on palliative care-related issues to inform their clinical practice and to develop relevant services and policy. We aim to develop students' knowledge and understanding of clinical, social, psychological, spiritual, and ethical issues in palliative and end-of-life care and their assessment and effective

management of patients with palliative care needs. In addition to being able to critically appraise evidence of new and existing treatments, we teach course participants how to formulate important research questions relevant to the specialty and how to design and conduct their own rigorous research studies to address these issues. Students are taught by world-leading experts from centres of excellence in the United Kingdom and worldwide.

Our international reputation attracts high-calibre and highly motivated students from all over the world. The range of countries currently and historically represented in the student body is very diverse including those from South Korea, Taiwan, Uganda, Brazil, Portugal, Columbia, Israel, Pakistan, Italy, the Netherlands, Vietnam, and Jordan amongst many others. The diverse multidisciplinary student body provides a unique opportunity to share experiences on how end-of-life care has developed across the world and to reflect on social and cultural approaches to death, dying, caring, and bereavement. Our multi-professional student body comprise physicians, nurses, allied health professionals, social workers, and clergy from both specialist and non-specialist palliative care backgrounds including, for example, anaesthesiology and care homes.

During the Covid-19 global pandemic, we successfully migrated all of our MSc teaching to online delivery. Then, in response to post-pandemic demand, we moved to HyFlex (hybrid and flexible) delivery. This means we now have students engaging in their studies from across the globe both in-person and online whilst maintaining a core component of highly interactive education with multidisciplinary, international peer-learning. We took this period of change as an opportunity to consult our student body to optimise access and learning outcomes to meet their needs.

Results from the Postgraduate Taught Experience Survey are consistently high with over 90% overall student satisfaction in the past five years, and 100% overall student satisfaction for three of those.

The EduPall project

The EduPall project was a two-year project funded by Sir Halley Stewart Trust to innovate Postgraduate Taught Palliative Care education to develop future international leaders in the field. The project comprised co-design workshops with current and past students from the UK and abroad, lecturers and education leads, and those with specialist knowledge in distance learning and international palliative care delivery. Qualitative interviews and two surveys (at the beginning and end of a cohort) were conducted with students and educators to further explore and evaluate changes made to the programme.

Findings formed four major themes:

1. International networks including collaboration with peers, alumni, and established leaders in the field.

2. Leadership skills to advocate for policy change and develop and establish palliative care services.

Where are they now?



Dr Eve Namisango completed the MSc in Palliative Care in 2012 and her PhD with the Cicely Saunders Institute in 2020. Since graduating, Eve has gone on to lead multiple research, service development, academic training, community engagement, advocacy, and policy engagement projects in her native Uganda and across Africa. She played a central role in developing the African Palliative Care Association Atlas for Palliative Care in her role as their Research Manager, pioneered the use of an app-based digital health programme to strengthen palliative care pharmaceutical systems in Africa, developed community led models of grief and bereavement care, and leads the development and validation of the Children's Palliative Outcome Scale in sub-Saharan Africa. Her impact on palliative care research and policy is international, and she served on the board of the International Association for Hospice and Palliative Care from 2019 to 2022 and continues to serve on the board of the Institute of Hospice and Palliative Care in Africa.

3. International context embedded into the curriculum and delivered by lecturers with international experience and expertise.

4. Flexible learning models, including options for online and face-to-face opportunities.

As a result of the EduPall project, the following changes have been implemented:

1. Change to HyFlex to reduce costs of travel and relocation and maximise accessibility and flexibility for all students.

2. Change from a January to September start in line with the academic year to maximise access to scholarships, accommodation, and English language courses.

3. Inaugural MSc student seminar in May 2023 to provide students with the opportunity to present their research projects, network, and develop collaborations.

4. Development of teaching resources including guidance on international teaching curriculum and use of accessible language.



Where are they now?

Prof Fliss Murtagh completed her PhD at the Cicely Saunders Institute in 2009. Since then, she has continued to excel clinically as a palliative care consultant and academically as a world-renowned palliative care researcher, focused on improving care for older adults with advanced illness; both cancer and non-cancer conditions. She has continued to pioneer implementation and use of person-centred outcome measures in palliative care, with 75% of UK palliative care teams now using the Integrated Palliative care Outcome Scale (IPOS). Currently, she is a Professor of Palliative Care at Hull York Medical School, Director of the Wolfson Palliative Care Research Centre at University of Hull, an NIHR Senior Investigator (2020–24), and a visiting Professor at the Cicely Saunders Institute. She leads and co-leads multiple research studies – funded by NIHR, Research England, Yorkshire Cancer Research, Marie Curie – and has won awards for her work. She has established herself as a leading palliative care academic and expert in the UK and internationally and is committed to growing the field through supervising PhD and MSc students and supporting the career development of early and mid-career researchers in palliative care research.



Where are they now?

Dr Duong Le Dai completed his MSc in Palliative Care in 2017. Since then, he has co-created, managed, and taught the first specialist palliative care training programme for physicians and nurses in his home country Vietnam and supports the implementation of the first randomized controlled trial in Vietnam to assess the effectiveness of a comprehensive palliative care service for advanced cancer patients. Now, Duong serves as the Educational Director of the palliative care programme for medical and nursing students at the University of Medicine and Pharmacy at Ho Chi Minh City and is pursuing his PhD in palliative care at the Cicely Saunders Institute. For his dissertation, he plans to develop and pilot test a novel interdisciplinary home-based palliative care intervention to be implemented in several districts in Vietnam.

5. Development of case studies to showcase international alumni who have become palliative care leaders.

The Medicine MBBS programme

The King's College London School of Medicine at Guy's, St Thomas' and King's College Hospital is the largest provider of undergraduate healthcare training in Europe with over 450 medical students each year. The undergraduate palliative care curriculum is designed to spread throughout the five-year MBBS.

Each MBBS year cohort is divided into 'clusters' according to the hospital students are based in. Within the Palliative Care Clinical Academic Group, the clusters that exist are King College Hospital, Guy's and St. Thomas', and Princess Royal. We also actively collaborate with the University Hospital Lewisham, the Queen Elizabeth Hospital, St Christopher's Hospice, and the Royal Trinity Hospice. Here, students benefit from teaching on topics including aging, palliative and end-of-life care, and bereavement. In addition, all the palliative care teams within each cluster site contribute regularly to educational supervision, deliver revision lectures and webinars, provide communication skills courses, supervise quality improvement projects, and participate as examiners.

Training and environment

Competitive fellowships

The Cicely Saunders Institute has had an excellent track record of mentoring early career researchers and clinicians and supporting them to win competitive national and international fellowships. Funding bodies recognise that the CSI offers an extraordinary training environment that is conducive to growing leaders in the field of palliative care. Students and early career researchers have been successful in winning competitive pre-doctoral and post-doctoral fellowships, including salary, training, and research costs, from the UK's National Institute for Health and Care Research, the Fullbright Foundation, UK Research and Innovation's Medical Research Council, Health Education England, the London Interdisciplinary Social Science Doctoral Training Partnership, and Cicely Saunders International.

Specialty training in palliative medicine

Dr Nick Gough is the Training Programme Director for London and chairs the London palliative care specialty training committee.

Dr Polly Edmonds is chair of the national specialty advisory committee (which oversees curriculum and quality of training) and is on the exam board for the specialty certificate examination. Feedback from trainees placed across King's Health Partners has been consistently good across all domains on the GMC training survey.

Multidisciplinary clinical academics in palliative care

A priority for our Palliative Care Clinical Academic Group (CAG) is to grow and sustain the clinical academic workforce by maximising career opportunities for all health professionals in palliative care to pursue and enjoy research. Our senior academic team demonstrates progress to achieving this with multi-disciplinary clinical academics in medicine (Sleeman, Bajwah, Higginson, Turner-Stokes), nursing (Evans), allied health professionals (Reilly, Ashford), social work (Harding, Marshall), and academics with clinical registrations (Maddocks, Ellis-Smith). The formation of the King's Clinical Academic Office (KCATO) in 2022 strengthens opportunities for all professions to engage in



Figure 4.1. Some of the Cicely Saunders Institute's post-doctoral fellows

research and pursue successful clinical academic careers (Figure 4.2). Prof Catherine Evans is a Deputy Director of the KCATO progressing the clinical academic pathway for health professions (outside of medicine) in King's Health Partners.

The development of clinical academics encompasses the career pathway of research Exposure, Education, and Engagement.

- **Exposure** to research includes the NIHR Integrated Academic Training programme for medical doctors. We continue to secure funded Academic Clinical Fellows in palliative care, with Prof Katherine Sleeman as the speciality lead, within King's College London bid. The MBBS programme (detailed in the Education section) provides opportunity for undergraduate medical students to gain exposure to research in palliative care. We also offered undergraduate nurses in the ursing, Midwifery, and Palliative Care Faculty opportunities for research placements and to complete summer research projects with us in the Institute.

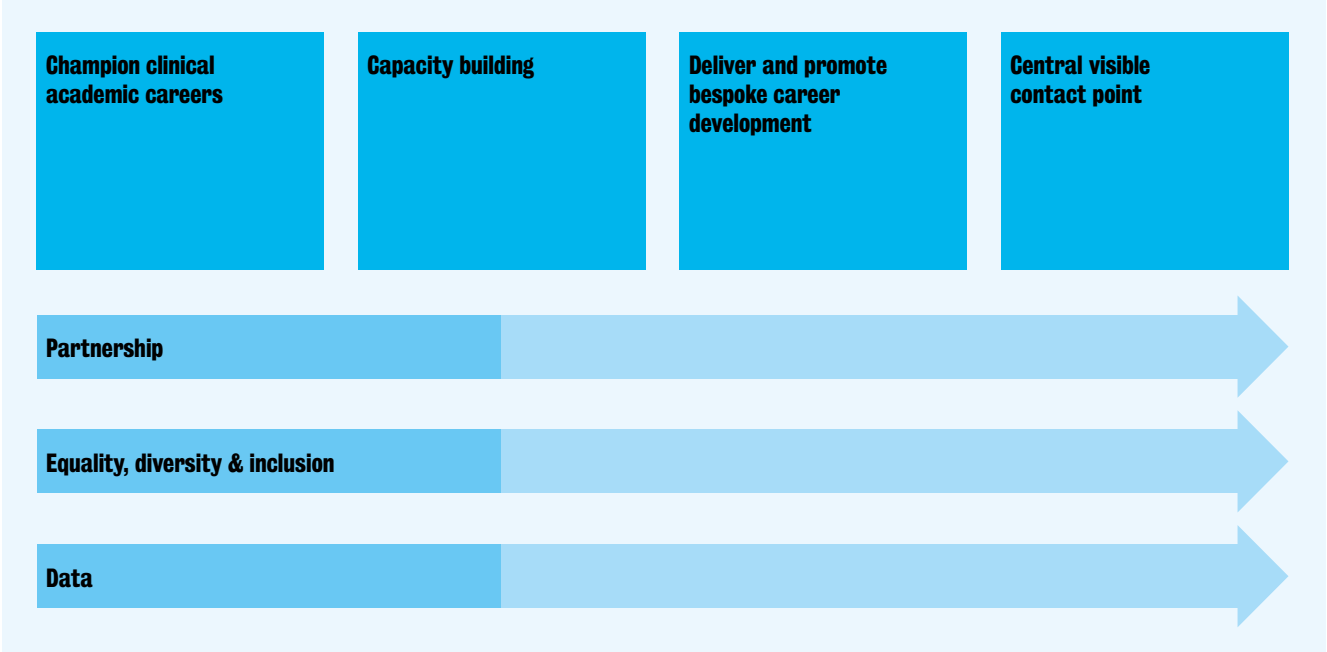
- Clinical colleagues have attained funded opportunities for research **education** securing Health Education England funded research internships (pre- and post-doctoral), and ACORN internships for nurses at Guy's and St Thomas NHS Foundation Trusts. We hosted NIHR pre-doctoral clinical academic fellows in palliative care nursing and dietetics and supported individuals' progression to secure doctoral funding. Dr Liam Gabb secured NIHR doctoral funding, progressing his career as a clinical academic in palliative medicine.

- **Engagement** involves progression of clinical academics to become leaders in the field. Dr Steve Ashford recently secured internal promotion as Honorary Reader in Rehabilitation, and Dr Charles Reilly secured a prestigious nationally competitive NIHR Advanced Fellowship. His fellowship is a joint clinical academic post as a Consultant Physiotherapist in Chronic Respiratory Disease, King's College Hospital and Adjunct Senior Clinical Lecturer, in the Institute.

BuildPall

The BuildPall programme is building a cadre of leading clinical academics, researchers, and educators to expand the global capacity for palliative care. The goal of the initiative is to train future clinicians, generate knowledge

Figure 4.2. King's Clinical Academic Training Office strategic goals and themes



through research, and improve palliative and end-of-life care for people affected by serious illness. Funded by Cicely Saunders International, this five-year programme supports PhD students, one clinical and one non-clinical, a post-doctoral fellow, and small grants for faculty for work that focuses on building capacity for palliative care services in the UK and globally. Dr Anna Peeler, a clinically trained nurse, has taken up the BuildPall post-doctoral fellowship. The PhD studentships have been awarded to Dr Duong Le Dai, a palliative care physician and previous MSc in Palliative Care graduate, and India Tunnard, a researcher at the Cicely Saunders Institute and NIHR pre-doctoral fellow.

Visitor programme

The Institute has welcomed individuals and groups, both academics and health professionals from a range of backgrounds and nationalities, to visit to learn more about our work. In some instances, visits have represented longer-term commitments where individuals have requested to work alongside academics to support existing programmes of work relevant to their professional interests.

In the last three years, we have hosted visitors from the UK, Belgium, Portugal, Austria, Czech Republic, and further afield including South Africa, South America, USA, South Korea, Singapore, China, and Australia. Visitors to the clinical team include medical doctors from Brazil, Portugal and the Czech Republic and nurses from the USA and Canada.



Figure 4.3. Prof Irene Higginson presents at the annual Palliative Outcome Scale Training Days held 15th and 16th May 2023

Seminars, workshops and the CSI YouTube channel

Many people have attended our events either physically at the Institute or remotely through video-links. Through our events series, we facilitate and optimise opportunities for local, national, and international networking to improve practice, education, and policy. During the past three years, the Open Seminar and other speaker series have provided an invaluable opportunity for knowledge sharing and networking, with local and international expert speakers attracting a range of health and social care professionals and the wider public. Recent seminars and workshops include:

2020

- Michal Galazka International Seminar presented by Dr Kathryn Mannix entitled "Re-claiming the public understanding of dying"
- "Palliative care and advance care planning in nursing homes: what will move the needle?" by Prof Lieve Van den Block, VUB-UGhent End-of-Life Care Research Group
- "It feels it's wasting whatever time I've got left': Living with treatable but not curable cancer during the Covid-19 pandemic" by Dr Lynn Calman & Dr Eloise Radcliffe, University of Southampton

2021

- "Clinical intuition or mathematical models – which are better for prognosticating?" by Prof Paddy Stone, University College London
- "Making a difference: Can implementation and improvement science help the Institute meet its mission to pioneer the very best in palliative care and rehabilitation?" by Prof Annette Boaz, London School of Hygiene and Tropical Medicine

- "Clinical Trials in Palliative Care: The Mystery of the Mechanisms" by Prof Gary Rodin, University of Toronto

- The Annual Palliative Outcome Scale (POS and IPOS) Training Days were held in March 2021. The workshops included talks from POS and IPOS experts who have used the POS family of measures in their everyday work, including Prof Irene Higginson, Prof Fliss Murtagh, and Prof Richard Harding.

- "Empathy in palliative care conversations: Insights from direct observational research on (recorded) real life palliative care consultations" by Prof Ruth Parry, Loughborough University

- "Exercise for people living with frailty and receiving haemodialysis: a mixed-methods randomised controlled feasibility study" by Dr Hannah Young, University of Leicester

- "Racial inequality of Covid-19" by Dr Sabrina Bajwah, Cicely Saunders Institute, King's College London

- "British Heart Foundation Data Science Centre, Consortium, and Projects" by Prof Cathie Sudlow, British Heart Foundation Data Science Centre

- "Palliative care for ageing populations: how do we improve care for people dying with frailty?" by Dr Daniel Stow, Newcastle University

- Michal Galazka Study Day September 2021 entitled "The role of palliative care in the public health response to Covid-19"

- "Re-thinking advance care planning" by Dr Andy Bradshaw, University of Hull

- "Health Data Research UK: National Core Studies" by Lara Edwards, Health Data Research UK

2022

- "Rethinking advance care planning" by Dr Chetna Malhotra, Duke-NUS Medical School



Where are they now?

Prof Katherine Sleeman was awarded a prestigious NIHR Clinician Scientist Fellowship in 2016 while working as a clinical lecturer at the Cicely Saunders Institute. Her fellowship research focused on understanding and improving patterns of care before death for people with dementia using clinical and administrative data sources. Since then, Prof Sleeman received the inaugural (2019) Women in Palliative Care award from the European Association of Palliative Care and has led numerous palliative care research projects, securing funding from NIHR, Marie Curie, and the Economic and Social Research Council. In 2021 she was appointed to the Laing Galazka Chair in Palliative Care at the Cicely Saunders Institute. She leads the Integrated Academic Trainee programme for palliative medicine and serves as the Academic Impact Lead for the NMPC faculty. She continues to work clinically as a consultant in palliative medicine.

- "Exploring the impact of Covid-19 on hospices and their staff" by Prof Catherine Walsh, Lancaster University

- "We're all cogs in a big machine: Learning from the experiences of primary care in the delivery of community palliative and end-of-life care during the Covid-19 pandemic" by Dr Sarah Mitchell, University of Sheffield

- "A Cross Country Comparison Expert Assessments of the Quality of Death and Dying, 2021" by Prof Eric Finkelstein, Duke-NUS Medical School

- "Children with life-limiting conditions" by Prof Lorna Fraser, University of York

- "Is rehabilitation really feasible in the palliative setting and why is it needed? Introducing the ENeRgy Trial- a randomised controlled trial of an Exercise and Nutritional Rehabilitation programme for people living with incurable cancer" by Dr Charlie Hall, St Columba's Hospice

- "What happened in care homes during the pandemic? Results from three prospective studies" by Prof Nancy Preston, Lancaster University

- "The Children's Palliative Care Outcome Scale (C-POS) study: findings and innovations" by Dr Debbie Braybrook and Lucy Coombes, Cicely Saunders Institute, King's College London
- "Preliminary trials – perspectives on their purpose and practice" by Prof Toby Prevost, King's Clinical Trials Unit
- We held a symposium entitled "Childhood bereavement: An international symposium on rights and support" welcoming a range of researchers and clinicians to the Institute
- "Communication following a positive newborn bloodspot screening result – the ReSPoND study" by Dr Jane Chudleigh, Cicely Saunders Institute, King's College London
- Michal Galazka International Study Day entitled "Inequalities in Palliative and End of Life Care" with a variety of talks covering socioeconomic position, ethnicity, and sexuality/gender identity

2023

- "Structural Racism and Engagement of Family Caregivers in Serious Illness Care" by Prof Jennifer Tjia, UMass Chan Medical School
- "Everyday ethics in palliative care" by Guy Schofield, University of Bristol
- "Strategies to help adolescents with a seriously ill parent" by Prof Denice Sheehan, Kent State University
- "Using big data to understand (and address) social inequality in palliative and end-of-life care" by Joanna Davies, Cicely Saunders Institute, King's College London
- "Managing patients at home: variation in non-conveyance rates between ambulance services in England" by Prof Alicia O'Cathain, University of Sheffield
- In May 2023 we held our first MSc Palliative Care Open Seminar giving putting the spotlight on our MSc students, and their contribution to palliative care research. Four current students presented their research study projects, covering a wide range of issues and settings within palliative care
- The Annual Palliative Outcome Scale (POS and IPOS) Training Days were held in May 2023, hosted by the Cicely Saunders Institute, King's College London and the Hull York Medical School. The workshops included talks from POS and IPOS experts who have used the POS family of measures in their everyday work
- "A Method for Determining the Burden of Serious Illness-Related Suffering and the Means to Relieve It" by Prof Eric Krakauer, Harvard Medical School
- Michal Galazka International Study Day on out-of-hours palliative care

The Institute's YouTube channel (www.youtube.com/user/CSIKCL) hosts approximately 100 videos and features recordings of seminars, lectures, and workshops, providing a platform for learning and engagement. Anyone from anywhere in the world can access important learning on palliative care and rehabilitation from world-leading experts. There is an excess of 30,000 views of our videos to date. We also live-stream events throughout the year enabling the widest possible global reach of events beyond those present in the room.

The Cicely Saunders Annual Lecture

The Cicely Saunders International Annual Lecture Speakers invites global leaders whose work has significantly influenced the palliative care field to speak on topics of their choosing. These lectures are a unique opportunity to learn from world-leading clinicians and scientists. Events are presented in hybrid format and welcome hundreds of guests from around the world. Attendees included academics, students, policymakers, patients, and carers. We also

provided outside video links to partners sites across the UK, Europe, USA, and Africa.

Recent lectures include:

- In November 2020 the Annual Lecture focused on the impact of the Covid-19 pandemic on palliative care. Dr Eve Namisango, Prof Steven Pantilat and Prof Irene Higginson presented 'Palliative Care in an era of Covid-19: Perspectives from three continents'

- In December 2021, Prof Per Sjøgren gave a lecture entitled 'The changing landscape of pain management in palliative care: Long term opioid therapy?'

- In October 2022, Dr Marie-Charlotte Bouësseau from the World Health Organization gave a lecture entitled 'Building palliative care services as we build houses: Improving quality of life for all through evidence-based policy".

- In May 2023, Dr Harvey Chochinov from the University of Manitoba gave a lecture entitled 'Improving End of Life Care: lessons learned, what now, what next?'

Evaluating and improving care

This programme strives to improve the care and treatments for people affected by serious illness and their families where they reside (own home, care homes) and receive care (own home, care homes, hospitals, hospices). Our research spans cancer and non-cancer conditions and encompasses understanding inequalities in existing services to inform intervention and policy priorities, developing and trialling refined or new service level interventions of care that better meet the needs of patients and families, and providing evidence about the effects of care and treatment. Our study designs include theory development, systematic reviews, service level interventions, feasibility testing, and definitive trials, including multicentre randomized controlled trials. Collaboration with patients, families, and the public is a core component of all our studies. We work to maximise the impact of these collaborations in our work with, for example, lived experts as co-applicants co-leading public involvement with researchers and co-design of interventions with public members and community partners.

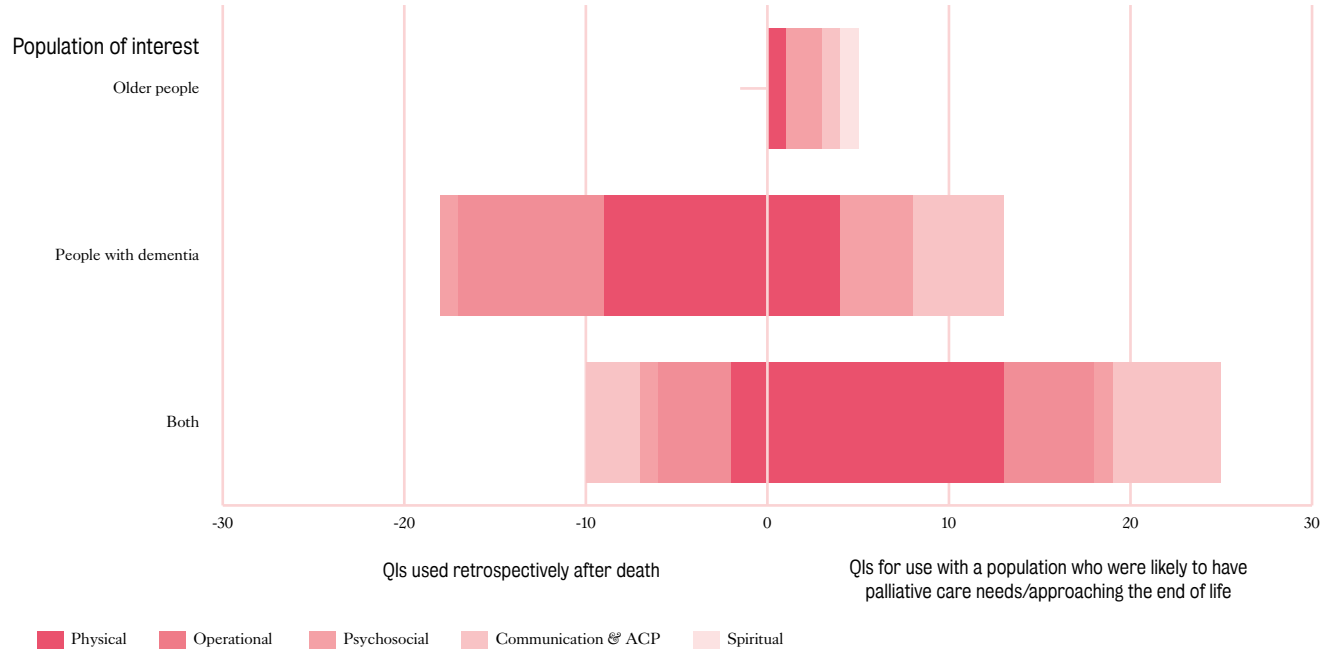
Dementia

Empowering Better End of Life Dementia Care (EMBED-Care) is a major £4.7 million joint research programme between the Cicely Saunders Institute, King's College London and the Marie Curie Palliative Care Research Department, University College London. Funded by the Economic and Social Research Council/National Institute for Health and Care Research, this programme brings together the specialist areas of palliative care and dementia care to leverage a step change in the provision of palliative care for people affected by dementia (Sampson et al. 2019). The programme spans multiple sequential workstreams including evidence syntheses to identify quality indicators for care, explore service use using linked routine data, and developing and co-designing the EMBED-Care framework as a digital intervention in the community (own home and care homes). The intervention is informing clinical care within the Dementia Palliative Care Service Toolkit, Derbyshire Community Health Services NHS Foundation Trust ('The Dementia Palliative Care Service Service Improvement and Delivery Toolkit: How to Guide' 2023).

Quality indicators for palliative dementia care

With the increasing number of people living and dying with dementia, understanding the quality of care experienced by people with dementia nearing the end of life and mapping out their patterns of healthcare use are essential for evidence-based policies and service planning. We systematically reviewed the literature and identified 976 quality indicators addressing the care of older people and people with dementia nearing the end of life (Yorganci et al. 2021). We provide 71 robust quality indicators which can be identified using routinely collected electronic data, across care settings. These were categorised as health processes or outcomes and mapped against six care domains (seen in Figure 5.1: 'physical', 'operational', 'psychosocial', 'communication, advance care planning (ACP), ethical & legal', 'spiritual & cultural', and 'other'). We assessed quality indicators using acceptability, evidence base, definition, feasibility, reliability, and validity. Prioritising routine electronic data collection for quality indicators could provide an overview of the quality of care provided to this large and growing population. Appropriate quality measures such as quality indicators and patient-reported outcome measures must be implemented to address the needs of patients and families and aid services with the provision of high-quality care. This systematic review

Figure. 5.1. Shortlist of 71 quality indicators for use with routinely collected electronic datasets



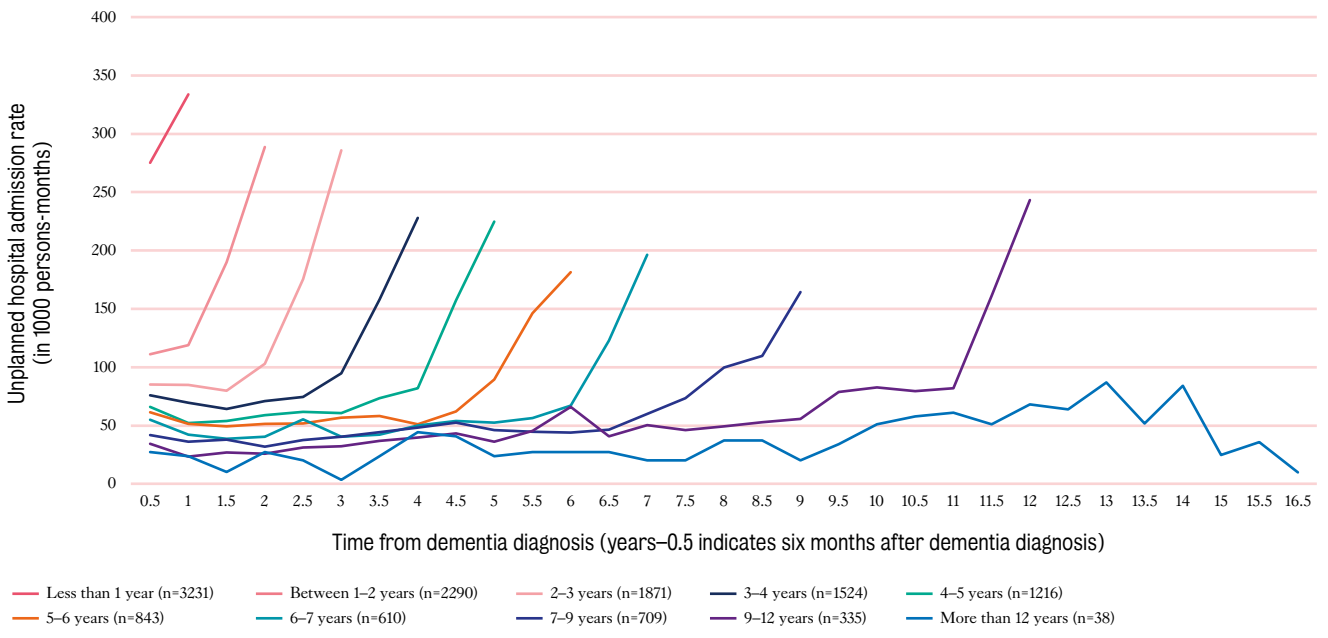
has been selected for the National Institute on Aging's IMPACT Collaboratory iLibrary, which is a new resource to identify readily measurable outcomes that matter for people with Alzheimer's disease and other dementias.

Unplanned hospitalisation and critical use for people with dementia

This study used routine datasets linked between South London and Maudsley's specialist mental healthcare and national hospital databases to examine unplanned hospital admissions from diagnosis of dementia to end of life (Yorganci et al. 2022). The findings showed that across duration of survival from diagnosis, unplanned hospitalisations increased markedly in the last year of life with 37% of admissions occurring during this time (Figure 5.2). Admissions ranged from 12–59 days. Admission can cause distress for the person and family and often near end of life, people's preference is to remain safely in their usual place of care (own home, care home). The study included data relating to 19,221 people diagnosed with dementia aged over 50 across a 22-year period (1995–2017) in four South London boroughs. Patient and public representatives informed the conception of the study's aim and the main messages from the findings. This study has been featured in the UK Parliamentary POSTnote on palliative and end-of-life care (Number 675, July 2022 ('UK Parlianment Post: Palliative and end of life care' 2022)), presented to the Department of Health and Care in England and Australia, and included in a policy brief presented at the House of Lords (Williamson et al. 2023).

We also used this linked dataset to examine critical care admissions for people with dementia. The findings showed that although critical care admissions are decreasing overall, the number of admissions in the last year of life increased slightly (Yorganci et al. 2023). The one-year survival of people with dementia following a critical care admission is 48%. This is a similar proportion to the general older population. Careful consideration of care needs, a multidisciplinary approach, and communication with the patient and their family about preferences and end-of-life wishes are vital for care planning during critical care admissions. While recognition of dementia by clinical teams has increased, skills and knowledge to deliver care for those who may be near end of life are often lacking. Quality indicators such as the percentage of people with dementia who had a critical care admission in the last month and year of life and the documentation of treatment and care preferences may drive improvements in care quality for people with dementia until the end of their lives.

Figure 5.2. Unplanned hospital admission rates for people who died with dementia (n=12,667) by duration of survival after diagnosis.



Developing and co-designing the EMBED-Care framework for palliative dementia care

The EMBED-Care framework as an intervention seeks to enhance person-centred holistic assessment using the IPOS-Dem outcome measure linked with evidence-based clinical decision support tools to optimise care provision and outcomes for people with dementia and their families. Person-centred care is vital to align care provision with individual priorities and preferences. Central to this is shared decision making for active involvement of individuals and their family carers in planning and reviewing care and treatment. Person-centred outcome measures are useful tools to enhance holistic assessment of needs, support communication between individuals and practitioners by having a shared language, and to review outcomes of care provision.

The EMBED-Care framework development was informed by a systematic review on how person-centred outcome measures enable shared decision-making for people with dementia and family carers (Aworinde et al. 2022). The findings showed that the use of person-centred outcome measures in routine care can facilitate shared decision-making through "knowing the person," "identifying problems, priorities for care and treatment and goal setting," and "evaluating decisions." Family carers were identified as crucial to upholding priorities for the person with dementia and supporting decision-making on care and treatment. This research informed understanding on how outcome measures can enhance shared decision-making in dementia care when used as a self-report (by a patient) and/or proxy reported (by family carer/professional).

Implementation of the EMBED-Care Framework is considered throughout the programme. This began with a systematic review on the 'Development of an implementation plan for a eHealth tool to improve holistic assessment and decision making for people with dementia in care homes' (Gillam et al. 2022). The review identified a widespread set of requirements for implementation in a care home that involved an interaction between the resident, staff, and the care home. The findings informed a model of eHealth implementation in long-term care

Figure 5.3. A model of factors that influence implementation of eHealth in care for people with dementia (Gillam et al. 2022)

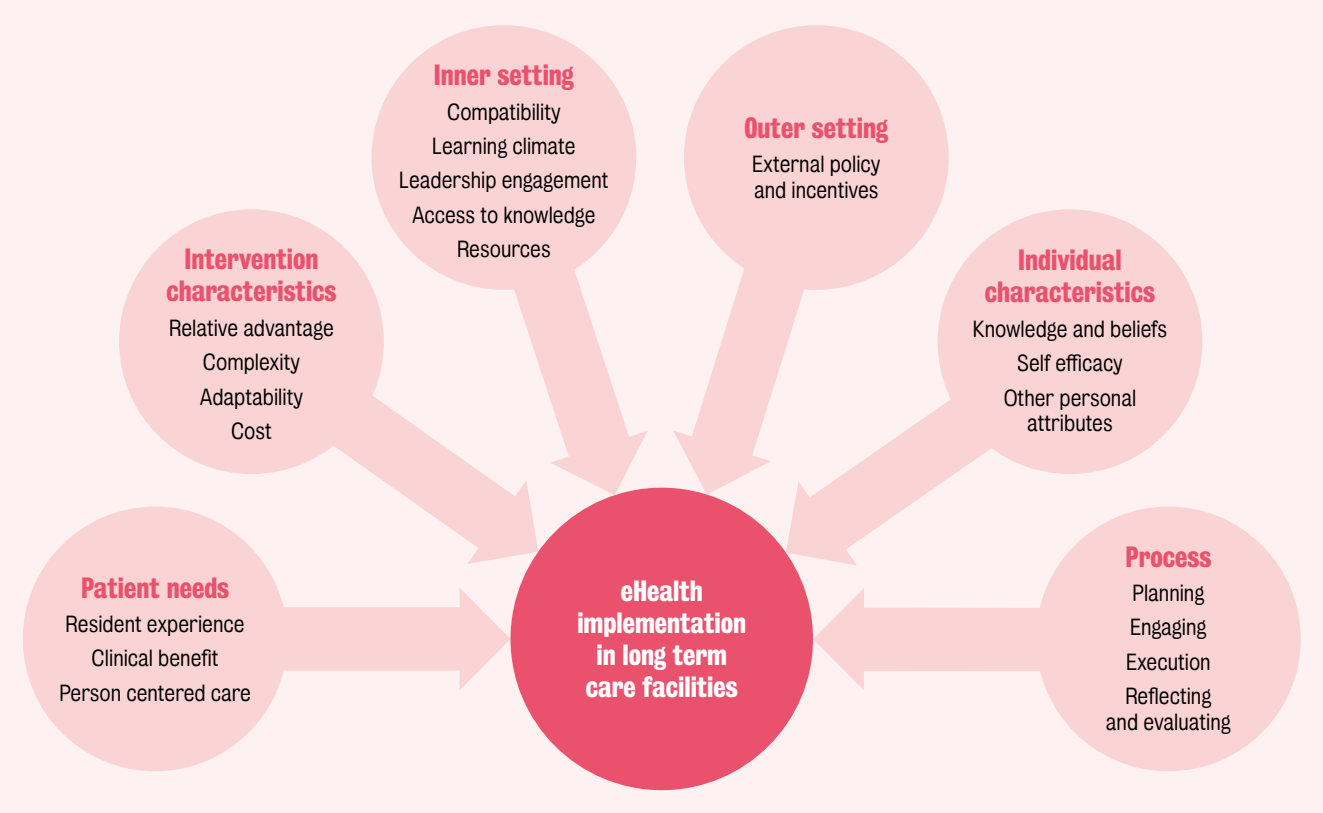




Figure 5.4. EMBED-Care co-design workshop with lived experts, health and social care professionals, and researchers.

for people with dementia (Figure 5.3). We identified four novel sub-constructs required to adapt the Consolidated Framework for Implementation Research (CFIR), an implementation framework, for the care home context and use of eHealth to enhance integrated care for people with dementia. The novel sub-constructs pertained largely to resident needs, acknowledging the increasing focus on person-centred care in healthcare interventions, and the importance of promoting the autonomy of individuals and families in their care and treatment. The findings were translated into 18 practical recommendations on implementation of eHealth in long-term care to guide implementers or innovators in care homes.

We pursued the findings and uncertainties identified in the systematic reviews in a series of co-design workshops with people with dementia, family carers, health and social care practitioners, and researchers (Figure 5.4). This workstream was led by Dr Nathan Davies, UCL, with Dr Clare Ellis-Smith, KCL. The workshops sought to understand the requirements to implement the EMBED-Care framework in routine care and linkages with clinical decision support tools and to enhance shared decision-making for people living with dementia at home, such as support for family carers. Throughout, stakeholder engagement and public involvement meetings were conducted with people affected by dementia to advise on planned content and priorities for the workshop and to interpret the data generated in the workshops to construct the intervention. This intended to optimize the relevance of the intervention for people living with dementia and clinical practitioners.

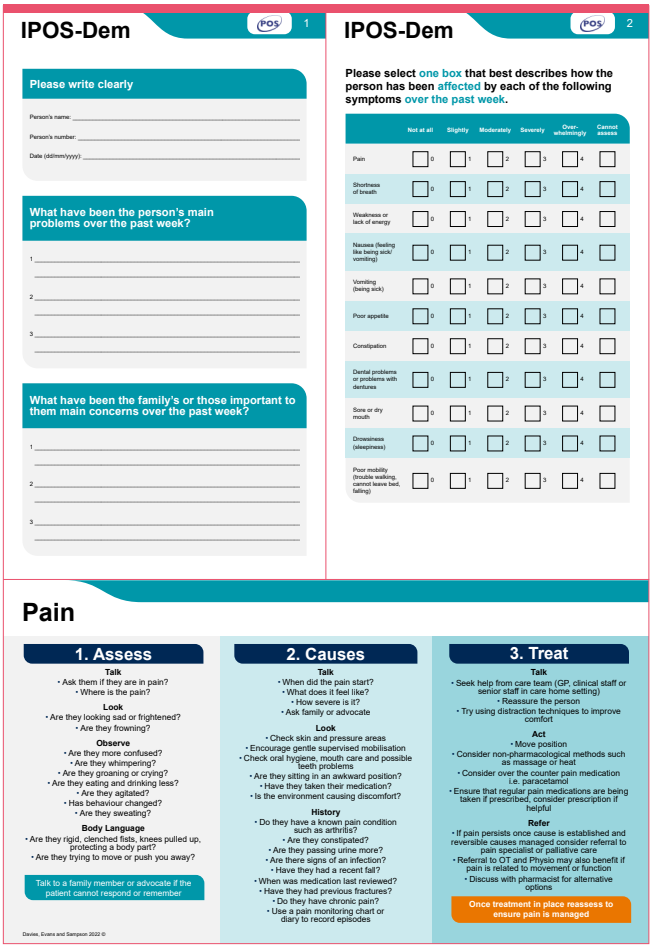


Figure 5.5: The EMBED-Care framework as an intervention for integrated palliative dementia care incorporating the IPOS-Dem for person-centred holistic assessment linked with clinical decision-support tools (example of tool for pain)

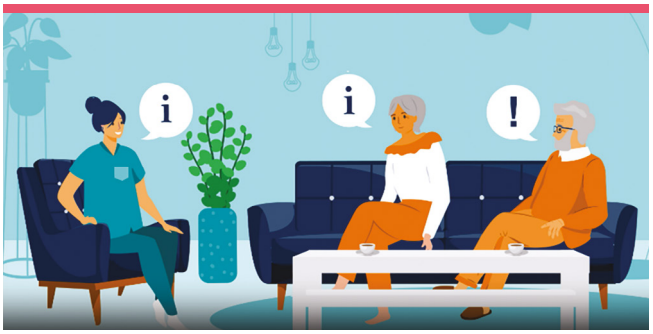


Figure 5.6. Picture from the animation on shared-decision making process

The co-design workshops constructed the EMBED-Care framework comprising a holistic outcome measure (IPOS-Dem) linked with clinical decision support tools (evidence informed guides to inform decisions about care and treatment) (Figure 5.5) and resources to support use with resources to support use, such as short-animations on, for example, process of shared-decision making (Figure 5.6). The workshops developed the EMBED-Care framework implementation plan as a multi-strategy, theoretically driven plan to implement

the framework as an eHealth intervention to support assessment and decision making for people with dementia in care homes strengthened through collaborating with end-users to increase its value, credibility, and real-world relevance (Gillam et al. 2023). The next steps are to evaluate the feasibility and processes of the intervention and implementation plan working with NHS community healthcare teams and care home providers.

Older people with frailty and multiple conditions

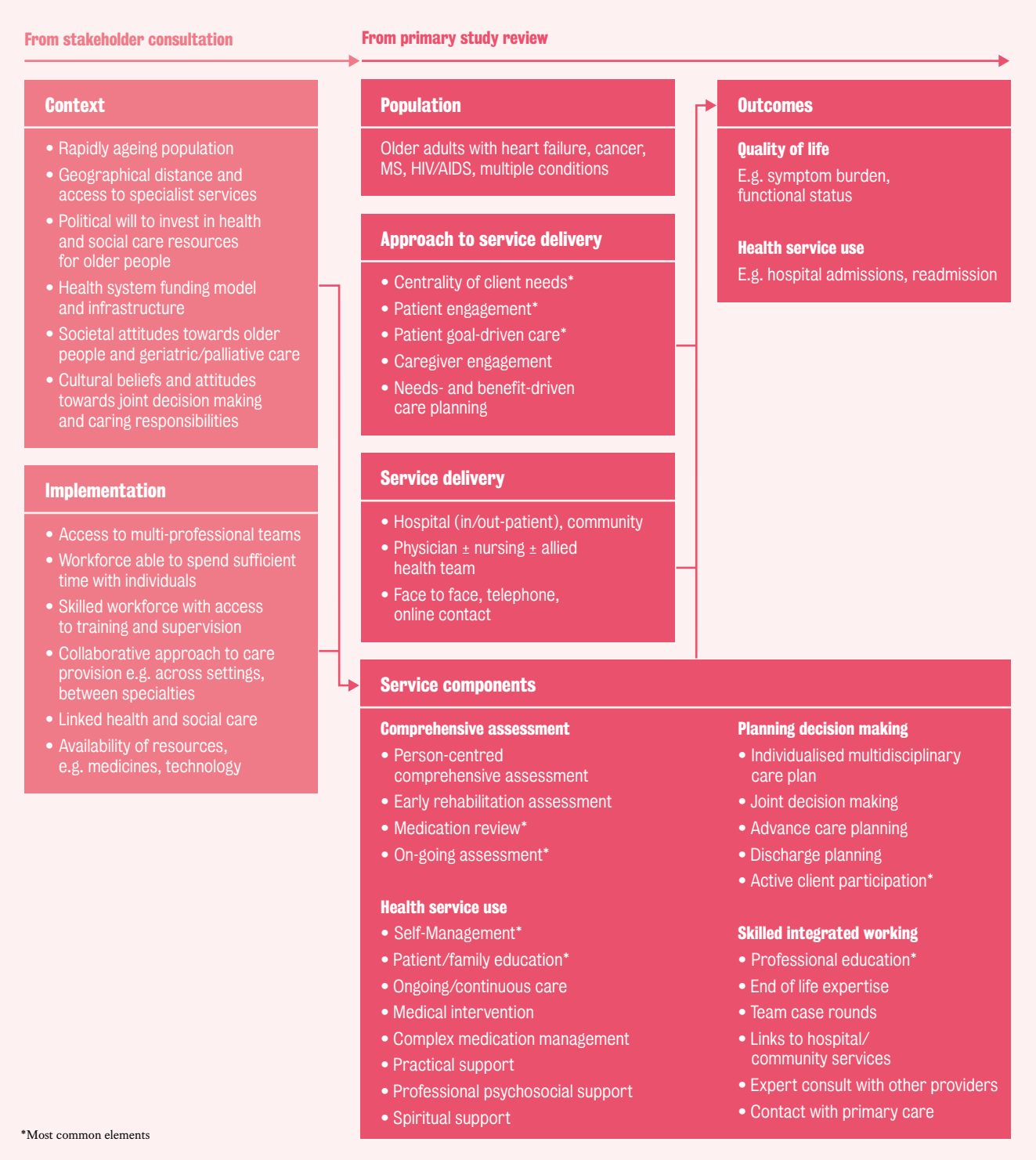
Ageing populations are a global phenomenon. Health and social care services worldwide need to support ageing populations to live well with advanced progressive conditions while adapting to functional decline and finitude. Using a tertiary systematic review, we aimed to identify and map common elements of effective geriatric and palliative care services and consider their scalability and generalisability to high, middle and low-income countries (Bayly et al. 2021). We used a staged, iterative process to develop a 'common components' logic model and consulted experts in geriatric or palliative care from high, middle and low-income countries on its scalability. The review included 78 studies (59 geriatric and 19 palliative care) spanning all WHO regions with data available from 17 739 participants. Common service elements (≥80% of studies) included collaborative working, ongoing assessment, active patient participation and self-management, and patient/family education. Effective services incorporated patient engagement, patient goal-driven care, and the centrality of patient needs (Figure 5.7). The final logic model combines elements of effective services to achieve optimal quality of life and health service for older people with advanced progressive conditions. The model transcends best practice in geriatric and palliative care and applies across the care continuum, from prevention of functional decline to end-of-life care.

With advancing age, adults increasingly live with frailty and multiple conditions. The Optimising palliative care for older adults (OPTCare Elderly) study was a randomised mixed method trial that demonstrated the effectiveness and cost-effectiveness of community-based short-term integrated palliative and supportive care for older people (n=50) with chronic noncancer conditions compared with usual care (Evans et al. 2021). This novel study demonstrated an effective service level intervention to provide specialist palliative care to adults severely affected by frailty and multiple conditions. The intervention comprised integrated person-centred palliative care delivered by multidisciplinary palliative care teams working with general practitioners and community nurses. This built on earlier development work (Bone, Morgan, et al. 2016; Bone, Gao, et al. 2016). The trial main outcome was change in five key palliative care symptoms (pain, breathlessness, patient anxiety, drowsiness, and constipation) from baseline to 12-weeks. Symptom distress reduced with decreased costs from the intervention compared with usual care, demonstrating cost-effectiveness. Qualitative interviews with patients (n = 19) and caregivers (n = 9) demonstrated themes about the value of the intervention of 'Little things make a big difference' with optimal management of symptoms and 'Care beyond medicines' of psychosocial support to accommodate decline and maintain independence. This is a clinically effective way to integrate specialist palliative care with primary and community care for older people with chronic conditions. Further research is indicated to examine its implementation more widely for people at home and in care homes.

Functional outcomes and cost efficiency of rehabilitation

The UK Rehabilitation Outcomes Collaborative (UKROC) was established in 2008 as a national clinical database and clinical registry for patients with complex rehabilitation needs undergoing specialist rehabilitation. The work was originally funded by a NIHR Programme Grant for Applied Research and has received ongoing funding from NHS England (NHSE).

Figure 5.7 Common components logic modelling detailing effective service delivery models for older people with advanced progressive conditions (Bayly et al. 2021)



All Level 1 (tertiary) and Level 2 (district) specialist rehabilitation units in England report mandatory data to the UKROC, encompassing 75 services. The central database has over 75,000 collated episodes. This has created a rich source of information to inform policy development and planning of services and to track the progress of individual patients towards rehabilitation and recovery. The database provides the only accurate source of costing information, and NHSE now relies on this for its published prices ("2023/25 NHS Payment Scheme" 2023).

Seminal publications from analyses of this dataset have demonstrated that rehabilitation is not only cost effective (as a result of improved independence), but also highly cost-efficient. On average the costs of a rehabilitation are recouped within 18 months from savings in the cost of care (Turner-Stokes, Williams, et al. 2016), and the savings accrued over a patient's life-time amount to between £¾ -1 million per patient, making rehabilitation one of the most cost-efficient interventions in healthcare (Turner-Stokes, Bill, et al. 2016).

In this 3 year period, further analyses led by King's have demonstrated the effectiveness and cost efficiency of rehabilitation for multiple sclerosis (Turner-Stokes et al. 2020), spinal cord injury (Turner-Stokes et al. 2021), and prolonged disorders of consciousness (Turner-Stokes et al. 2022). Even in these more complex or progressive conditions, rehabilitation proved to be highly cost-efficient. On average, costs were recouped within 16 months for multiple sclerosis and 30 months for spinal cord injury. Savings were similar for patients over and under 65 and for both traumatic and non-traumatic spinal cord injury. In all conditions, however, the most dependent patients were the most cost-efficient to treat by about 6-fold. This is an important finding as in many countries these highly dependent patients would not be accepted for rehabilitation.

International research strengthening integration of palliative care in health systems

Community-based HIV care in Ghana

As part of her PhD work, Dr Mary Abboah-Offei used systematic review and qualitative interviews to develop a novel community-based enhanced care intervention to improve person-centred outcomes for people living with HIV in Ghana (Abboah-Offei et al. 2021; Abboah-Offei et al. 2020a). The intervention was tested in a feasibility mixed method cluster randomised controlled trial (Abboah-Offei et al. 2020b). The trial enrolled 60 people living with HIV (30 allocated to each arm). The findings indicate potential effect on improved person-centred outcomes, medical outcomes in HIV, patient experience, and staff empathy. Qualitative interviews revealed general acceptability of the intervention. The findings confirmed the feasibility of the enhanced care intervention to improve person-centred outcomes for people living with HIV and that a full trial is warranted.

Primary palliative care in Malawi, Zimbabwe, and Ghana

The Multimorbid Ageing Primary Palliative Care (MAP-Care) study, funded by the Medical Research Council, aimed to develop and test the feasibility of a model of person-centred care for older people with multiple serious conditions, delivered within primary care in Sub-Saharan Africa. Importantly, the model needed to be feasible within available resources, acceptable for patients and families, and deliverable within staff workforce capacity.

To develop the intervention, our team established an African patient and public involvement palliative care network to inform research procedures and dissemination throughout the study. We engaged primary care staff, patients, and family members and identified views of costs, barriers, facilitators, and necessary support to achieve primary person-centred palliative care for older adults with multimorbidity. We then conducted Theory of Change workshops in each country and developed process maps for the novel model suitable for older people in primary care to construct a person-centred logic model of primary palliative care. Key components included buy-in, resources, training, awareness, treatment and care, immediate outcomes, long-term outcomes, and impact.



Figure 5.8. Contributors to the Theory of Change workshop in Zimbabwe



Figure 5.9. Theory of Change workshop in Ghana



Figure 5.10. Healthcare professionals' training in Ghana

Having co-developed the new model of care, we then conducted training and feasibility testing. Training was attended by health professionals in Ghana (n=12), Malawi (n=12), and Zimbabwe (n=15) and community health workers (n=10), combined with weekly follow-up mentorship sessions (face-to-face, Zoom and WhatsApp). The training focused on person-centred communication, principles of palliative care, and pain and symptom management. A poster was designed to guide health professionals to deliver person-centred communication using the ASK, ASK, TELL, ASK, ASK, PLAN framework displayed as posters in the clinics.

The feasibility study recruited n=36 older people/caregiver dyads in each country, with most patients remaining in the study over four months (Zimbabwe 86%, Ghana 83%, and Malawi 86%). The findings established that it is feasible to recruit and retain older people with serious illness and family caregivers primary care in these settings.

Primary palliative care in Nigeria

Dr Oladayo Afolabi, a nurse from Nigeria, studied and completed his doctoral research which developed and tested the feasibility of an intervention to integrate palliative care with primary healthcare in Nigeria. He developed an African-specific framework to understand the nuanced contextual differences in palliative care needs among patients with serious illnesses (Afolabi et al. 2021). He worked with local stakeholders by interviewing patients living with serious illnesses, their family caregivers, and primary healthcare providers to understand the gaps in care and their expectations within a primary palliative care intervention. The findings highlighted the fearful response of primary healthcare providers to patients living with serious illness leading to referral without engagement (Afolabi et al. 2022). There was also a cycle of distrust within primary healthcare in Nigeria around the management of patients with serious illnesses within primary healthcare. Patients and families distrust the quality of care and competence of the primary healthcare providers, while doctors, nurses, and community health extension workers distrust each other providing care within primary healthcare due to ambiguous role structures. Moreover, tertiary healthcare providers distrust in the capabilities of the primary healthcare providers which leads to fragmented referral systems. Based on this, he conducted two Theory of Change workshop sessions with primary healthcare providers and specialist palliative care providers to develop the integrated palliative care intervention and the intervention training approach.

The intervention adopted a multidisciplinary approach to training to reinforce trust among the healthcare providers. The feasibility of the intervention training was tested among primary healthcare providers from three primary healthcare centres and was perceived as feasible, appropriate, and acceptable. This intervention has the potential to scale up access to palliative care where the need is greatest.



Figure 5.11. Theory of Change workshops in Nigeria

Developing a global practice-based framework of person-centred care

This was a cross-national project delivered in collaboration with University of Cape Town in South Africa, King Hussein Cancer Centre in Jordan, and Mahidol University in Thailand. The team conducted two systematic reviews: One review was led by Dr Alessandra Giusti, as part of her PhD on the meaning of person-centred care in serious illness (Giusti et al. 2020). This review concluded that there's a need for primary data investigating the meaning and practice of person-centred care in a greater diversity of diagnostic groups and settings and a need to ground potential components of person-centred care within broader universal values and ethical theory. Another review was led by Dr Kennedy Nkhoma on the impact of person-centred interventions for serious physical illness in terms of outcomes and costs (Nkhoma et al. 2022). The review concluded that person-centred interventions using self-management have some effects in reducing costs of care and improving quality of life. Technology-based interventions improve self-efficacy but have no effect on quality of life.

These reviews informed the design of a large qualitative study to develop a global practice-based framework of person-centred care (Giusti et al. 2022). This qualitative study incorporated primary data from three countries involving patients with: advanced cancer in Jordan (n=50), their caregivers (n=20), and healthcare professionals (n=20); chronic obstructive pulmonary disease in South Africa (n=22), their caregivers (n=19), and healthcare professionals (n=22); and heart failure in Thailand (n=14), their caregivers (n=10), and healthcare professionals (n=12).

The findings showed specific practical actions that contribute towards delivering person-centred care and highlighted new cross-national domains of person-centredness: interdependency and collectivism; bringing care into the home and community; equity and non-discrimination; addressing health and illness within the context of limited resources; and workforce well-being. The data suggest that patient-centred care requires particular structural features of the healthcare system to be in place, such as professional education in person-centred care values and partnerships with community-based workers. These structures may better enable person-centred care processes, including tailored information sharing and providing genuine opportunities for patients to do the things that matter to them, such as making informed care decisions and sustaining social relationships. Person-centred care must also accommodate a collectivist perspective and support the well-being of the workforce.

Resource-limited settings: Remote consultation in Nigeria and Tanzania (REaCH)

Our team has studied innovations in remote consultations in primary care in Nigeria and Tanzania (REaCH trials), including stepped-wedge trials of training, mobile data allowance, and implementation. The REaCH intervention comprised training and mobile data allowance provision for mobile phones to support remotely delivered primary care in Africa compared with no training and mobile data allowance. This work aimed to estimate the effects of REaCH among adults with non-communicable diseases on remote and face-to-face consultation rates, patient safety, and trustworthiness of consultations.

Two independent stepped-wedge cluster randomised controlled trials enrolled 20 primary

care clusters in Nigeria and Tanzania. Overall, 40 clusters comprising 8776 (Nigeria) and 3246 (Tanzania) patients' open cohort data were analysed (6377 [72.7%] of 8776 females in Nigeria, and 2235 [68.9%] of 3246 females in Tanzania). We found that providing training and airtime resulted in increased remote consulting. In Nigeria, remote consultation increased four-fold with no evidence of a reduction or increase in the rate of face-to-face consulting. In Tanzania, there was no increase in remote consulting where phoning health workers was already encouraged when the trial started. We also found that remote consulting is safe and trustworthy: in both Nigeria and Tanzania there were no changes in prescribing and investigation rates. Trustworthiness scores were also unchanged suggesting that remote care was no more or less trustworthy than face-to-face care. REaCH can be implemented and could improve health-care access (Sturt et al. 2023).

Symptom-led research

At the core of our symptom-led research is assessment to identify symptom distress and interventions to improve and relieve common symptoms in advanced disease. Our research programmes examining individual symptoms or symptom clusters are conducted in the context of the holistic needs of the person. Our goal is to better understand the symptoms experienced by patients with advanced illness and their families, and to discover more effective ways to prevent and manage the impact and distress they cause.

Breathlessness

Breathlessness is a transdiagnostic problem, worsened by social, environmental, and economic problems. The burden of breathlessness on individuals, family, society, and health systems is increasing with population ageing and multimorbidity and amplified by the Covid-19 pandemic. Proactive approaches to management of breathlessness are required to build capacity and resilience within health care systems, especially given rising health and social care costs and workforce challenges.

Clinical management of breathlessness is challenging; optimal pharmacological treatment of the underlying disease is the first step. Even so, disease specific management alone does not guarantee symptom control. Breathlessness increases with disease progression, resulting in poor quality of life, increased disability, and high health and social care costs.

We have shown that face-to-face delivered breathlessness supportive services (BSS), which focus on education and non-pharmacological approached to chronic breathlessness self-management, improve breathlessness and symptom control in patients with advanced disease (Brighton et al. 2019; Higginson et al. 2014). Moreover we have demonstrated that BSS models are both cost effective and highly valued by patients (Yi et al. 2022). Traditional face-to-face clinical consultations as standard are being re-examined, and online services may offer one possible solution. Our research highlighted that the Covid-19 pandemic has increased the acceptability, use, normalisation, and value of the internet for many patients with chronic breathlessness due to advanced respiratory disease. We have demonstrated that individuals living with chronic breathlessness due to advanced disease with internet access are willing to use online breathlessness self-management interventions, if available (Charles C Reilly 2022).

Working with patients living with Chronic Breathlessness, Dr Charles Reilly and colleagues at the CSI developed SELF-BREATHE. SELF-BREATHE provides patients with education and non-pharmacological self-management interventions targeting breathlessness during daily life and at the point of crisis. A feasibility randomised controlled trial between February 2021 and 2022 demonstrated that SELF-BREATHE is feasible to deliver, acceptable, and valued by users. Patients reported that SELF-BREATHE helped them during daily life and during breathlessness crisis. Dr Reilly has been awarded a NIHR Advanced Clinical Academic Fellowship, as part of which he will testing if SELF-BREATHE improves patients' breathlessness in a multi-centre randomised controlled trial.

The BETTER-B project (www.betterbreathe.eu) focuses on breathlessness that persists despite optimal treatment of the underlying disease, usually referred to as chronic or refractory. New treatments for chronic breathlessness are urgently needed as there is currently no widely licensed drug. The overall objective of the BETTER-B project is to test whether mirtazapine, a drug currently used to treat depression, is an effective and cost-effective medicine for the relief of patient-reported chronic or refractory breathlessness in patients with chronic obstructive pulmonary disease (COPD) and interstitial lung diseases (ILD). Concurrently, the project maps and compare views, usual prac-

"Covid-19 and lockdown has driven lots to use the internet. You know, the grandchildren are teaching grandparents, "This is how to use your phone," and because people are having to buy things online, I think it wouldn't be that long before there wouldn't be anyone left who doesn't know how to use a mobile phone or computer".

Female, COPD, 71–80 years

"I started to see the benefits of how to control my breathing when moving around and walking ... I'm now above 5,000 steps a day. It takes commitment from you to take part but is so very worth it. I know I can't be cured but it has certainly helped me in controlling my breathing and my mental health."

Male, ILD, 51–60 years

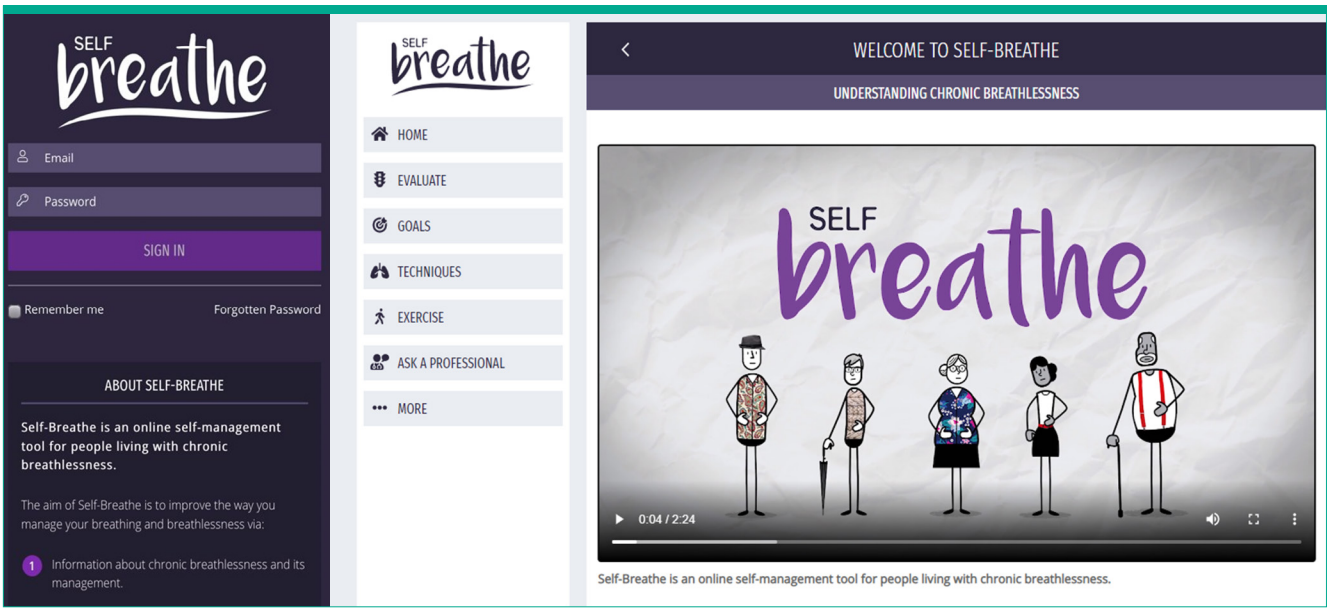


Figure 6.1. SELF-BREATHE mobile app and online interface

tice, and experiences of palliative and respiratory clinicians across Europe on the main medications to alleviate breathlessness in COPD and ILD. BETTER-B also produces European guidance on the management of breathlessness in the form of a Practice Review in Palliative Medicine, seeks to better understand patient and caregiver experiences with the treatment, and disseminate information on best practice.

A Europe-wide survey of respiratory and palliative care physicians to explore current management of chronic breathlessness and to determine the influence of practice guidance on management has been completed (Krajnik et al. 2022). The survey included 450 responses and found a varied approach to breathlessness management across specialties, across and within diseases. People are receiving different levels of care based on where they are treated and the disease that they have. Some people may be seen by a respiratory specialist, while others may be treated by palliative care specialists. We have successfully completed recruitment into the BETTER-B trial with a total of 225 patients and 75 caregivers enrolled from the UK, Europe, and Australia, which represents the largest trial of mirtazapine for chronic breathlessness in our patient population. We have also carried out interviews with 23 patients and 8 caregivers from across the UK and Italy to understand their experiences of taking the trial medication. Our findings will help guide and inform clinical practice and policy.

Frailty in chronic respiratory disease

Frailty is a multidimensional syndrome characterised by decreased reserve and diminished resistance to stressors. If a person is living with frailty, their overall resilience is impacted, meaning they will probably find it harder to recover from medical issues. People living with long-term lung conditions, like COPD, are twice as likely to develop frailty as people without a lung condition (Maddocks et al. 2017). Evidence suggests that exercise-based interventions such as pulmonary rehabilitation are successful in supporting people with frailty and COPD, so it plays an important role in improving outcomes for this group. And yet, many people with COPD and frailty face challenges when it comes to undergoing the pulmonary rehabilitation programme prescribed to them. Improvements to pulmonary rehabilitation are needed to ensure it's accessible for everyone.

Our team have recently tested a new approach to adapt pulmonary rehabilitation for people with COPD and frailty by integrating Comprehensive Geriatric Assessment alongside their rehabilitation programme (Brighton et al. 2021). The Breathe Plus feasibility trial builds on our growing understanding of the needs of people living with COPD and frailty and brings together elements of best practice from both respiratory and geriatric care. Early findings

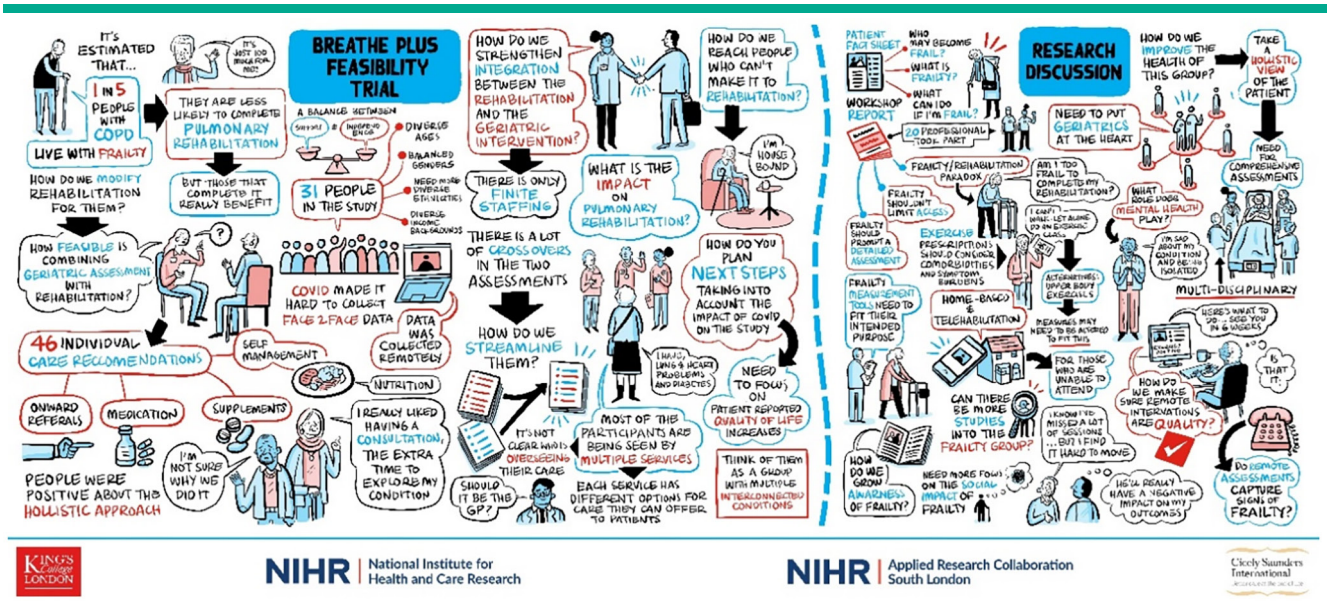
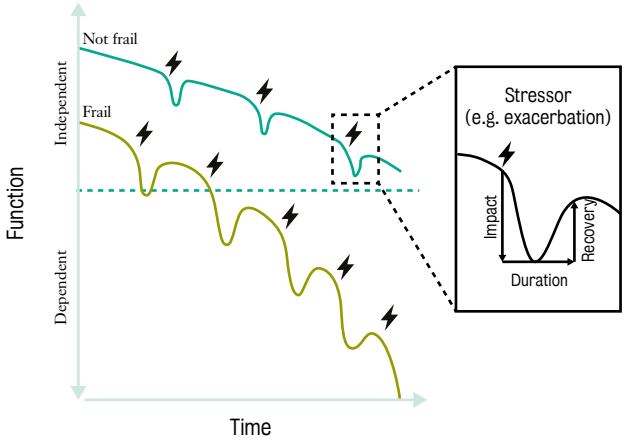


Figure 6.2. Infographic from Breathe Plus results interpretation workshop

from the trial suggest that the Comprehensive Geriatric Assessment is acceptable and potentially a valuable addition to the support of people with COPD and frailty. However, it was also challenging to implement Comprehensive Geriatric Assessment alongside their rehabilitation (Figure 6.2). The team are now exploring other avenues for connecting people with COPD and frailty with geriatric expertise, both within and beyond the rehabilitation context.

Our work supporting people with respiratory disease and frailty has also influenced outputs from international respiratory societies, for both professionals and people living with respiratory disease. Our researchers co-led a European Respiratory Society Statement on Frailty in Chronic Lung Disease (Osadnik et al. 2023), and an American Thoracic Society Workshop Report on Pulmonary Rehabilitation for people with Respiratory Disease and Frailty (Maddocks et al. 2023), both of which incorporated findings from this research (Figure 6.3). Our team also worked with people affected by lung disease to create a patient-facing fact sheet on frailty (Brighton et al. 2023). Together, these activities have ensured our findings will inform evidence-based approaches to supporting people with respiratory disease and frailty.

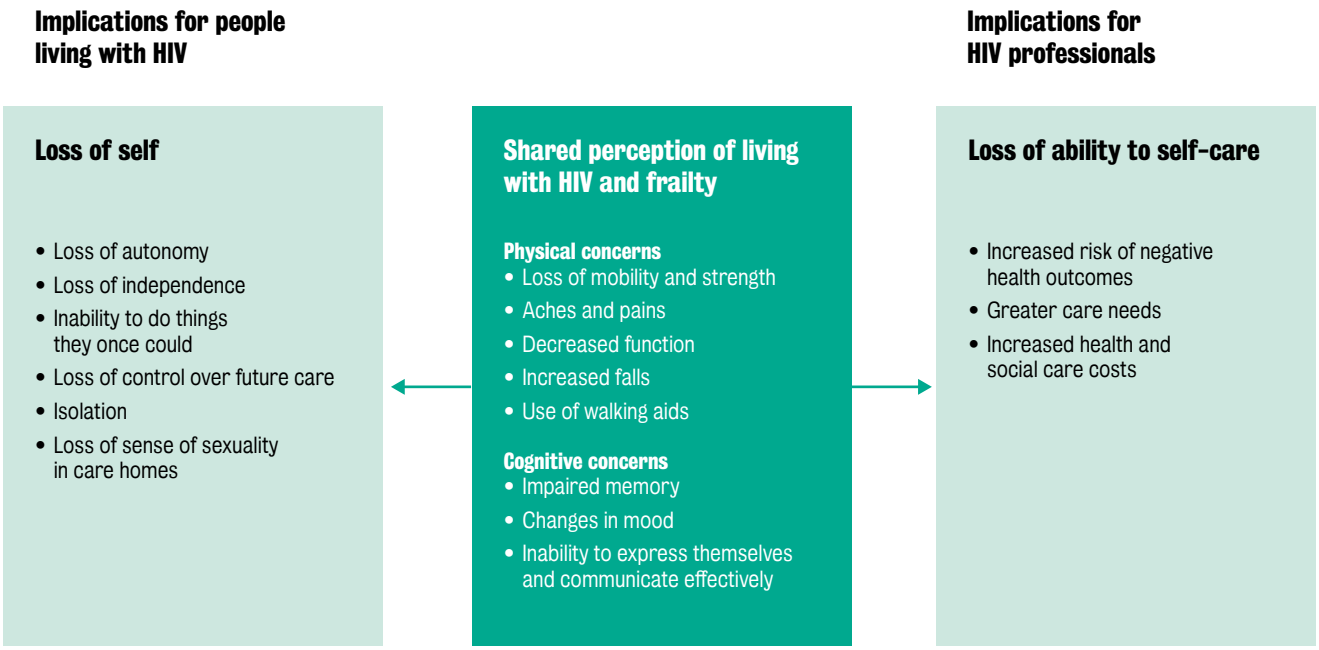
Figure 6.3. Excerpt from the European Respiratory Society Statement on Frailty in Chronic Lung Disease



Symptom burden in people living with COPD

The CSI's research exploring the impact of physical and psychological symptoms in patients with COPD extends to international settings. To determine the prevalence and burden of symptoms in people living with COPD in South Africa and determine predictive factors of high symptom burden, we recruited 387 people living with COPD from primary care centres in Western Cape, South Africa to conduct a cross sectional survey. In multivariate analysis, we found that global, psychological, and physical symptom distress were all individually associated with increased impairment

Figure 6.4. Perceptions of living with HIV and frailty from the perspective of patients and healthcare professionals



on person's life, decreased ability to perform activities of daily living, and decreased social support (Nkhoma, Farrant, et al. 2023). This highlights the high prevalence and burden of physical and psychological symptoms in people living with COPD and provides strong evidence for integrating person-centred assessment and management of symptoms in primary care settings.

Symptoms associated with HIV

People living with HIV are an ageing population with an increasing prevalence of frailty. Management of frailty requires assessment, communication, and information sharing with patients. However, evidence regarding the meaning of frailty for this population and the acceptability of frailty screening is limited.

We interviewed 45 people living with HIV and 12 HIV professionals (St Clair-Sullivan et al. 2023). Frailty was described as a series of losses around mobility, social inclusion, independence, and mental acuity, which could happen at any age. Regarding language, for people living with HIV, explicitly using the word frail was acceptable during screening when approached sensitively and alongside provision of information and support to slow the progression of frailty. However, HIV professionals described concerns about using the word frail for fear of causing distress or offence. Professionals described frailty in terms of functional deficits, whereas people living with HIV described a loss of personhood. Although there is a clear desire among people living with HIV to be informed of their frailty status, approaching conversations about frailty with understanding and compassion is vital. To gain the most from the screening, it is essential that frailty status is shared alongside a clear plan of actionable steps for care (Figure 6.4).

With colleagues in Brighton, UK, we also evaluated the implementation of frailty screening older people living with HIV. Of 456 people screened, 56 (12%) were identified as frail and 118 (26%) prefrail. People who living with frailty had been living with HIV for longer and had a greater number of comorbidities and medications.

In another project we explored how the experience of living with HIV and chronic pain influences pain beliefs, health-seeking, and pain management in the UK (Baker et al. 2023). Thirty-nine people with HIV and

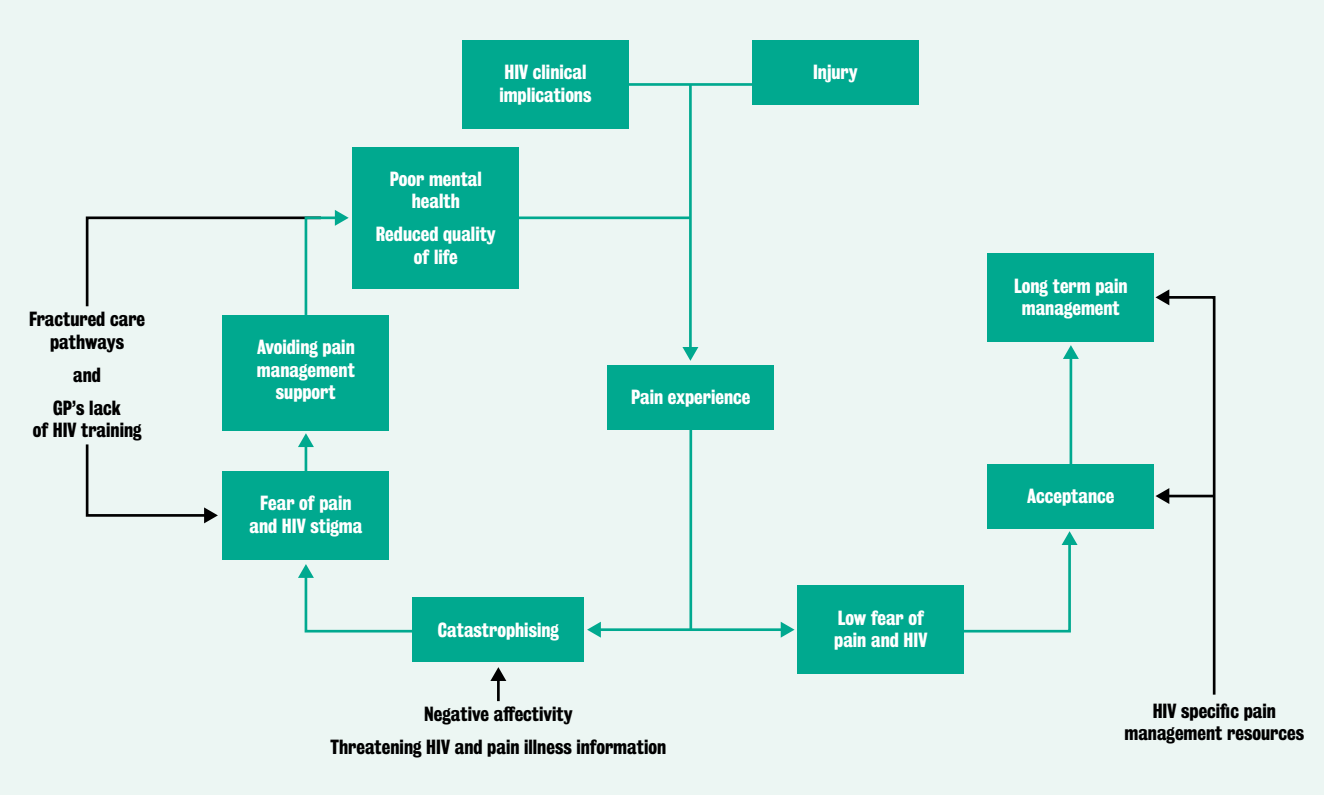
chronic pain participated in focus groups. They described HIV stigma, fractured care pathways, and general practitioners lack of HIV training as barriers to supported pain management. Pain results in poorer mental health and reduced quality of life, which has important clinical implications for HIV treatment adherence. Developing HIV-specific pain resources, activating social networks, and creating pain self-management techniques are potential solutions. We refined the Fear Avoidance Model that introduces a dimension of HIV-specific behaviours that impact people living with HIV who are seeking chronic pain management (Figure 6.5).

Internationally, we studied pain self-management for adolescents living with HIV in Malawi. Malawi has one of the highest HIV prevalence rates globally, and data suggest 27% pain prevalence among adolescents, which is under-reported. People told us they experienced "total pain": physical, psychosocial, and spiritual pain which impacted their daily life activities and preferred group-based self-management approaches facilitated by healthcare professionals or peers. They described using prescribed drugs, traditional medicine, and non-pharmacological interventions, including exercise, as current pain strategies (Nkhoma, Mwalabu, et al. 2023).

Spasticity treatment, rehabilitation, and evaluation

Many people have difficulty controlling muscles following stroke and brain injury. Some are also left with muscle tightness called 'spasticity'. Spasticity is often painful, like a muscle cramp. It can limit mobility and independence and contribute to changes in muscle structure (contractures), skin damage, or pressure sores. Information on the number of people with spasticity is varied, but it has been reported in up to 42% of stroke survivors (about 500,000 people in the UK). Spasticity is a disabling problem limiting many functional activities and rehabilitation progress, but there are solutions and ways to control it.

Figure 6.5. The adapted Fear Avoidance Model for people living with HIV and chronic pain



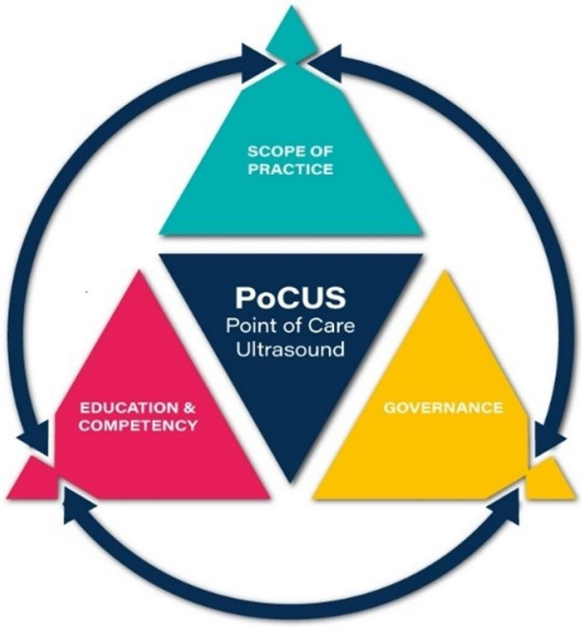
Spasticity and contracture treatment

Botulinum toxin (BoNT) injection is used widely for treatment of focal spasticity to support physical rehabilitation and management interventions (Sutherland et al. 2022). Accuracy of delivery for BoNT injection in spasticity management is important to achieve the best outcome. We have developed international guidance for best practice in the use of ultrasound to achieve this (Zeuner et al. 2017; Ashford, Morris, and Smith 2023). We produced a scope of practice, competency, and governance within a framework to provide a mechanism for increased user access to accurate, safe, and effective focal spasticity treatment.

In a usual practice cohort study, we identified significant improvement in range of movement following treatment for ankle contracture and spasticity in people with complex brain injury and stroke. Treatments included stretch interventions such as serial casting, standing programmes, orthotics (splints), and task practice (functional self-exercise). People were categorised with mild, moderate, or severe contractures. Statistically significant change in range of movement was not seen in the mild category but was in the moderate and severe categories. Improvement in locomotion was noted in all three groups but was most pronounced in the moderate and severe groups. The diagnostic categorisation was useful in identifying management approach and specific treatment and should be used widely to help plan and target care (Ashford et al. 2023).

We have also examined routinely collected therapy dependency data which has allowed us to quantify the impact of spasticity and contracture on therapy inputs, length of stay, functional gains, and costs. People with contractures following acute brain injury stayed on average 31 days longer with an additional mean episode cost of £25,588. Despite this, they made similar overall functional gains resulting in similar long-term savings in the cost of ongoing care. However, they required more therapy time in rehabilitation to achieve similar functional gains, but nevertheless were cost-efficient to treat (Ashford et al. 2022).

Figure 6.6. The Point of Care Ultrasound (PoCUS) framework triangle



A framework for PoCUS. Concept by Dr Mike Smith (Cardiff University UK), created by Dan Molloy (freshwater.media)
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The Abolish Leg Spasticity study and Upper Limb International Spasticity III study conducted with industry partners (Ipsen ltd) have used goal setting and specific outcome measures developed by our team to evaluate functional improvement following spasticity treatment. In the Abolish study, stroke survivors with leg spasticity were treated with botulinum toxin to reduce the spasticity and enable physical therapy. Findings from this study (including 384 patients with lower limb spasticity from 9 countries) show that most stroke survivors were also treated for arm spasticity, and many patients also had significant motor, sensory, communication, and cognitive impairments. For stroke survivors who are still able to walk at least 5 steps, the priority treatment goal was to improve their walking, followed by pain management, and prevention of contractures (Esquenazi et al. 2023).

The Upper Limb International Spasticity (ULIS-III) study is an international, longitudinal study that explored real-life clinical practice in the integrated management of upper-limb spasticity using botulinum toxin-A (BoNT-A) in conjunction with physical therapies. The study provides evidence for the sustained functional

benefit of repeated cycles of BoNT-A. Those patients who continued to receive repeated injections for up to 7 cycles in 2 years showed relevant goal attainment and higher rates of goal achievement related to passive vs active function (86.6% vs 71.4% achievement). Standard outcome measures supported the rates of goal achievement; ratings of pain, involuntary movements, and active and passive function all improved significantly over each treatment cycle. The successful results from ULIS-III highlight the importance of accurate and clear goal setting during BoNT-A treatment to help target clinical intervention and the use of focused outcome measurement (Turner-Stokes et al. 2021).

We have brought these elements together to create and test outcome measurement tools (Turner-Stokes et al. 2022b, 2022a) with a systematic, goal-directed approach to clinical decision-making and treatment planning. We've also developed a preliminary structure for rehabilitation planning in this area of clinical need. Outcome measures include a new tool to measure spasticity-related quality of life (the S-QuoL 6D (Turner-Stokes et al. 2022b, 2022a)). Future work will incorporate this preliminary plan in the Direct-Rehab project which will enable focused rehabilitation and care for people with spasticity to improve provision of the most appropriate treatment.

Person-Centred Outcome Measures (PCOMs)

Palliative Outcome Scale Family of Measures

Palliative Care Outcome Scale (POS) family of measures are validated tools that assess patients' physical, psychological, emotional, and spiritual symptoms, as well as information and support needs. Globally, they are among the most widely used multidimensional measures in advanced illness with a 25-year history of evolution and use (Collins et al. 2015). They are used in over 160 countries in clinical care, audit, research, and training, among people affected by over 15 different diseases (such as cancers, respiratory diseases, neurological diseases) and in multimorbidity. The POS family of measures, including the Integrated Palliative Outcome Scale (IPOS), have validations or translations in 38 languages and have been adapted to new settings, patient groups, and illnesses such as heart failure, dementia, and renal disease.

Most recently, IPOS has been adapted to severe Covid-19 patients to support clinical decisions and to inform case management and monitoring of patients severely ill with Covid-19 (Hocaoglu et al. 2023) as part of a multicentre cohort study of Covid-19 patients seen and treated by palliative care services (www.kcl.ac.uk/research/covpall). IPOS-COV is the first patient-centred measure adapted for severe Covid-19 to support timely management. It is a 14-item brief multi-dimensional tool, adapted for proxy-reporting. IPOS-COV has four clinically relevant subscales: (1) the Breathlessness-Agitation (Agitation, Anxiety and Breathlessness), (2) Gastro-intestinal (Nausea and Vomiting), (3) Drowsiness-Delirium (Drowsiness, Weakness or lack of energy, Confusion or Delirium) and (4) Flu (Sore or dry mouth or throat, Fever, Cough, Shivering, Pain) subscales. Individual item scores can also be used to monitor certain symptoms or identifying predictors of clinical outcomes (Hocaoglu et al. 2023). IPOS-COV is available to download from Palliative care Outcome Scale website (www.pos-pal.org).

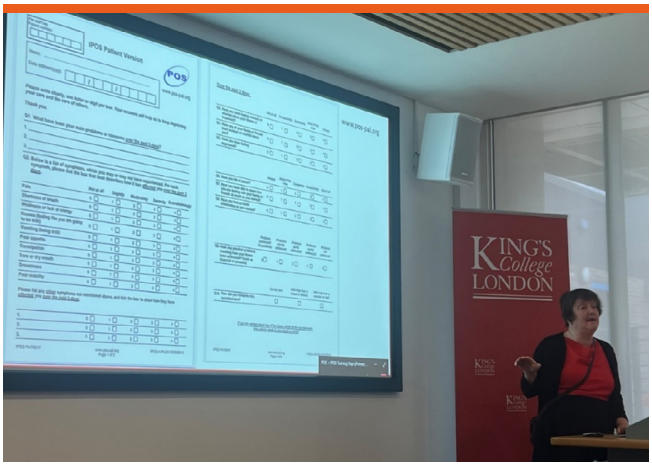


Figure 7.1. Prof Fliss Murtagh presenting at the the annual Palliative Outcome Scale Training Days held 15th and 16th May 2023

In the last three years, the POS Development Team has organised three annual workshops, training and supporting more than 600 clinical and research teams from around the world to use the POS family of measures. The most recent Palliative Outcome Scale (POS and IPOS) Training Days, held on May 15th and 16th 2023, was hosted by the Cicely Saunders Institute at King's College London and the Hull York Medical School. On the first day, we covered essentials in three sessions for those using the POS family of measures in research, health, and social care. POS and IPOS experts as well as clinicians and researchers who use the POS family of measures in their everyday work talked about the history and rationale behind the measures, their value in research, health and social care, and new advances person-centred outcomes research. On the second day, sessions focused on advanced applications, methodological considerations, and implementation.

In the last 3 years, the POS family of measures have been adapted to new cultures and settings such as to Hindi (Bhardwaj et al. 2023), Portuguese (Antunes and Ferreira 2020), and Chinese (Long et al. 2021). Additionally, they have been used in evaluating the relationship between socioeconomic position and symptoms in hospitalised patients seen by specialist palliative care services

POS

www.pos-pal.org

in two large teaching hospitals in London, highlighting how targeting resources to address practical concerns could reduce inequalities (Davies et al. 2023). Researchers from CSI have also used the POS family of measures to understand the symptom clusters, associated factors, and health-related quality of life in patients with chronic obstructive pulmonary disease (Fei et al. 2023). Furthermore, researchers have used artificial intelligence and network analysis to inform responsive person-centred care by identifying phases in patient palliative status through symptoms reported on the POS family of measures (Sandham et al. 2022).

Developing person-centred outcome measures for children and young people with life-limiting and life-threatening conditions

Our commitment to robust person-centred paediatric palliative care outcome measures has driven global advances in this emerging field. We have worked across continents to strengthen



C-POS:UK
Children's Palliative Care Outcome Scale UK

the development and validation of measures for children, young people, and their families.

"The tool helped to improve the relationship between the healthcare workers and the children/caregivers. For example, one respondent came later to complain that the drugs the child had been given were not working and thus needed them changed. Their participation in the pilot got them thinking and to be freer with the healthcare workers."

Health worker (Namisango et al., 2022)

We followed our earlier systematic review, qualitative study, and development work for the Children's Palliative care Outcome Scale African version (C-POS-Africa) with qualitative and cognitive interviews nd an evidence-based mapping exercise. This determined the face and content validity, feasibility, and acceptability of C-POS-Africa in clinical settings in three sub-Saharan African countries(Namisango et al. 2022). Children, family carers, and health workers demonstrated comprehensibility and acceptability of C-POS-Africa and some areas for improvement. Work has begun to further refine and validate C-POS-Africa, the first outcome measure for children and families facing life-limiting or -threatening illness.

Additionally, we have advanced our work on development, validation, and implementation of the UK version of the C-POS (C-POS:UK). Our systematic review to enable children and young people to participate in valid and reliable self-reporting of their health outcomes (Coombes et al. 2021) has informed our development of the C-POS:UK tool. Recall period, response scale format, and administration modality were considered, and eight recommendations were made for future development of self-reported outcome measures for children and young people.

Our qualitative interview study, which involved 106 children, parents, siblings, and health professionals, identified key symptoms, concerns, and care priorities of children with life-limiting conditions and their families (Coombes et al. 2022), and specific design and administration preferences (Coombes et al. 2023). We identified physical, psycho-emotional, social and practical, and spiritual and existential concerns. Additionally, the theme of 'normality' was identified which cross-cut all other themes (further discussed in the Living and dying in society section) (Coombes et al. 2022). Children expressed the importance of having someone from the healthcare team to talk to during or after measure completion, seen in Figure 7.2 (Coombes et al. 2023).

We undertook work to gain expert stakeholder consensus on the items for inclusion in the tool in two phases, alongside consultation with a Young Person's Advisory group (Coombes et al. 2023). We began with a Delphi survey (N=82) and found that agreement increased, indi-

Figure 7.2. Design and administration preferences of person-centred outcome measures of children and young people with life-limiting and life-threatening conditions mapped on to COSMIN properties of content validity, feasibility, and acceptability

PROM design aspect	Relevance	Comprehensibility	Acceptability	Feasibility
Recall	A few days to a week so focus is on current symptoms	A few days to a week was understood by all participants	Long recall periods less acceptable, as participants did not want to dwell on past periods of ill health	Most participants were able to recall up to the past week
Response format	Visually appealing response formats most relevant	All participants understood the faces scales, pain block scale and colour scale; those ≥ 8 years could use a numerical rating scale	Visually appealing response formats were most acceptable; use of emojis to anchor Likert scales; colours less acceptable, as traffic lights often used for behaviour management in schools; colour block scale least acceptable	≥ 5 years could use faces scales; ≥ 8 years could use a numerical rating scale
Measure administration	Adults assumed computerised measures would be more relevant to CYP; some CYP preferred paper based	All participants understood how to use iPad/ computerised and paper and pencil-based measures	Most participants found computerised measures acceptable; a small number expressed a preference for paper and pencil	Option for both computerised and paper and pencil measure should be given
Measure length	Not applicable	Not applicable	10 questions optimal	10 questions maximum
Completion time	Not applicable	Not applicable	5–15 min optimal	No more than 10 min, due to concerns regarding illness fatigue and attention

Source: Coombes et al. 2023

cating movement towards consensus (Kendall's W = 0.17 to W = 0.61), but professionals prioritised physical symptoms, whereas parents prioritised psychosocial and practical concerns. Members of the Young Person's Advisory Group (N=22) selected items similar to items prioritised by adult participants, although they also prioritised items related to living a 'normal life'. This demonstrates the importance of involving all stakeholders in priority setting for person-centred care. An item generation meeting was then held with bereaved parents, academics, and clinicians.

We worked together to agree priorities (Figure 7.3) for five developmentally appropriate child and proxy-reported versions of C-POS:UK, in preparation for psychometric validation.

Work to develop an implementation strategy for the C-POS:UK has also begun. We conducted a systematic review to identify barriers and facilitators to implementation of child-centred outcome measures in paediatric healthcare settings globally (Scott et al. 2023).



Strategies to support successful implementation of the C-POS:UK tools into routine care for children and young people with life-limiting and life-threatening conditions were identified, including education and training as to what outcome measures are, what benefits they have, and how to use them.

We have worked to ensure that we involve children in a meaningful way throughout this research. Our engagement with our bereaved

Figure 7.3: Domains and agreed items for C-POS:UK

Child symptom and concern items (self-reported or proxy-reported)	
Domain	**Question item**
Physical	Pain
	Other symptoms
Social/practical	Being able to ask questions
	Being able to undertake usual activities
Emotional/psychological	Worry
	Sharing feelings
	Being able to do things you enjoy
Spiritual/existential	Being able to do things you enjoy
	Living life to the fullest
Parent/carer items	
Physical	Getting enough sleep
Social/practical	Access to information about child's condition
	Support needed to care for child
	Support to plan for future care
Emotional/psychological	Impact of child's condition on family
Spiritual/existential	Support to plan future care

Source: Coombes et al. 2023b



Figure 7.4. NIHR ARC Blog written in partnership with C-POS bereaved parent PPI members

PPI members (Figure 7.4) alongside our continued work with Young Person's Advisory Groups in both London and Leeds helps to design our studies in a way that best meets the needs of children with life-limiting and life-threatening conditions and to contextualise our findings to ensure they are meaningful and can drive change.

Work has begun to develop a version of C-POS for children and families in Turkey and Jordan, including those who are refugees or displaced people (Boufkhed et al. 2023). We conducted in-depth qualitative interviews with 104 stakeholders (further discussed in the Livingand dying in society section). Five key domains of concerns and priorities were identified: (1) Physical pain and symptoms; (2) Psychological concerns and needs; (3) Spirituality, uncertainty over the future; (4) Negative impact on social life; and (5) Burden on caregiver and their families. This work will help to inform further development of child- and family-centred outcome measures in the Middle-East region, where managing complex medical needs is balanced with limited resources.

We support the adaptation and testing of POS measures in different settings, provided partners follow the standard POS guidelines. We have started work with partners across several countries in East Asia to culturally adapt C-POS:UK.



The IPOS for Dementia

People with dementia typically live with multiple chronic conditions, meaning that they may have high levels of palliative care needs throughout their dementia trajectory. Even so, they continue to have poor access to palliative care and frequently are only referred when dying is imminent. The IPOS-Dem is a person-centred outcome measure to reduce distress and improve wellbeing of people with dementia and their family carers through systematic and holistic assessment and early identification and management of palliative care needs. It is easy-to-use in routine care by non-specialist practitioners and scalable across health and social care settings (Kinley et al. 2019). As such, the IPOS-Dem addresses an important gap and urgent need to provide palliative care for the growing numbers of people living with dementia and experiencing distressing unmet palliative care needs.

Originally developed for the care home setting, our research confirmed acceptability and feasibility for care home staff and ensured that IPOS-Dem incorporated the most common symptoms and concerns affecting people with dementia and multi-morbidities (Ellis-Smith et al. 2016 first published on October 25, 2016 doi:10.1177/0269216316675096; Ellis-Smith et al. 2018). Since its publication in 2016, IPOS-Dem has had international impact. Teams in Germany (Hodiamont et al. 2021), Italy, Sweden (Martinsson and Sahlén 2022), and Switzerland have translated and cross-culturally adapted the IPOS-Dem, whilst Dutch, Japanese, Mandarin, Persian, Swiss French, and

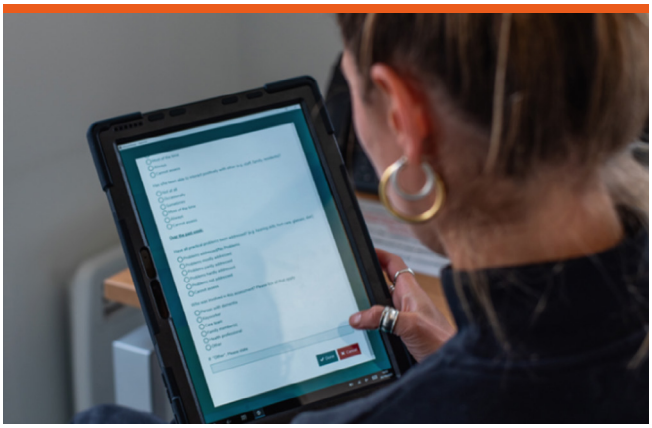


Figure 7.5. A researcher uses the IPOS-Dem mobile application

Thai are underway. In the UK, multiple settings have implemented IPOS-Dem into their care of people with dementia including care homes, community teams, and specialist palliative care teams. The IPOS-Dem with implementation resources, feature in an NHS palliative dementia toolkit, the NHS England Midlands – Dementia Palliative Care Service Improvement & Delivery Toolkit, which was launched regionally and nationally in 2023 ('The Dementia Palliative Care Service Service Improvement and Delivery Toolkit: How to Guide' 2023).

IPOS-Dem forms a key component of the largest palliative dementia grant awarded in the UK. Empowering Better End of Life Dementia Care (EMBED-Care) is a five-year programme grant funded by the Economic and Social Research Council/National Institute for Health Research. The EMBED-Care programme develops IPOS-Dem as a digitally-delivered palliative dementia intervention across settings and tests it in a feasibility and pilot trial (Sampson et al. 2020).

Positive outcomes: A novel patient-reported outcome measure for people living with HIV

Background

From diagnosis onwards, people living with HIV have complex physical, psychological, and social needs and poorer health-related quality of life (HRQoL) than the general population. The World Health Organization (WHO)

Figure 7.6. Model of current standard HIV care

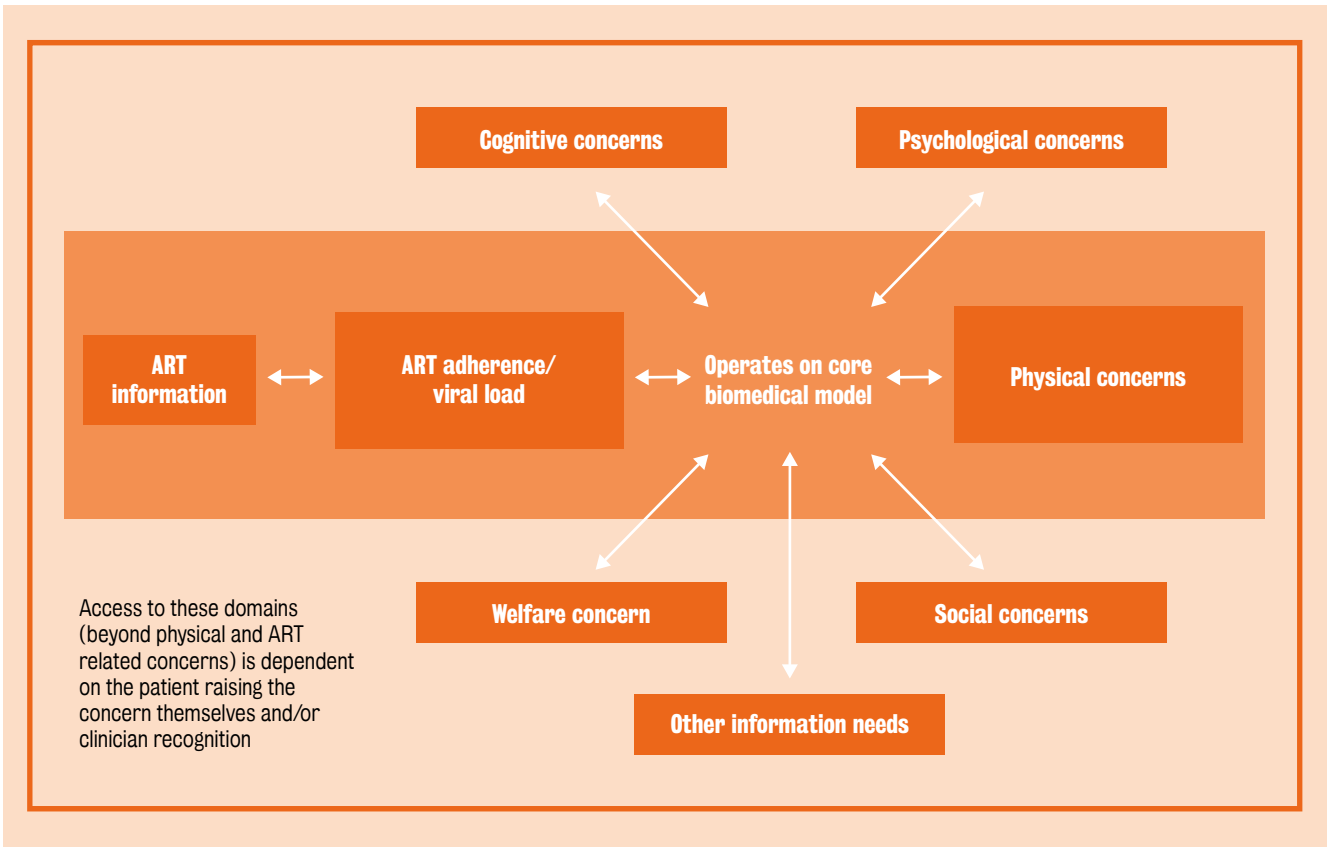
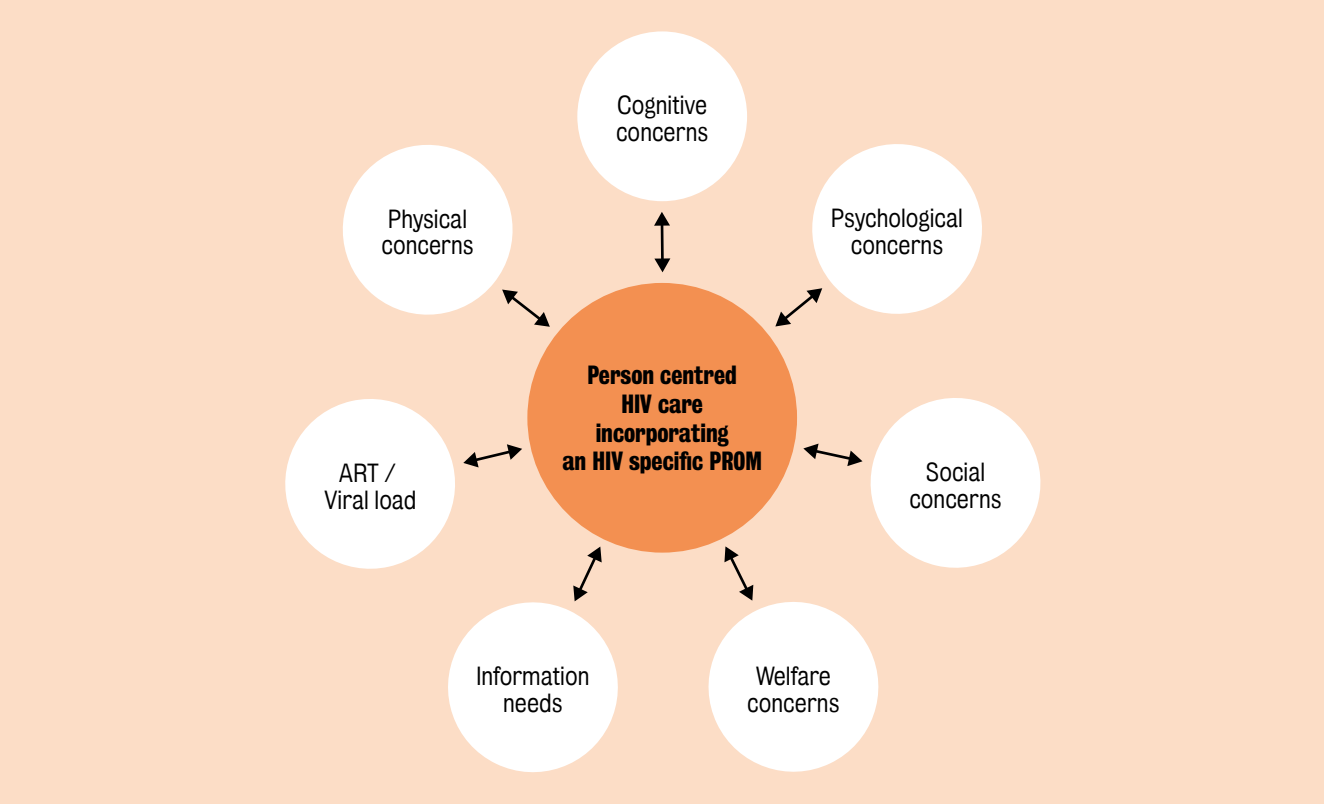


Figure 7.7. Person-centred care incorporative an HIV-specific PROM



recognises that, particularly for long-term conditions, care must respond to the individual's preferences and concerns and be coordinated around their needs. People living with HIV receiving out-patient care perceive that care frequently does not address the broader issues that matter to them, including physical and psychosocial concerns (See Figure 7.6) (Bristowe et al. 2019). One potential solution is the 'personal outcome approach' incorporating person-centred care alongside valid patient-reported outcome measures (PROMs). While PROMs for single-dimension outcomes exist (e.g. depression, stigma or HRQoL) there is no brief, patient-centred PROM with face and content validity that reflects the range of outcomes relevant to people living with HIV to drive and evaluate routine care (Kall et al. 2020). The Positive Outcomes study aims to develop and validate a novel brief patient-centred PROM for use in routine HIV care.

Development of the Positive Outcomes PROM

Funded by the British HIV Association and St Stephen's AIDS Trust, the development of the novel Positive Outcomes HIV PROM was undertaken following the COSMIN (COnsensus-based Standards for the selection of health Measurement INstruments) taxonomy and guidance for relevance and comprehensiveness of PROMs to ensure content validity and the Rothrock guidance on the development of valid PROMs in three phases: (1) gathering input from key stakeholders to define concepts and develop a conceptual model; (2) item generation; and (3) item improvement. Following identification of the need for a new PROM, a PROM development steering group was created to guide the process, including: four people living with HIV, four health services researchers, and five HIV healthcare professionals.

1. Gathering input from key stakeholders

The first stage of PROM development was to gather information from key stakeholders, to define concepts and form a conceptual model to underpin the item generation, and ensure face and content validity. A cross-national multicentre qualitative interview study (in London, Brighton, and Dublin) was carried out with adults living with HIV (n=28), HIV health care professionals, (n=21) and HIV commissioners (n=8). Interviews were analysed using thematic and framework analysis. Participants described

concerns related to living with HIV across six domains: physical (e.g. pain and gastrointestinal symptoms), cognitive (e.g. memory and sleep), psychological (e.g. anxiety and depression), social (e.g. isolation and intimacy), welfare (e.g. finances and fears regarding change of immigration status), and information (e.g. long-term outcomes) needs. Themes were highly interrelated, impacting across domains of need (e.g. physical and cognitive problems impacting on psychological and social wellbeing). Perceived benefits of using PROMs in routine HIV care included improved person-centredness and patient empowerment, fewer missed concerns, increased engagement with services, and informed planning of services (see Figure 7.7). Potential challenges included heterogeneity of people living with HIV, literacy, and utility for those who struggle to engage with care (Bristowe et al. 2019).

2. Item generation

Item generation involved a full day item generation meeting attended by the PROM development steering group where a summary of the domains and draft items was agreed upon, followed by refinement of the items for inclusion and a second round of the item generation meeting. The prototype 23 item Positive Outcomes HIV PROM was then finalised and formatted for cognitive testing and item improvement.

3. Item improvement

Cognitive testing of the Positive Outcomes HIV PROM was conducted. Recruitment continued until thematic saturation was achieved and no new problems or concerns with the measure emerged from subsequent interviews (achieved after 6 interviews with people living with HIV). All cognitive interview data were reviewed by the research team, and consensus was reached regarding whether the change should be implemented. The final version of the PROM was circulated to the PROM development steering group and agreed (Bristowe et al. 2020).

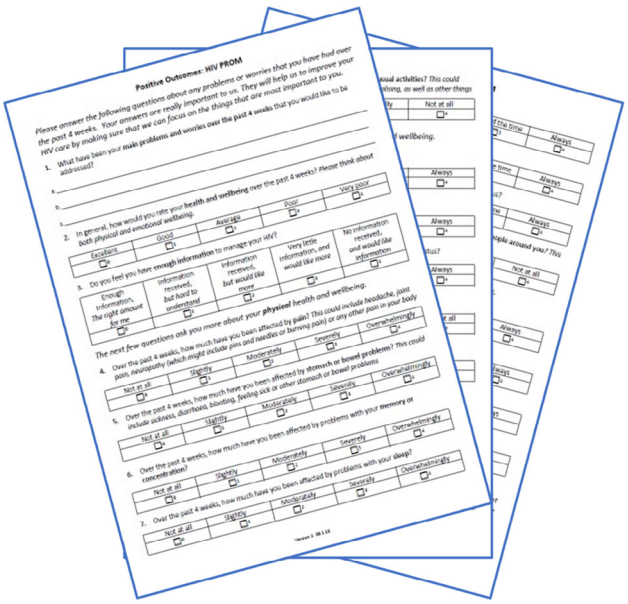
The Positive Outcome HIV PROM

The 23 item PROM opens with one open-ended question offering the individual the opportunity to report their three main priorities for focus within their HIV consultation, then 22 questions with standard Likert (five point) response scales. The first of these is a global assessment of wellbeing, and the remaining 21 ask about specific constructs within the 6 domains of need. The completed PROM therefore highlights three priority areas for discussion within the consultation and gives a score of 0–88 for problems and concerns (the higher the score, the higher the burden of symptoms and concerns) (see Figure 7.8).

Validation

The validation study was performed as a sub-study within the EmERGE programme which co-designed, implemented, and evaluated a digital health pathway for people living with stable HIV in five European cities (Antwerp, Barcelona, Brighton, Lisbon, and Zagreb). Data from 1392 adults living with HIV were included in the validation study. The Positive Outcomes questionnaire comprises four domains: factor 1, 'emotional wellbeing'; factor 2, 'interpersonal and sexual wellbeing'; factor 3, 'socioeconomic wellbeing'; and factor 4, 'physical wellbeing'. These collectively measure the construct 'symptoms and concerns' among adults living with HIV. Results of this study demonstrate that the Positive Outcomes measure has sound psychometric properties (validity, reliability, and responsiveness)

Figure 7.8. Positive Outcomes HIV PROM



for measuring the construct 'symptoms and concerns' among adults living with HIV (Harding et al. 2022).

Impact

Positive Outcomes has been included in the national survey run by the UK Health Security Agency and Office for Health Improvement and Disparities (Positive Voices) which goes to all people in the UK attending NHS HIV services. It has also been included in the forthcoming WHO report on living well with HIV.

Next steps

We have won a large £1.58m Gilead funded grant to implement Positive Outcomes in routine practice in UK/USA demonstration sites (commencing 2024) and to test the impact on outcomes at each facility.

Goal attainment scaling – a person-centred outcome measure for rehabilitation

Originally developed in the 1960s, goal attainment scaling (GAS) represents an approach for assimilating an individual's own priority goals for treatment into a single overall measure of goal attainment. However, it can be time-consuming to apply. Since 2005, Prof Lynne Turner-Stokes and Dr Steve Ashford have spearheaded a drive to make GAS simple enough to be used by clinicians in routine clinical practice to reflect each patient's own priority goas for rehabilitation and the extent to which the intentions of treatment were achieved (Turner-Stokes 2009). "The GAS-Lite" is shown to be valid and reliable compared to the original GAS and has since been widely taken up both in clinical practice and as an outcome for research.

The Upper Limb International Spasticity (ULIS) programme is a large international series of cohort studies that examines the use of botulinum toxin for management of spasticity in real life clinical practice (Turner-Stokes et al. 2019) that has evolved in three stages since 2005. Because of the diversity of patients, practices, and individual goals for treatment on this area, GAS was adopted as the primary outcome measure. It was shown to be more sensitive than standardised measures to demonstrate the functional benefits of treatment in the areas that matter most to patients.

However, a valid criticism of GAS is that it does not provide comparable data. For the third stage of the programme (ULIS-III), we developed a more structured approach called the GAS Evaluation of Outcome in Upper Limb Spasticity (GAS-eous) tool (Turner-Stokes et al. 2021). The GAS-eous is constructed around the six main goals areas for treatment that have been identified through the programme. Its introduction immediately improved the quality of goal setting, even by clinicians who were previously unfamiliar with the technique. Used alongside a battery of six standardised measures that are applied according to the chosen goals for treatment, this hybrid approach has enabled the collation of comparable data that are still driven by the patient's own priorities for treatment.

Using this approach across 14 countries, ULIS-III (Turner-Stokes et al. 2021) is the largest international longitudinal study to examine the effects of repeated injections of botulinum toxin in clinical practice. Applying GAS as the primary measure, it demonstrated the sustained benefits of treatment over a 2-year period. The rates of goal achievement for using the arm/hand in active function were not only sustained but actually increased across 7 cycles of treatment.

Other structured applications of GAS developed at King's include the development of a structure goal inventory for use in patients with prolonged disorders of consciousness (Turner-Stokes et al. 2020).

Living and dying in society

Societies are changing across the globe. Those who are suffering, have profound disability, or are dying are especially vulnerable. To future-proof palliative care and bereavement care, we study the needs and preferences of vulnerable, disadvantaged, or overlooked groups: children, older people, caregivers, those facing bereavement, and people from minoritised groups. Our findings address important, policy-relevant questions around how to meet the needs of people throughout the life course including children facing life-limiting or life-threatening conditions, the growing ageing population, and those who may be marginalised in their experiences and face poorer outcomes in life, death, and bereavement.

Achieving child-centred care among children with life threatening conditions

Involving children with life threatening conditions and their families in research that informs care is fundamental to ensuring that the priorities of children are meaningfully considered in their care. Our earlier systematic review highlighted low involvement of children in research that will inform their care (Namisango et al. 2019), and we have worked to address this. Our advancing understanding of what is important to these children is linked to our pioneering work in paediatric palliative care outcome measures (further discussed in the Person-Centred Outcome Measures section).

Our qualitative study in the UK, funded by the European Research Council, sought to identify and describe the concerns and priorities of children with life threatening conditions (Coombes et al. 2022). We interviewed 26 children with life threatening conditions, 40 parents and carers, 13 siblings, 15 health and social care professionals, and 12 commissioners of paediatric palliative care services. The interviews demonstrated that all aspects of childhood were impacted by interconnected concerns and care priorities. All stakeholder groups shared concerns regarding burdensome physical symptoms such as pain, infection, and seizures. Children and families spoke about spiritual and existential concerns, but professionals shared that they lacked confidence in discussing these with families. Emotional and psychological concerns, such as the life-altering impact of living with a life-limiting condition, was a concern for all stakeholders.

Impacts on social life were also shared, such as interruptions to attending school and seeing friends. A cross-cutting theme of 'normality' was identified, defined as children's desire to undertake usual activities.

Parents and professionals prioritised practical aspects of care, but children did not identify such concerns, thus demonstrating the importance of, wherever possible, involving children in research and also in decisions about their care. Children in our study wanted to be seen as children first, with their condition coming second to this, reinforcing that children do not want to be defined by their condition. Children want to focus on pursuing normal childhood activities, but need a holistic approach in addressing their care needs to achieve this. Improvements in accessibility, availability, and coordination of relevant health services are required.

We also conducted a qualitative interview study in the Middle East to understand the palliative care symptoms and concerns of children with advanced cancer and their families, funded by UK Research and Innovation Global Challenges Research Fund for Health in Conflict. We worked with two paediatric cancer centres in Jordan and Turkey, where the patient population includes refugees and displaced people. Across Jordan and Turkey we interviewed 104 participants, comprising 50 children, 30 parents or caregivers, and 24 healthcare professional(Boufkhed et al. 2023). Interviews found that participants' concerns spanned five domains: (1) Physical pain and symptoms; (2) Psychological concerns and needs; (3) Spirituality, uncertainty over the future and use of "tawakkul", meaning faith and reliance on God; (4) Negative impact

"Even if I have this disease, I want to live my life normally and it will get better. I mean the treatments already started so now I will get more en...I will have more energy and I'm looking forward to just enjoying what ... what is coming"

15-year-old with metabolic condition (Coombes et al. 2022).

"We stayed at the border for three days, we slept in the middle of the desert. I thought he was scared of the police or the shootings, and he was stuck to me the entire time. When I got off to open the suitcase at the checkpoint, he would scream his head off, I thought he was scared. He has been normal his entire life, he never complained."

Palestinian mother receiving care in Jordan (Boufkhed et al. 2023)

"I never expected the operation like this. I had a lot of pain, and I could never move my foot. I said, it's over now, that's it. Mean it is fate. This fate. [...] I guess that moment [...]. I mean something like the end of life, at that moment it was really hard for me"

Turkish child, aged 11-16 (Boufkhed et al. 2023)

"When Dr first explained the illness to me, she did it using Lego with trucks, these things [...] like some little kids, like when they come to the center this toy idea, these ideas would really help them."

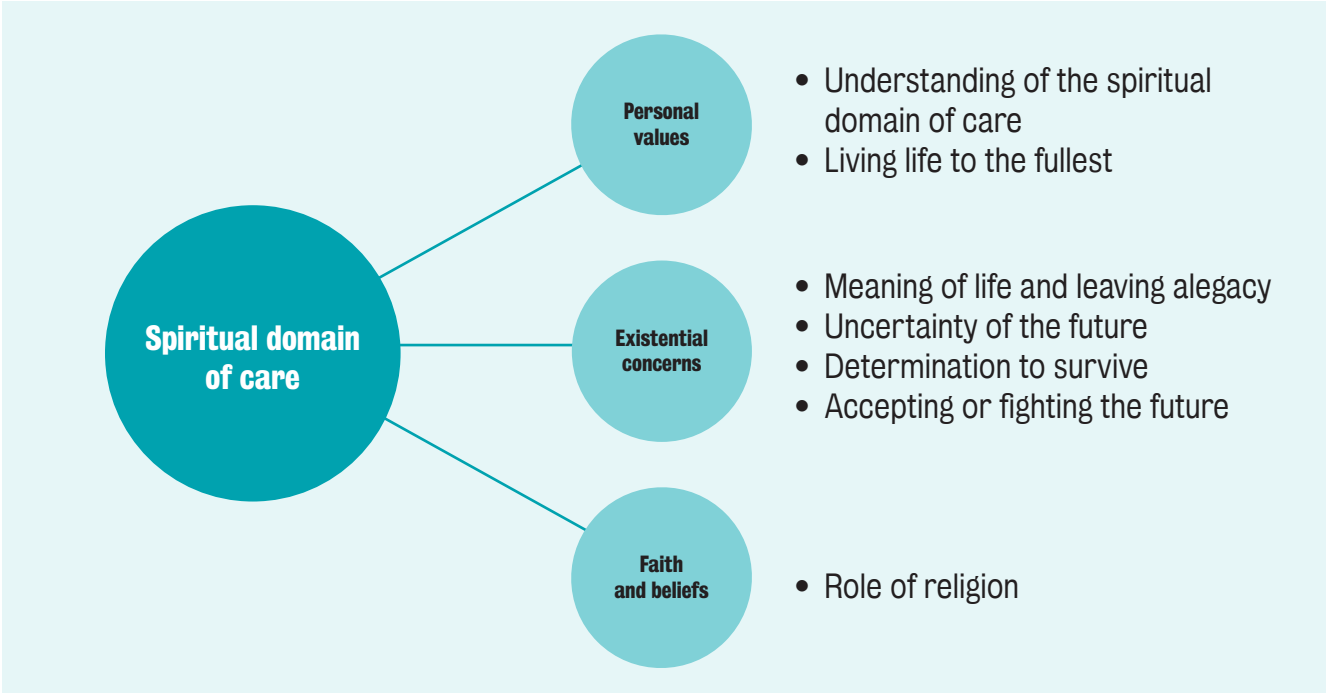
Jordanian child, age 16 (*Alarjeh* et al., 2023)

on social life; and (5) Burden on caregiver and their families. Migrant and refugee patients had amplified experiences of psychological distress and social isolation, as they had often travelled far and away from their social network.

Spiritual and existential needs are particularly important to consider for this population, where "tawakkul" often features, defined as the support of religion for coping and providing hope. Although less is understood about spiritual care for children with life threatening conditions, spiritual, religious, and existential concerns of children with life threatening conditions were also identified in our studies based in the UK (Coombes et al. 2022; Scott et al. 2023). Children have spiritual concerns when facing life threatening conditions, and when explored appropriately, have the capacity to articulate these (Figure 8.1) (Scott et al. 2023). Working with children and their families to identify the things that give their lives meaning, and setting achievable goals can support a meaningful life and hopes surrounding a child's legacy.

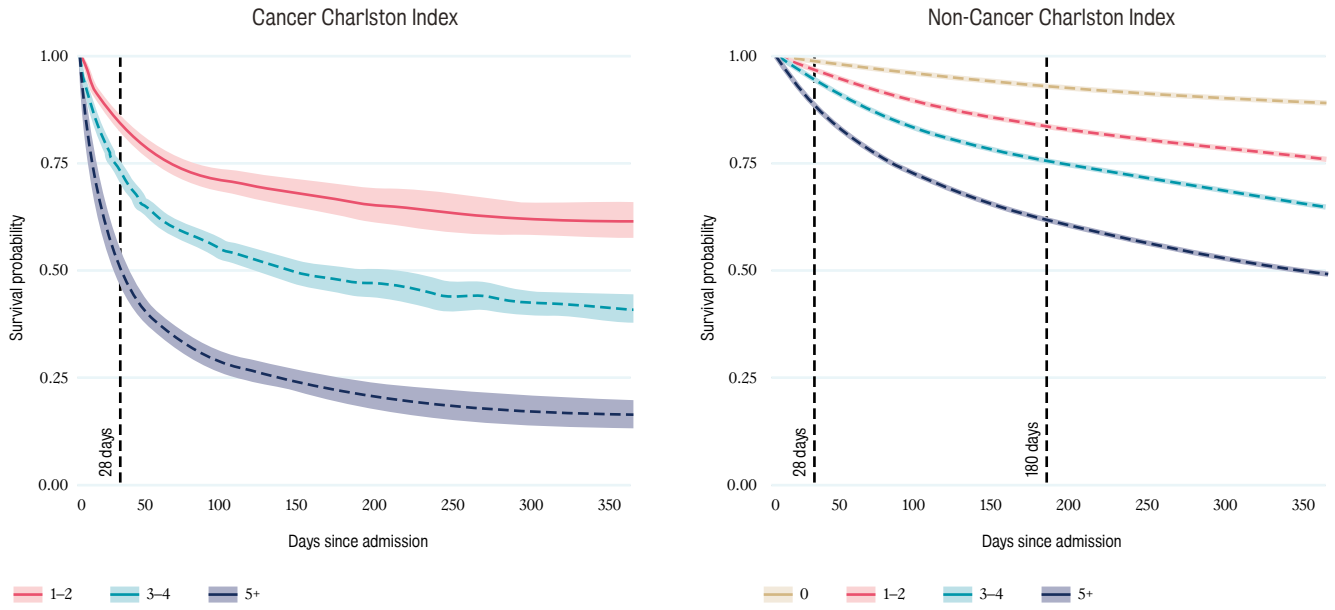
Effective communication is an important aspect of child-centred care. We also explored communication and information-sharing preferences and practices of children with advanced cancer, their caregivers, and health care professionals in Jordan (Alarjeh et al. 2023). Our qualitative interviews indicated four themes: 1) Hiding information between the three stakeholders (children, parents, and health care professionals), often to protect one another; 2) Communication and sharing of clinical versus non-clinical information; 3) Preferred communication

Figure 8.1. Spiritual domains of care for children and young people with life-limiting and life-threatening conditions



Source: Scott et al., 2022

Figure 8.2. Multiple conditions by cancer and non-cancer and mortality over 1-year post-admission to a community hospital in England (Evans et al. 2021)



styles; 4) Communication and information sharing with refugees. Our findings emphasize the need to respect patients' and caregivers' rights and preferences and the importance of knowing how and when to share information in line with cultural and educational backgrounds. Greater awareness of palliative care for children, families, healthcare professionals, and the wider public will support this.

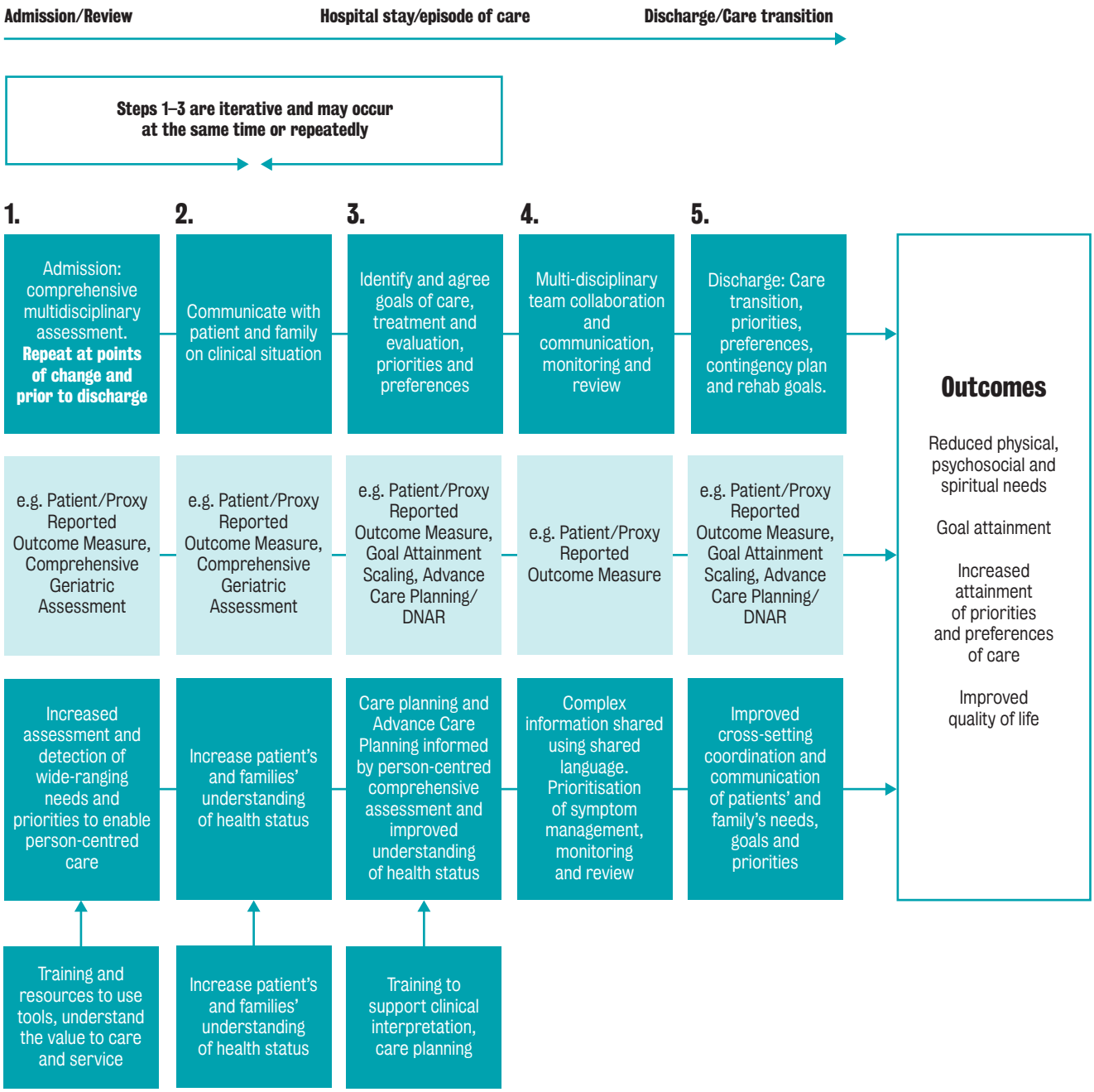
Needs, preferences, and service use among older people

Community hospitals provide intermediate care for mainly older adults with frailty and multiple conditions in transition between hospital and home to regain function and anticipate and plan for the end of life. These facilities provide care closer to home, are more common in rural communities than urban areas, and are typically nurse led within the multidisciplinary team focusing on rehabilitation and recovery. They are an under-researched, key part of the health system for older adults to maintain independence and plan future care. The development and feasibility evaluation of an intervention, the Symptom and Psychosocial Assessment and Communication Evaluation (SPACE), sought to improve communication and palliative care provision for older people in community hospitals and during clinical uncertainty. The study was funded by a Health Education England/NIHR and by Cicely Saunders International.

To understand who used community hospitals and how close people in community hospitals were to the end of life, we conducted the first national cohort study using linked databases to examine the characteristics and mortality rates over 1 year following admission to a community hospital in England (Evans et al. 2021). Over 76,704 patients were admitted to 220 community hospitals over 1 year. Overall, 28% died within 1 year of admission. Mortality varied according to whether people had cancer (total n = 3680, 70.8% died) or a non-cancer condition (total n = 73,024, 25.8% died). Risk of death rose with increasing number of conditions (Figure 8.2). Overall, over one in four patients died within a year of admission, indicating that the traditional emphasis on rehabilitation and recovery in community hospitals has changed with an ageing population and the need for greater integration of palliative care.

We developed the SPACE intervention, which involves using evidence-based tools to optimise the management of clinical uncertainty for older adults near the end of life in community hospitals. To develop this intervention

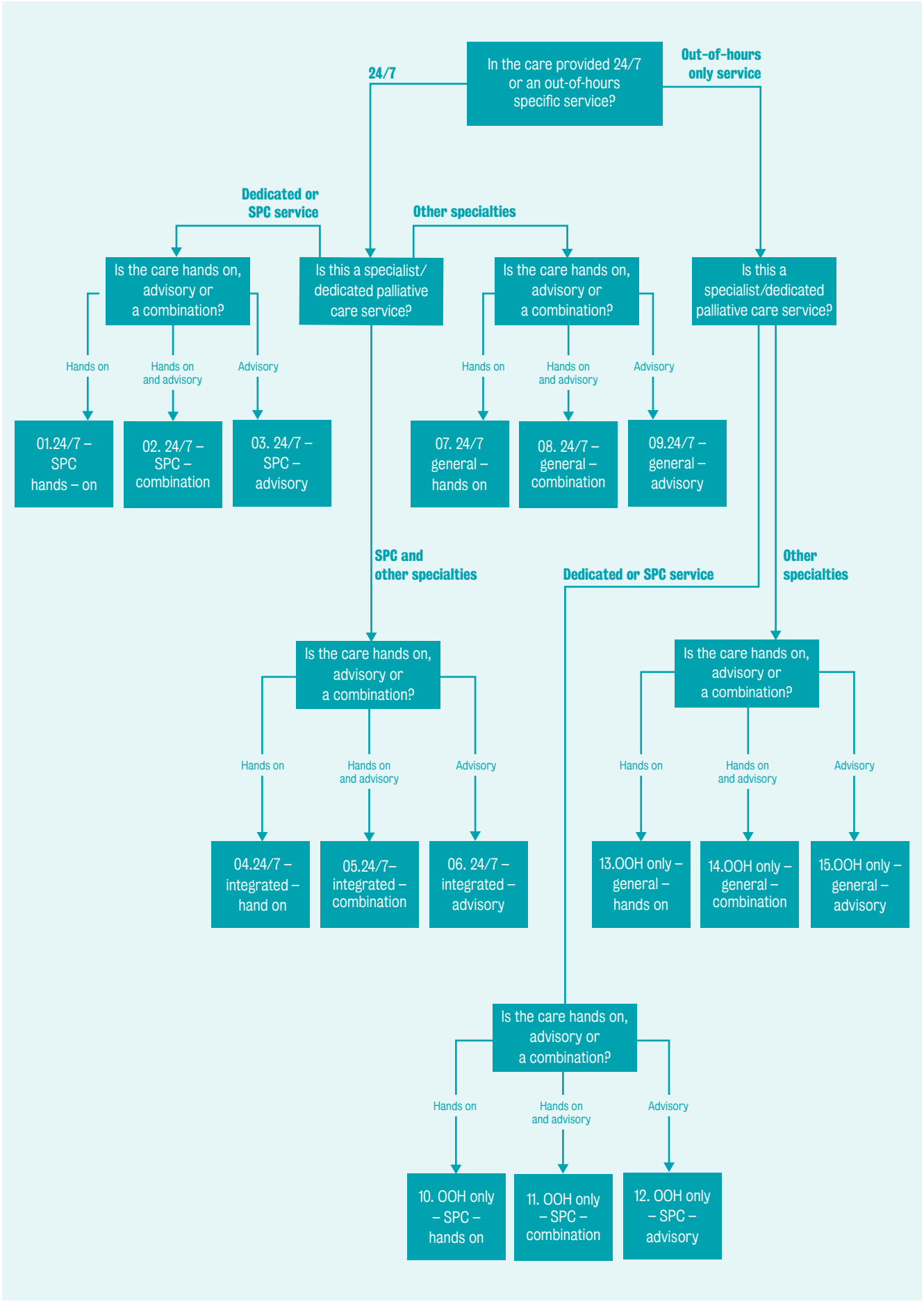
Figure 8.3. Logic model depicting use of evidence-based tools to manage clinical uncertainty for older people near end of life (Ellis-Smith et al. 2021)



we conducted a systematic review to identify ways to strengthen palliative care provision using person-centred tools to manage clinical uncertainty for older adults near end of life (Ellis-Smith et al. 2021) (Figure 8.3). The review identified 63 tools and showed that tools used in clinical care could improve identification of patient priorities and needs, support partnership working between patients and practitioners, integrate care within and across teams, and improve patient outcomes such as quality of life and satisfaction with care. However, we found that communication about clinical uncertainty with patients and families was little considered.

We refined the SPACE intervention for the context of community hospitals using a discrete choice experiment with patients (n=33) to identify preferences and priorities for care and using stakeholder consultations with multi-disciplinary professionals (n=48) to identify ways to enhance care processes to manage clinical uncertainty (comprehensive

Figure 8.4. Typologies of out-of-hours care



assessment, communication, and continuity of care) (Tunnard et al. 2021). Patients prioritised a service where family were contacted on admission and discharge, care was received closer to home, and the GP is fully informed about care. Four stakeholder consultations generated 20 recommendations centred around tailoring care processes to manage multiple care needs for adults with frailty and multiple conditions; the importance of ongoing communication with the patient and family; and clear and concise evidence-based tools to enhance communication between clinical teams and continuity of care on discharge. We tested the feasibility of the SPACE intervention in two community hospitals, demonstrating that it was feasible and acceptable for staff to use evidence-based tools to enhance processes of assessment, communication with family, and continuity of care on discharge.

Priorities and preferences for patients requiring palliative care outside of normal working hours

The provision of community palliative care outside of normal working hours in the UK is highly variable. This study, funded by Marie Curie, sought to understand and improve community-based palliative care outside of normal working hours and to inform policy priorities for service provision. The initial systematic review on 'How is community based out of hours care provided to patients with advanced illness near end of life' identified two main themes: (1) importance of being known to a service and (2) high-quality coordination of care (Firth et al. 2023). A typology of out-of-hours service provision was constructed using three overarching dimensions (service times, focus of team delivering the care and type of care delivered) resulting in 15 categories of care (Figure 8.4). Randomised controlled trials were uncommon limiting the ability to identify effective models on improving patient outcomes. The findings were pursued using a Delphi study to establish consensus with healthcare professionals, patients, and family carers on the most important components of out-of-hours community care for adults near the end of life (Goodrich et al. 2022). Over two rounds, a final consensus was reached on 45 components, with highest consensus for: prescription, delivery and administration of medicines; district and community nurse visits; and shared electronic patient records and advance care plans. The study has continued with qualitative interviews with professionals providing out-of-hours care and patients and families receiving care. The findings are informing policy priorities to provide optimal palliative care outside-of-working hours.

Use of routine data to understand end-of-life care for people with dementia and older people

Our systematic reviews have shown that the quality of end-of-life care for older people and people with dementia is variable, often associated with unnecessary emergency hospitalisation and escalating care costs (Williamson et al. 2021; Leniz, Yi, et al. 2021). With innovative approaches to linking and analysing different routine data, combined with patient and public narratives, we have advanced current understanding of those at greatest risk of poorer quality care and identified opportunities for intervention.

Using hospital records of 74,486 decedents with dementia from across England, we found that 83% attended the emergency department at least once in the last year of life (Williamson et al. 2023). Linking this data with service workforce and capacity data from five separate databases,

"I suppose you could argue it's not a pull system, it's a push system. And it relies very much on the support that those people are receiving because, you know, to get the best treatment and help for them. Yeah, it's not a pull system. You have to get very pushy. It's quite hard I think to navigate."

Bereaved carer (Williamson et al., 2023b)

Figure 8.5. Factors associated with ED visits among people with dementia in the last year of life

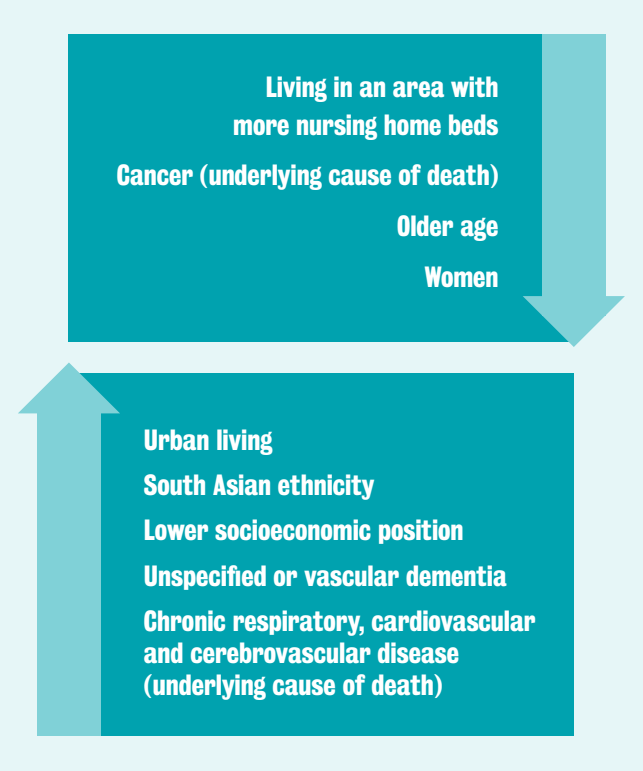
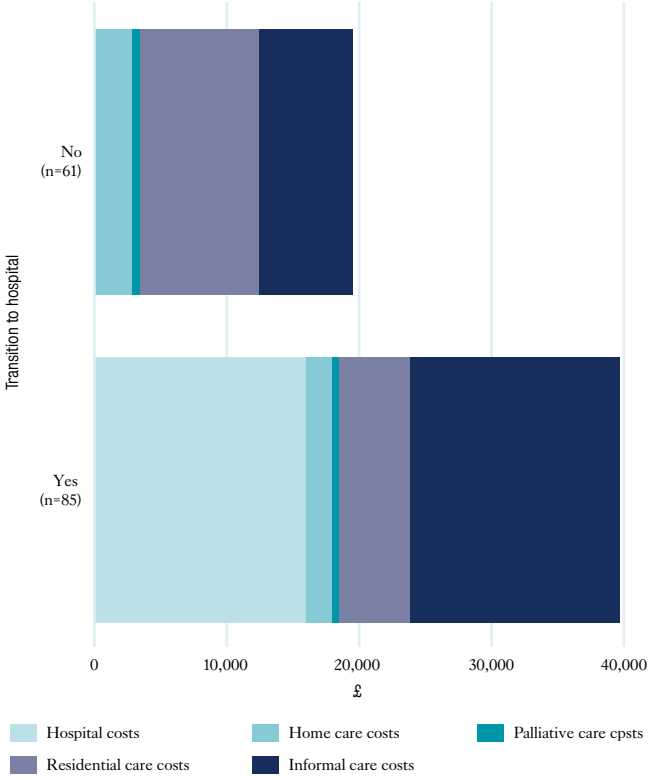


Figure 8.6. Observed mean costs by cost components in the last three months of life by transition to hospital



we found that living in a local authority with more nursing home beds, but not residential home beds, was associated with fewer emergency department visits. We also identified South Asian ethnicity, lower socioeconomic position, and urban living associated with more visits (Figure 8.5).

Our engagement with PPI members and qualitative work helps to contextualise these findings and suggests that the health and social care system requires people to push or fight for care. This drives inequitable access to timely clinical care in the community, making emergency department attendance the path of least resistance. Only when individuals with dementia are recognised as nearing the end of life is the emergency department more readily avoided, but recognition is often late (Williamson, Sleeman, and Evans 2023).

This work builds on another study we conducted with routine data, which found that only one third (33.6%) of people with dementia who died had their palliative care needs identified in primary care (Leniz, Higginson, et al. 2021).

We found that this group had a lower risk of multiple hospitalisations in the last three months of life, emphasising the importance of integrated primary and community care in meeting the palliative care needs of people with dementia.

Further research in primary care settings has highlighted the benefits of continuity of care with GPs. Using nationally representative data on 33,714 decedents with dementia, we showed that better continuity of care was associated with a lower risk of multiple hospital admissions in the last 90 days of life. We found that this was particularly beneficial for those with multiple long-term conditions and those living at home (Leniz, Gulliford, et al. 2022).

With important policy implications, our work using routine data includes the costs as well as patterns of care towards the end of life. In a study of 146 decedents with dementia in London and the South East, we found that adjusted total costs were higher among those who went to hospital than those who did not (£33,239.20 vs £21,522.00). Our analyses

showed that care home residents with dementia had lower total costs compared to people at home, even when considering the cost of the care home, mainly due to a lower rate of hospital admissions (Figure 8.6) (Leniz, Evans, et al. 2022).

This work has been cited in the Independent, Evening Standard, and several online media outlets. We also included this work in a policy brief that we shared with key policymakers at a Parliamentary event during Dementia Action Week 2023 (Williamson et al. 2023) (Figure 8.7).

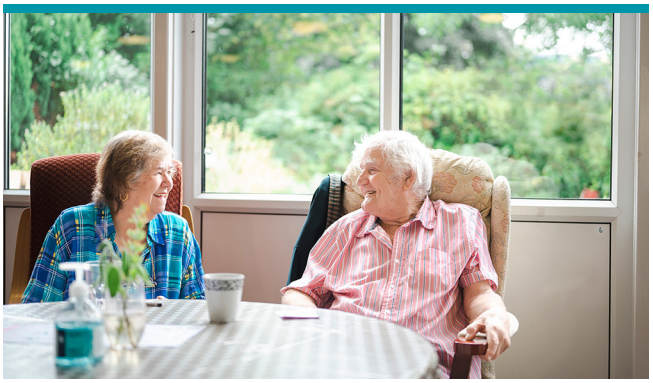




Figure 8.7. Policy brief: A right to be heard (Williamson et al. 2023)

Within the policy brief, we developed eight evidence-informed recommendations across four calls to action:

- Prioritise dementia as a life-limiting condition.
- Ensure equitable access to integrated palliative dementia care.
- Optimise investment in community and primary care closer to home.
- Invest in palliative dementia care research.

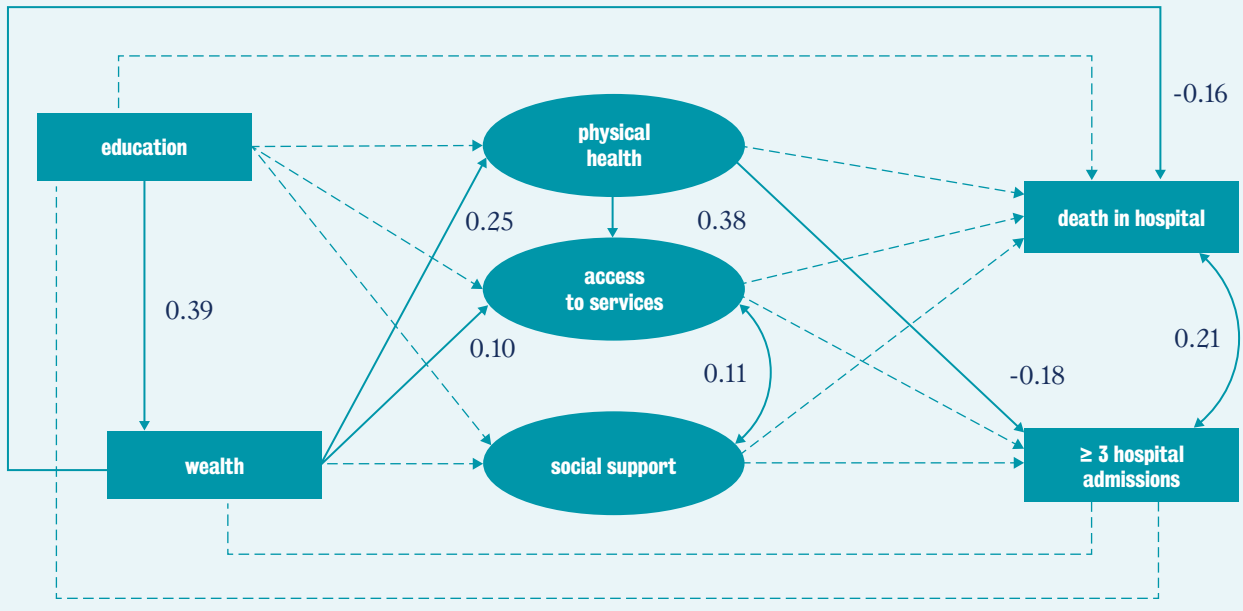
The policy brief has since been shared nationally across clinical, commissioning, and community groups and has been referenced in a House of Lords debate on dementia palliative care teams (HL Deb 15 June 2023, vol 830, col 2101).

Another source of 'big data' is from large longitudinal studies such as the English Longitudinal Study of Ageing (ELSA), a nationally representative study of people aged 50 and over living in England, collecting data at regular 2-year intervals since 2002. In a study using data collected from family members of deceased ELSA participants, we explored the social determinants of higher use of hospital care towards the end of life (Davies et al. 2021). Our findings suggest that worse health and function could partly explain why people with lower wealth have more hospital admissions, highlighting the importance of socioeconomically driven health differences in explaining patterns of hospital use towards the end of life (Figure 8.8).

National clinical guidelines for prolonged disorders of consciousness (PDOC)

Following catastrophic brain injury some patients will remain in a prolonged disorder of consciousness (PDOC) for many months, years, or even permanently. Whilst clinicians start from the strong presumption that it is in a patient's best interests to prolong life, not everyone would wish to be kept alive indefinitely

Figure 8.8. Path model showing the relationships between socioeconomic position and use of hospital-based care towards the end of life, via three explanatory pathways



if there is no chance of regaining a quality of life that they themselves would value. In 2020 the Royal College of Physicians published updated National Clinical Guidelines for Prolonged Disorders of Consciousness, a process led by Prof Turner-Stokes (RCP 2020).

In 2022, Prof Turner-Stokes and her team at Northwick Park published an 8-year mortality review describing the lessons learned from providing end-of-life care for 80 patients who had died following catastrophic brain injury on the Regional Hyperacute Rehabilitation Unit (Turner-Stokes, Thakur, et al. 2022). This was the first published review of the experience of end-of-life in PDOC. Tube feeding was withdrawn in 39/80 (49%) of the patients, over half of whom were already imminently dying. Even in a centre where patients are referred for this purpose, elective withdrawal is comparatively rare (just 14 patients since 2018). The requirements for external scrutiny were met in all cases. The recommended end-of-life protocol provided good symptom control for the majority of patients (77%) to support a peaceful and dignified death.

About a quarter of patients had symptoms that were difficult to control requiring higher doses of medication, but there was no evidence that this hastened death.

A critical factor to consider when making life and death decisions following catastrophic brain injury is the likelihood of the patient emerging into conscious. Prof Turner-Stokes and her team have identified cut-off scores in the UK FIM+FAM (the primary functional outcome measure for rehabilitation used in the UK) that identify patients in PDOC versus those who have emerged into consciousness with 87% sensitivity and 88% specificity (Turner-Stokes, Rose, et al. 2022).

Working with Prof Richard Siegert and colleagues in Auckland University of Technology, she applied these cut-off points to FIM+FAM data in the national UKROC clinical database (that is routinely collected for all patients undergoing inpatient specialist rehabilitation in England) to identify patients who did and did not emerge into consciousness (Turner-Stokes, Rose, et al. 2022). They then

applied machine learning techniques to explore factors within the routinely collected clinical dataset that identify those patients who were in PDOC on admission but who regained consciousness by discharge. Triangulation of results using a set of individually tested rules produced an algorithm that predicted emergence into consciousness with 95% sensitivity and 82% specificity (Siegert, Narayanan, and Turner-Stokes 2023). Whilst statistical predictions should be treated with caution when predicting outcomes for individual patients, this work provides some practical assistance to clinicians when discussing these difficult decisions with patients' families in the aftermath of profound brain injury.

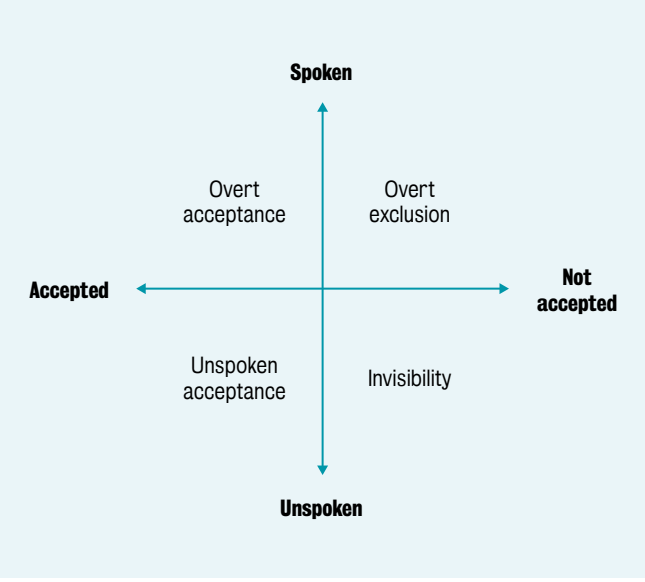
Improving care for LGBTQ+ people facing advanced illness, serious illness, and bereavement

The ACCESSCare programme of research, which commenced in 2013, has focused on improving care for lesbian, gay, bisexual, and/or trans (LGBTQ+) people facing advanced illness. Our earlier work provided insight into the barriers LGBTQ+ people experience both across the UK and in other settings (Zimbabwe) and identified key areas for further research. Through our systematic reviews, and qualitative work (Harding, Epiphaniou, and Chidgey-Clark 2012; Bristowe et al. 2018; Bristowe, Marshall, and Harding 2016; Hunt et al. 2019; Hunt et al. 2017), we identified that there is a lack of research focusing on outcomes and experiences in bereavement for LGBTQ+ people outside of the context of HIV/AIDs and that communication is central to enabling LGBTQ+ people to access the care and support they need when they need it.

The ACCESSCare B (Bereavement) study, funded by Marie Curie, included a retrospective post-bereavement survey comparing outcomes in bereavement for same gender partners compared to different gender partners and a nested qualitative study. Supported by the Office for National Statistics, we used death registration data to identify individuals who had registered the death of a civil partner or spouse (233 same-gender partners and 329 of different-gender partners). Levels of complicated grief were high amongst both groups, however we found that those in same-gender relationships experienced more psychological distress in bereavement than those bereaved of a different-gender partner (Timmins et al. 2022). Loneliness and poor social support were associated with grief intensity.

The nested qualitative study of 21 LGBTQ+ people provided further insight into these experiences. LGBTQ+ individuals described the impact of challenging intersections and fears of discrimination on their access to support (e.g. concealing their relationship and bereavement to preserve relationships with family for whom the relationship was at odds with religious beliefs or from employers due to fears of discrimination) (Bristowe et al. 2023). This resulted in varying degrees of disclosure across social networks. As such, individuals were multiply disadvantaged with less access to both formal and informal support. The findings from both the quantitative and qualitative data provided evidence to support the Acceptance-Disclosure model of LGBTQ+bereavement (Figure 8.9) (Bristowe, Marshall, and Harding 2016). This model recognises that experiences of bereavement for LGBTQ+ partners are shaped

Figure 8.9. Acceptance and Disclosure Model of LGBTQ+ Bereavement



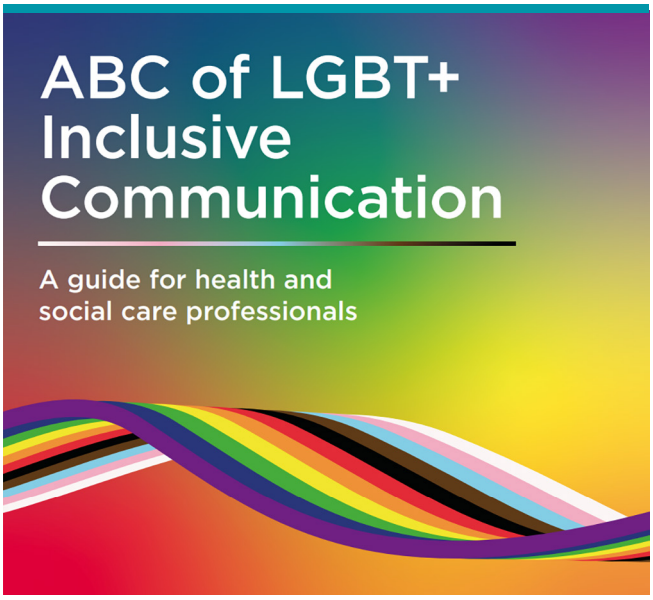


Figure 8.10 ABC of LGBT+ Inclusive Communication

by the extent to which they feel able to disclose the nature of their relationship and bereavement to those around them and the degree to which that loss is acknowledged and accepted. However, the findings also highlighted the role of agency within these experiences, as individuals described choosing to control the disclosure of their relationships with some social contacts as a means of protecting themselves or preserving relationships. This important study combined novel sampling methods to achieve a population-based LGBTQ+ sample and advance our theoretical understand of grief and bereavement for minoritised groups.

The ACCESSCare C (Communication) Project, funded by the NIHR Research for Patient Benefit Programme, was designed to develop evidence-based guidance to improve inclusive communication for LGBTQ+ people facing serious illness. We interviewed 74 stakeholders (34 LGBTQ+ patients with serious illness, 13 significant others, and 27 multi-professional clinicians). The interviews demonstrated that (1) 'Creating positive first impressions and building rapport' were central to relationship building. These were enacted through routine use of inclusive language, avoiding potentially negative non-verbal signals, and echoing terminology used by patients and caregivers. Participants also described the importance of (2) 'Enhancing care by actively exploring and explaining the relevance of sexual orientation and gender identity'. Participants described the benefits of clinicians initiating these discussions, pursuing topics guided by the patient's response or expressed preferences for disclosure. Active involvement of significant others was encouraged to demonstrate recognition of the relationship. Lastly, they also highlighted that (3) 'visible and consistent LGBTQ+ inclusiveness in care systems' was vital to underpin this (Braybrook et al. 2022).

This work provided the evidence to inform the ABC guide to inclusive care for LGBTQ+ people, which was codeveloped with LGBTQ+ community members and advocacy groups and is freely available to download (Figure 8.10). To support this, we have also developed a e-learning programme, funded by Higher Education England (ACCESSCare E) which is hosted by the King's Health Partner platform, and a suite of poster to prompt inclusive care. The posters are designed to be used by health and social care organisations highlighting ways that professionals can care inclusively. Each poster links to the full evidence-based guide which provides practical guidance (Figure 8.11).



Figure 8.11. ACCESSCare Posters

Lastly, a task force on improving palliative and end-of-life care for LGBTQ+people was set up by the ACCESS Care research team. Following a successful opening meeting at the European Association for Palliative Care (EAPC) World Congress in 2019, a team involving international members from 13 countries was convened, and the group are working together to improve outcomes and access to palliative care. The task force has developed an evidence-based inclusive communication guide for professionals informed by the research. The guidelines have been translated into 6 languages and adapted for local use. In addition, the team have contributed to the Care Quality Commission End of Life Care guidelines ensuring LGBTQ+ communities were included and submitted written evidence to the Parliamentary Office of Science and Technology research briefing, focussing on LGBTQ+ people's experiences and needs.

The ACCESSCare team has a dedicated patient and public involvement group who have provided vital support, guidance, and insight throughout the ACCESSCare studies (Figure 8.13). As experts by experience, they ensure the research remains grounded in the needs of those who are intended to benefit.



Figure 8.12. European Association of Palliative Care Guidance on providing LGBT+ inclusive palliative and end of life care



"I am one of the few transgender people who are enough in the public eye to influence public awareness of what needs to be done for equality, care and understanding. It is a role I am happy to fulfil."

Ruth Rose, trans woman



"The project is really inclusive. I feel respected and valued and that my voice matters."

Liz Day, queer lesbian and supporter of trans rights



"My experiences of being part of this particular research project have been more than enjoyable, they have been experiences of learning."

Paul Clift, gay man

Response to Covid-19

Cicely Saunders' vision of synergistic palliative care research, education, and clinical care was exemplified in the Institute's response to Covid-19. In a coordinated response, researchers, clinicians, and staff of Cicely Saunders Institute worked together to identify priority needs for patients, families, and healthcare providers, design, implement, and disseminate high-quality research to meet urgent needs, and develop evidence-based guidelines for palliative care delivery during the pandemic and beyond. With internal, national, and international collaborators, we moved the dial to keep palliative and end-of-life care at the forefront of the global pandemic respons

Evidence-based information and guidance materials

In early 2020, the 1st wave of Covid-19 brought the urgent need for palliative care delivery by non-specialists. Clinical academics at the CSI rallied and led multi-disciplinary experts to produce urgent national and international guidance whilst working clinically on the Covid-19 frontline (Bajwah et al. 2020b). These guidelines were downloaded over 9,000 times in first week of publication online. In addition, we produced urgent BMJ educational guidance (Ting et al. 2020). Both of these resources have improved clinical knowledge and reduced patient suffering nationally and internationally.

In March 2020, Covid-19 patients admitted to King's College Hospital lacked information about the disease and what to expect. For non-English speaking patients who had lost their translators, this was particularly difficult, resulting in fear and reduced ability to make informed decisions. Advocating for these vulnerable patients, researchers at the CSI approached the European Lung Foundation patient group and rapidly co-developed factsheets to meet information needs of patients and families. We lobbied and mobilised translation companies to secure free resources translated into 25 different languages, including the top 10 non-English speaking languages in UK. These are available online and are now used routinely in clinical care locally, nationally and internationally, empowering patients and families (Bajwah et al. 2020a).

International cooperation

During the Covid-19 pandemic, our global partnership came together to understand the challenges that Covid-19 posed to palliative care provision. Building on the networks developed by Profs Massimo Costantini and Irene Higginson, we surveyed palliative care providers in India (Lin, Boufkhed, Pai, et al. 2021), Asia Pacific (Lin, Boufkhed, Kizawa, et al. 2021), the Middle East (Boufkhed et al. 2021), and in sub-Saharan Africa (Boufkhed et al. 2020). Common findings across regions included the high psychological strain on clinical staff, the low availability of personal protective equipment, and the stigma faced in the community by those caring for patients with Covid-19.



Information for patients admitted to hospital with COVID-19

COVID-19 can cause minor to serious illness.

You have been admitted to hospital with COVID-19 so that we can monitor your breathing. Your breathing may need to be supported with oxygen and sometimes with a ventilator (artificial breathing). We also want to help with any symptoms you may have.

This leaflet will explain what treatment you may receive, and what support will be available.

What treatment will I receive?

Alongside active measures to treat the disease, it is important that we reduce the distress that you may experience. This is done through treating your symptoms:

- *Breathlessness* can be improved by keeping as calm and relaxed as possible, but if your breathlessness gets worse, we will use medication to help with this. Morphine is the most common medicine used. Although usually given for pain, morphine can be used safely to relieve the feeling of breathlessness.
- *Cough* can also be relieved by morphine.
- *Anxiety* can be common; medicines used to help with this symptom include lorazepam and midazolam.
- *Restlessness* can occur if you develop a fever and this can be controlled using paracetamol.

All medicines will be given regularly and when you need them. If you become unable to swallow the medicine, it can be given as an injection either through a vein or under the skin.

In the most serious cases, COVID-19 can severely affect the lungs, stopping them from working normally. A ventilator may be used to move air into and out of the lungs to help you breathe. You may need to be on a ventilator for several days until your lungs are able to work properly again.

Can I decide how I am treated?

You should talk to the doctors about what is important to you. You may have preferences about how and when certain actions should be taken. For example, when to start ventilation or whether to restart the heart if it stops. The doctors will take your views into consideration together with your medical condition. Difficult decisions about your medical care may need to be made quickly if you become unwell so it is important that you let the medical team know what you want them to do. If you are unsure, please discuss this with a member of the medical team.

How can I communicate with those important to me?

There are strict isolation rules in place both outside and inside the hospital, which means that you may not be allowed visitors. Any visitors will have to wear personal protective equipment (otherwise known as PPE – face masks etc.). Where possible, ward staff will try to help you communicate with people important to you by telephone or video calls. Please let the ward staff know if you are happy for them to share information in this way and if there are specific

કોવિડ-19 સે પ્રભાવિત અસ્પતાલ મેં ભતી મરીઝોં કે વલયે જાનકારી

કોવિડ-19 છોટી મોટી બીમારિયોં સે લેકિ વકસી ગંભીર બિમારી કા કારિ બન સકતા હૈ

કોવિડ -19 સે ગ્રસ્ત હોને કે કારિ આપકો અસ્પતાલ મેં ઇસવલએ ભિતી વકયા ગયા વક હમ આપકી સાંસ કી ગવત કો મૉનિટર કિ સકેં । સાંસ લેને કી વલએ આપકો ઑક્સીજન કી સહાયતા લેની પડ સકતી હૈ। ઔર કુ છ મામલોં મેં આપકો સાંસ વિલાને વાલી મશીન (વેંટિલેટર) પર રખા જા સકતા હૈ । યદિ ઇસકે અલાવા કોઈ ઔર લક્ષણ યા વસમ્પટમ દિખાઈ પડ રહે હૈં તો હમ ઉન પર ભી ધ્યાન રખેંગે ।

યહાઁ યે સમઝાને કી કોવશા કી ગયી હૈ વક આપકા ઇલાજ વકસ તરહ સે વકયા જાએગા ઔર આપકો વકસ તરહ કી સહાયતા દી જાએગી ।

મેરા ઇલાજ વકસ તરહ વકયા જાએગા?

બીમારી કે લક્ષણોં કે સીધે ઇલાજ કે સાથ-સાથ, યહ ભી ઝરૂરી હૈ વક આપકો હોને વાલે માનવસક અસાર્ઔર ઔસે કો ભી કમ વકયા જાયે । યે કાયય આપકે લક્ષણોં કે ઇલાજ સે વકયા જાતા હૈ ।

- યદિ આપકો સાંસ લેને મેં કઠિનાઈ હો રહી હૈ તો આપકો શાંત ઔર આરામ સે રહને કી કોવશા કી જાએગી ।લેવકન યદિ આપકી હાલત વબગડ઼તી હૈ તો હમેં ઉસે રોકને કી જરૂરત હોગી । ઐસી વસ્થવત મેં આમતૌર પર મૉર્ફીન કા પ્રયોગ વકયા જાએગા । મૉર્ફીન અક્સર દિ કો કમ કરને કે વલએ દી જાતી હૈ લેવકન યદિ સાંસ લેને મેં કઠિનાઈ હો તો ભી ઇસકા પ્રયોગ વકયા જા સકતા હૈ।
- મૉર્ફીન કે દ્વારા ખાંસી કે લક્ષણોં મેં ભી આરામ વમલ સકતા હૈ ।
- કોવિડ -19 કે કારિ આપ અક્સર વંતા યા એંક્ઝાયટી કે ભી વશકાર હો સકતે હૈ । ઇસ વસ્થવત મેં આપકો લોરાઝેપામ (Lorazepam) ઔર વમડાઝોલમ (Midazolam) જૈસી દિ એં દી જા સકતી હૈં।
- યદિ આપકો બુખાર આતા હૈ ઔર બૈનૈની કી વશકાયત હોતી હૈ, તો ઐસે મેં પૈરાસીટામોલ (Paracetamol) સે હિત દી જા સકતી હૈ ।

યે સભી દિ એં આપકો વનયવમત રૂપ સે દી જાએંગી । યે દિ એં ઝરૂરત કે અનુસાર ઇંજેક્શન સે ભી દી જા સકતી હૈં । ય ઇંજેક્શન નસોં મેં યા વિત્વિ યા વસ્કન મેં ભી વિયા જા સકતા હૈ ।

કુ છ ઝ્યાદા ગંભીર મામલોં મેં, કોવિડ – 19 વિરસોં રોગિયોં કો બુરી તરહ સે પ્રભાવિત કિ સકતા હૈ। રોગિ સામાન્ય રૂપ સે કામ કિના બેહોશ હોતે હૈં । ઐસી વસ્થવત મેં રોગિયોં મેં સાંસ પહુંચને ઔર ઉસે બાહર વનકાલને કે વલએ વેંટિલેટર કા પ્રયોગ વકયા જા સકતા હૈ । યે વેંટિલેટર કઈ વિન તક લગાના પડ સકતા હૈ, જબ તક વક આપકે ફેફડ઼ે બીમારી સામાન્ય વગત સે કામ ન કિને લગેં।

ક્યા મૈં યે તય કર સકતા હૂઁ કી મેરા ઇલાજ કૈસે વકયા જાયે?

આપકો ઇસ બારે મેં ડૉક્ટર સે બાત કરની ચાહિએ વક આપકે વલએ ઝરૂરી ક્યા હૈ । વકસ સમય ક્યા કાર્યવાહી કી જાયે ઇસ બારે મેં આપકી કોઈ પ્રાથવમકતા હો સકતી હૈ । ડૉક્ટર હિણ કે વલએ, આપકો મેડિકલ કંડીશન કબ વિયા જાયે યા વિપરીત આપક

વિલ કી ધડ઼કન રુક જાતી હૈ તો વિલ કી ગવત કો રીબાર્ઔ સે લાયા જાયે અથવા નહીં । કોઈ મેડકલ કૌંસલર કિને સે પહલે ડૉક્ટર આપકી હાલત ઔર આપકે વિકોં કા ખયાલ રખના ચાહેંગે । યદિ આપકી હાલત વબગડ઼તી હૈ તો કુ છ મુવકલ કૌંસલે જલ્દી સે લેને હોંગે, ઇસવલએ યે ઝરૂરી હૈ વક આપ અપને

Figure 9.1. Information leaflet for hospitalised patients with Covid-19 in English and Gujrati

Covid-19 Research on death, dying, and bereavement

Researchers at the Cicely Saunders Institute have led internationally recognised research on the impact of the Covid-19 pandemic on dying, death, and bereavement. An important aspect of this has been research that examined changes in the place of care and the place of death during the Covid-19 pandemic.

The Better End of Life programme is a three-year research programme funded by Marie Curie, led by researchers at the Cicely Saunders Institute in collaboration with Hull York Medical School at the University of Hull and the University of Cambridge. Published in April 2021, the first Better End of Life report shone a spotlight on the impact of Covid-19 on dying, death, and bereavement across the UK, drawing on published data, experiences of caregivers, and new analysis of mortality trends across the UK (Sleeman et al. 2021). It was reported across major news outlets, including the BBC, and led to a Parliamentary Question to the Secretary of State for Health and Social Care.



Figure 9.2. The first Better End of Life Research Report: Death, Dying, and Bereavement during Covid-19

The report identified the sustained increase in home deaths that had occurred since the start of the pandemic even outside of pandemic waves, seen in Figure 9.2. This finding was explored further in the second and third Better End of Life reports and academic papers (Sleeman, Leniz, et al. 2022; Pask et al. 2022). We found that the increase in home deaths that occurred during

Figure 9.3. Deaths during the Covid-19 pandemic between 7th March 2020 and 12th February 2021 in England

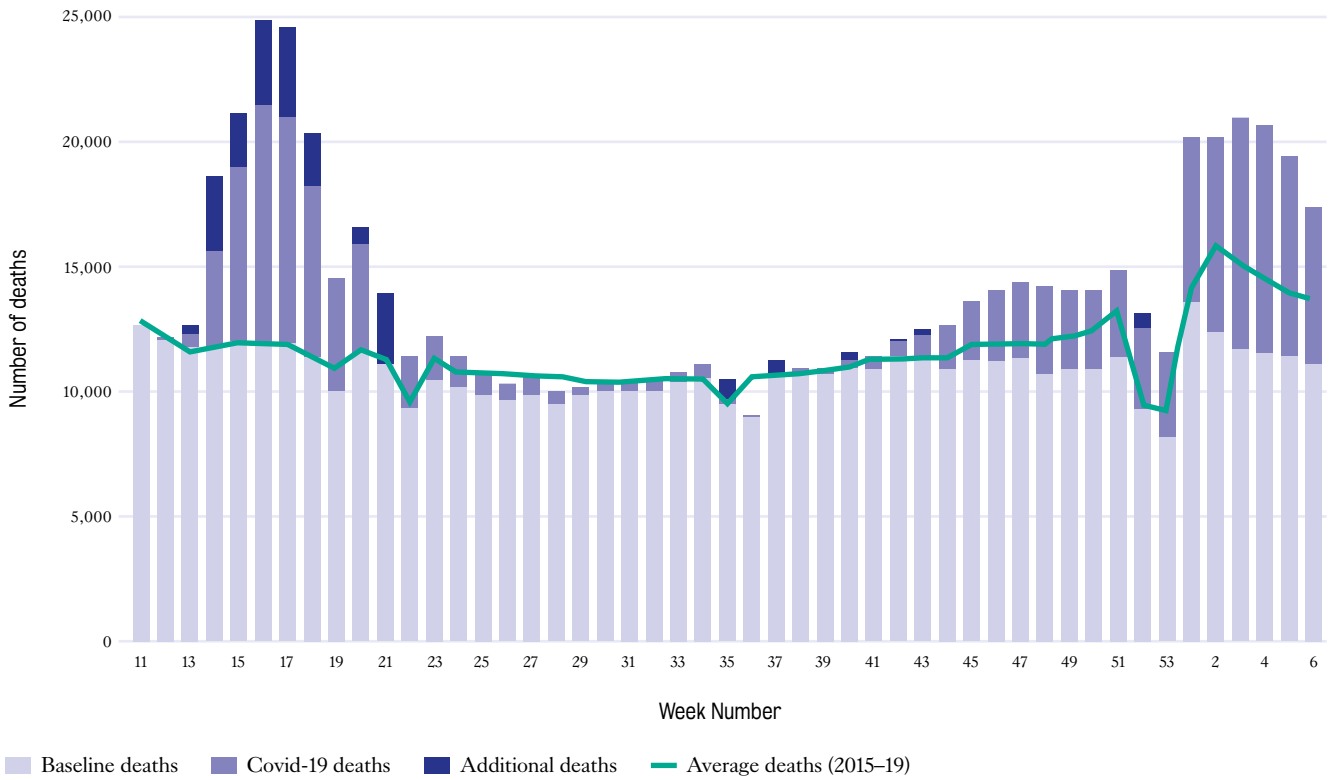
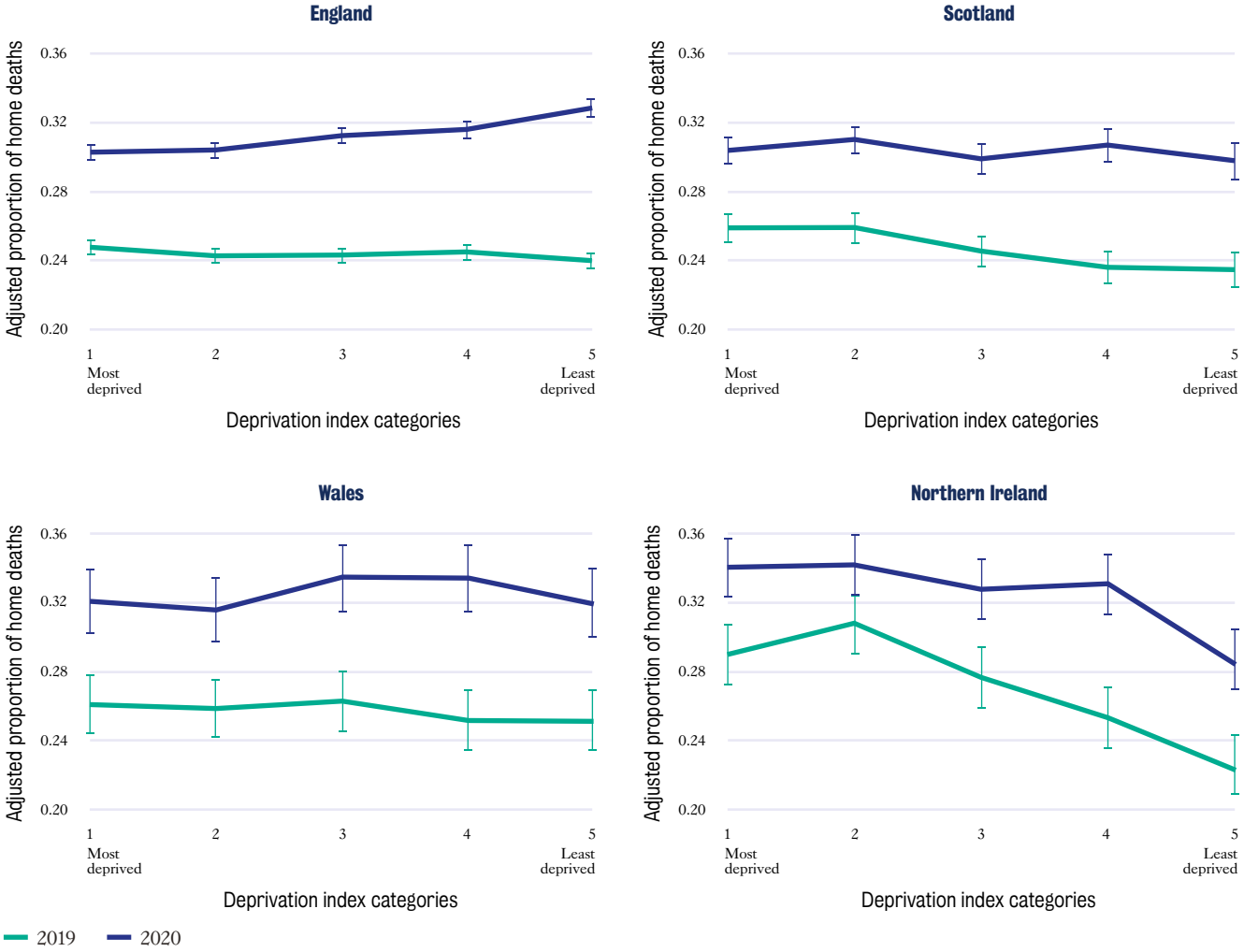


Figure 9.4. Proportion of home deaths (age and sex adjusted) by deprivation and year of death in the four nations of the United Kingdom between the 28th March to 31st December for 2019 and 2020



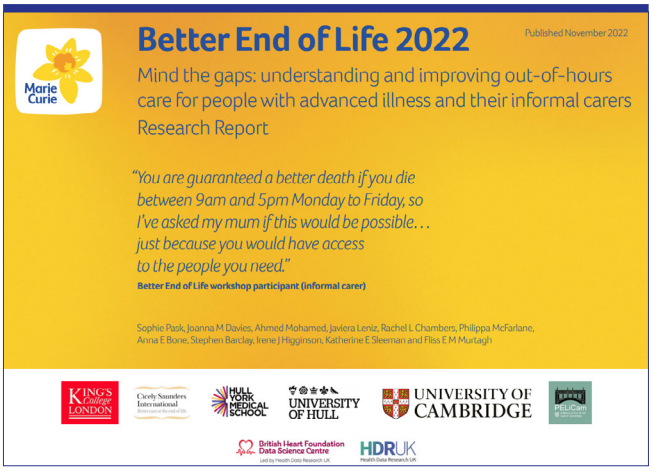


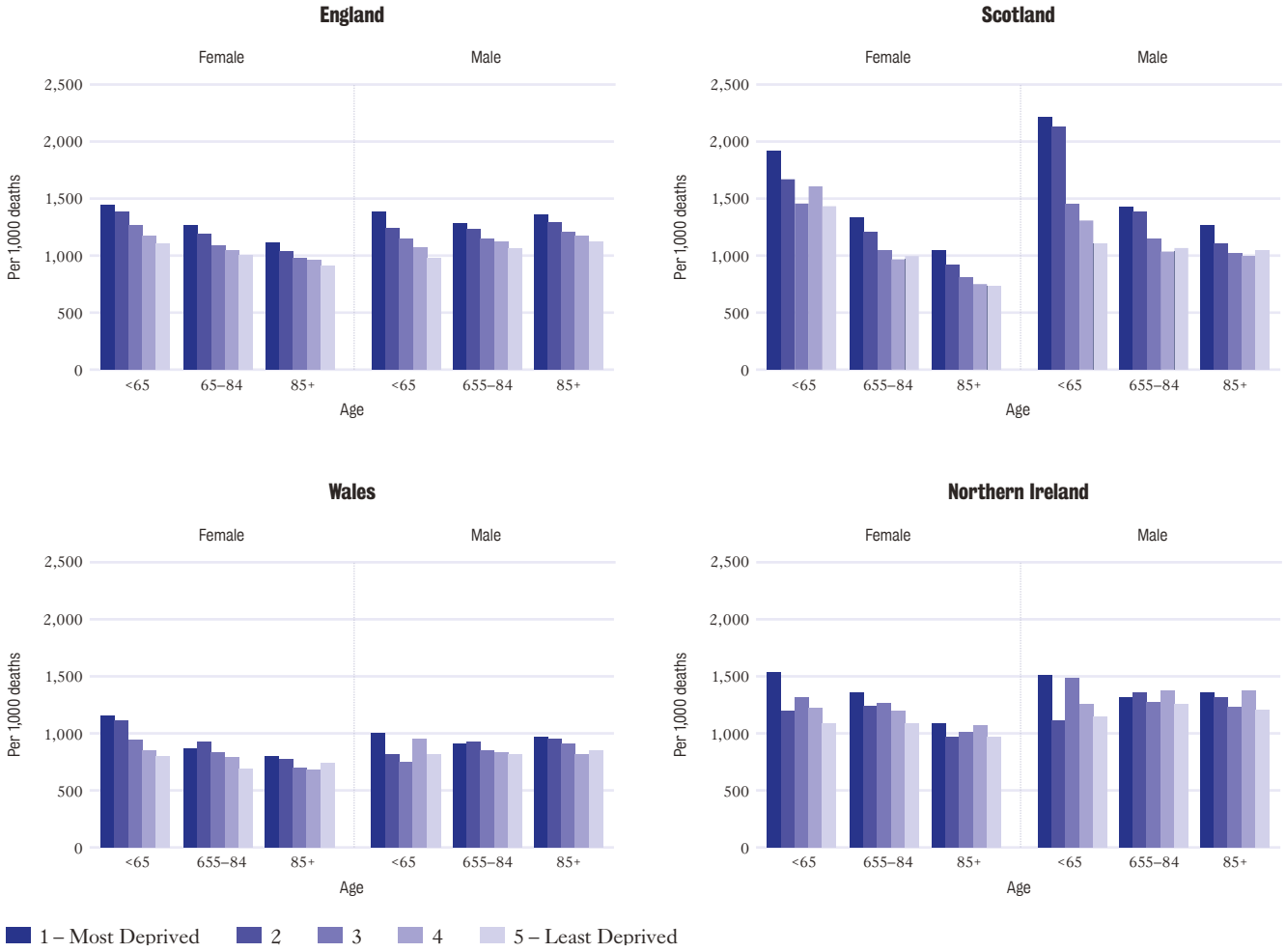
Figure 9.5. The third Better End of Life report: Mind the Gaps (2022)

the pandemic was mainly experienced by people living in the least deprived areas. This indicates that the pandemic exacerbated inequalities relating to end-of-life care.

The third Better End of Life report concerned out of hours care for people with advanced illness living in the community (Pask et al. 2022). The report used routine data analysis, alongside 71 structured interviews with health leaders across the UK, to examine out of hours care and support. The report found that out-of-hours emergency department attendance in 2021 was more common among people living in the most socioeconomically deprived areas; and that there are gaps and variation in out of hours services, including telephone line support, access to medicines and equipment. The report was reported widely including by the BBC and led to six written Parliamentary Questions, an Early Day Motion and a Policy Round Table at the Department of Health and Social Care.

During the pandemic, many hospice and palliative care services rapidly innovated,

Figure 9.6. Out of hours emergency department attendance for people in the last year of life in 2020 by age, sex and deprivation quintile



reconfiguring services, increasing community outreach, and adopting new technology for communication with patients, families, and professionals (Dunleavy et al. 2021). While some hospice and palliative care services reported being busier, others reported being less busy than before. Using data from the CovPall study, we explored the factors that were associated with hospice and palliative care services being more/less busy, seen in Figure 9.8 (Sleeman et al. 2021). Our findings indicated that services providing community care, and publicly managed services, may have been better able to respond to escalating needs during the pandemic. This has potential implications for both service delivery and funding models.

The CovPall Care Homes project examined the response of care homes in England to meet the rapidly increasing need for palliative and end-of-life care for residents during the Covid-19 pandemic (Bradshaw et al. 2023).

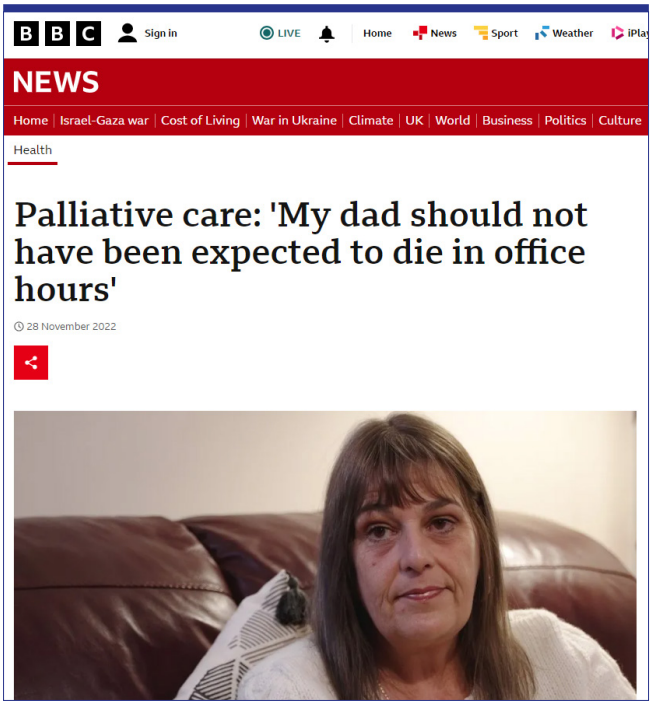
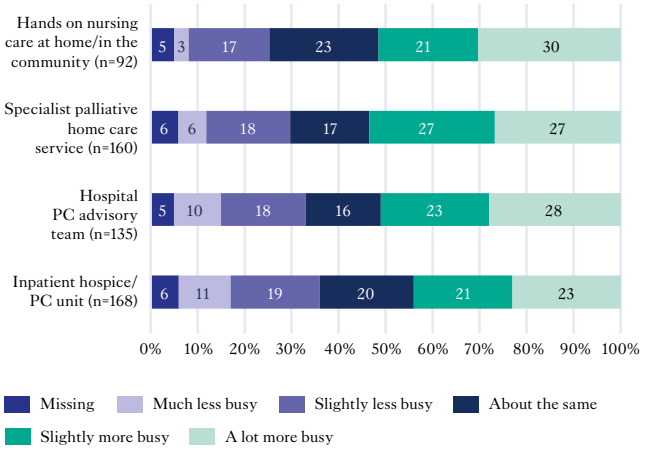


Figure 9.7. BBC news article in 2022 reporting the Better End of Life findings ('Palliative care: 'My dad should not have been expected to die in office hours" 2022)

Figure 9.8. The activity of hospice and palliative care services in the UK according to type of service provided



The study consisted of a survey sent to care home leads, followed by qualitative interviews. The findings were discussed in a series of conversations with stakeholders, including care home staff, family carers, academics, and policy experts. From this we developed policy recommendations for palliative and end-of-life care in care homes, in five areas (Sleeman, Bradshaw, et al. 2022):

1. Valuing the role of care homes and care home staff
2. Support for care home managers
3. Workforce development, training, and support in delivering palliative and end-of-life care
4. 'Spirit of partnership': Integration with primary and specialist palliative care
5. Digital inclusivity

Symptoms and measurement in Covid-19

The CovPall study, jointly funded by UKRI, Cicely Saunders International, and NIHR Applied Research Collaboration South London (South London ARC), is a key international study of specialist palliative services response to the Covid-19 pandemic. The CovPall study had two main parts: 1) collecting service data from 458 services, and 2) collecting patient data from 572 patients. The CovPall study showed that palliative care services supported people during the Covid-19 pandemic, developed 'frugal innovations' to care for more people (Dunleavy et al. 2021), and produced evidence on how to best manage symptoms (Oluyase et al. 2021; Sleeman, Cripps, et al. 2022; Higginson et al. 2022; Bradshaw et al. 2021; Walshe et al. 2022; Bajwah et al. 2021). It has been recognised as the most successful response to the Covid-19 pandemic informed by applied research at NIHR ARC South London's *Know your ARC Awards.*

The CovPall study has transformed the understanding of role palliative care services in pandemics and the importance of palliative care in the management of complex symptoms.

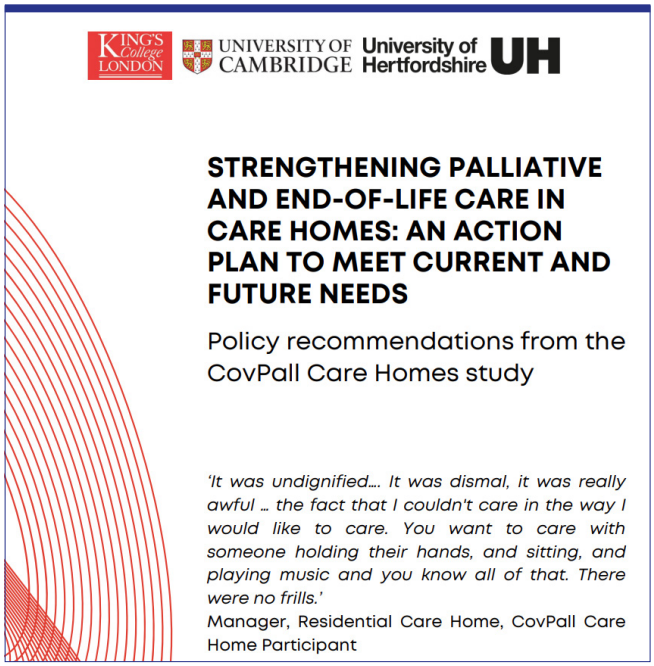
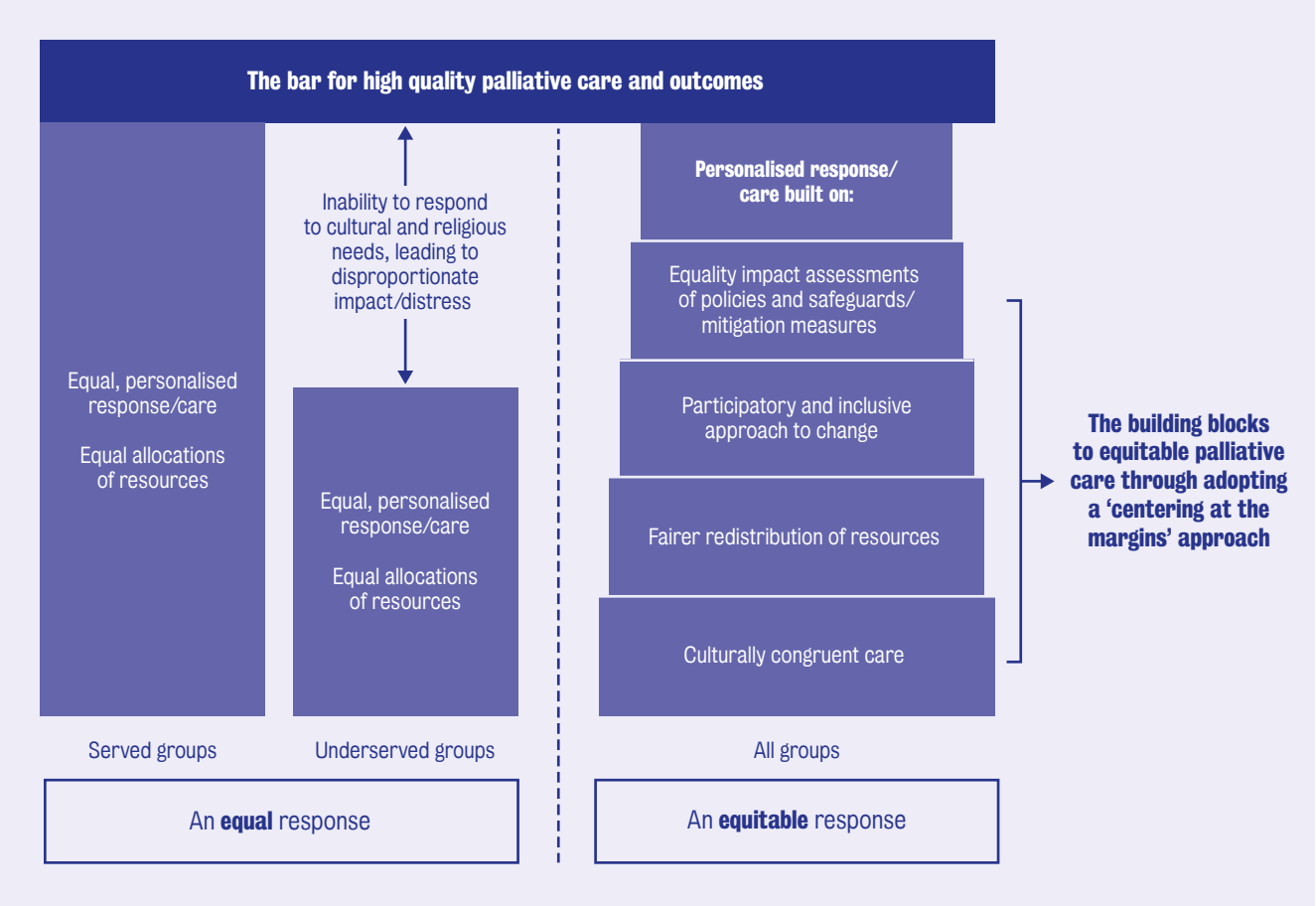


Figure 9.9. CovPall Care Homes policy brief



Figure 9.10. CovPall received the "Most successful response to Covid-19" awards at the NIHR ARC South London *Know Your ARC Awards*

Figure 9.11. The delivery of equal palliative care during the Covid-19 pandemic and recommendations for the future



Data from 572 patients with severe Covid-19 seen by 25 NHS and non-NHS palliative care services across England and Wales showed that palliative care can control symptoms in persons severely ill with Covid-19 (Higginson et al. 2022). Some of these patients were known to the services, while some were unknown but living with multiple long-term conditions. Among the 572 patients with Covid-19, breathlessness, cough, pain, anxiety, confusion/ delirium, agitation, fever, sore/dry mouth, and nausea significantly reduced between first and last assessment while they were receiving palliative care.

As part of the study, a new measure, Integrated Palliative care Outcome Scale was adapted and validated for Covid-19, named IPOS-COV. IPOS-COV is designed to support clinical decisions, inform case management, and improve monitoring of patients severely ill with Covid-19 (Hocaoglu et al. 2023). IPOS-COV is the first patient-centred measure adapted for severe Covid-19 to support timely management of symptoms and concerns.

With the Medical Research Foundation, we are co-designing and sharing information about the main evidence of the CovPall study, including how to best manage symptoms. We are developing and evaluating easily accessible, user-friendly, free resources for members of the public, patients, their loved ones, and leaders within health and social care, especially Integrated Care Boards and their system partners (i.e., local authorities and voluntary, community, faith and social enterprise organisations). We aim to mobilise the palliative care evidence to transform the understanding and integration of palliative care evidence so more people can benefit in a long-lasting way.

Covid-19 and inequalities at the end of life

The CovPall project also aimed to gain insight into the response of palliative care services for people from ethnically diverse groups during Covid-19. In total, 277 UK services responded, including 168 hospice teams (representing 76% of all UK hospice teams). Services supporting those from ethnic minority groups were more likely to include hospital-based teams and less likely to include hospice or home care teams. A third of services had cared for patients with Covid-19 or families from ethnic minority groups. Two-thirds of these services stated that there was no difference in how they supported or reached these groups during the pandemic (Bajwah et al. 2021).

Furthermore, we explored the impact of policies introduced during the pandemic and how they impacted ethnic minority groups. Themes from our findings include: 1) the disproportionate adverse impact of restricted visiting, 2) compounded communication challenges, 3) and unmet religious and faith needs, 4) mistrust of services by ethnic minority groups, and 5) equal and individualised care. As part of the published paper, we developed recommendations for the delivery of equitable care for underserved groups for the future.

These findings and recommendations have been presented at national and international conferences reaching 1000s of delegates, including plenary lectures at Marie Curie and Hospice UK conferences. In 2022, this research was cited in Parliamentary POSTnote on Palliative and end-of-life care ('UK Parlianment Post: Palliative and end of life care' 2022). In 2023, this research was cited in the World Health Organisation policy, Transforming the health and social equity landscape ("Transforming the health and social equity landscape: Promoting socially just and inclusive growth to improve resilience, solidarity and peace" 2023).

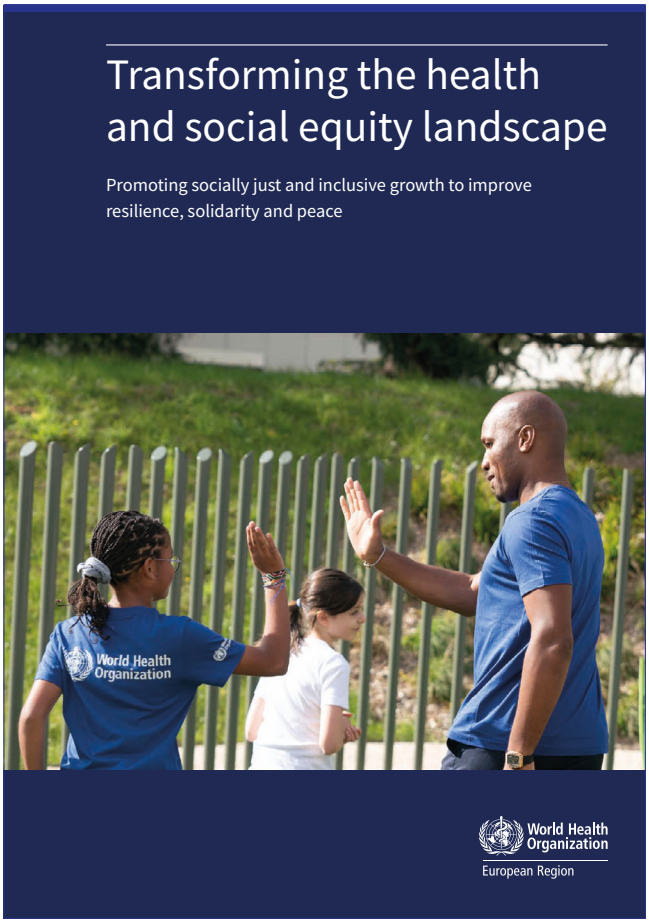


Figure 9.12 Transforming the Health and Social Policy Landscape, a World Health Organization report

Staff and contributions to the discipline

Staff lists 2020–2023

Academic

- **Dr Sabrina Bajwah** Senior Clinical Lecturer
- **Dr Anna Bone** Lecturer
- **Dr Lisa Brighton** Lecturer
- **Dr Katherine Bristowe** Senior Lecturer
- **Dr Jane Chudleigh** Senior Lecturer
- **Dr Clare Ellis-Smith** Lecturer
- **Professor Catherine Evans** Professor of Palliative Care and Honorary Nurse Consultant
- **Professor Lorna Fraser** Professor
- **Professor Wei Gao** Professor of Statistics and Epidemiology
- **Professor Richard Harding-Swale** Herbert Dunhill Chair of Palliative Care and Rehabilitation
- **Dr Lesley Henson** Clinical Lecturer
- **Professor Irene Higginson** Professor
- **Dr Jonathan Koffman** Reader
- **Professor Matthew Maddocks** Professor
- **Dr Peter May** Senior Lecturer
- **Professor Charles Normand** Professor
- **Dr Bethan Page** Lecturer
- **Professor Toby Prevost** Nightingale-Saunders Chair in Complex Clinical Trials and Statistics
- **Professor Katherine Sleeman** Laing Galazka Chair
- **Professor Lynne Turner-Stokes** Northwick Park Professor of Rehabilitation Medicine

Researchers

- **Tofunmi Aworinde** Research Assistant PhD Student
- **Izabele Batkovskyte** Research Assistant
- **Dr Jo Bayly** Research Associate
- **Abdelhamid Benalia** Research Assistant
- **Dr Sabah Boufkhed** Research Associate
- **Dr Andy Bradshaw** Research Associate
- **Dr Debbie Braybrook** Research Associate
- **Molly Brittain** Research Project and Coordination Assistant
- **Dot Brown** Research Associate
- **Joana Carvalho Vasconcelos** Research Fellow
- **Rachel Chambers** Research Project and Coordination Assistant
- **Dr Emeka Chukwusa** Research Associate
- **Dr Sarah Crabtree** Research Assistant
- **Dr Joanna Davies** Research Fellow
- **Marsha Dawkins** Clinical Research Fellow
- **Dr Liz Dzeng** Senior Research Fellow
- **Dr Annabel Farnood** Research Associate
- **Dr Lucy Fettes** Research Assistant
- **Alice Firth** Research Assistant PhD Student
- **Dr Liam Gabb** Clinical Research Associate PhD Student
- **Inez Gaczkowska** Research Project and Coordination Assistant
- **Juliet Gillam** Research Assistant PhD Student
- **Dr Joanna Goodrich** Research Associate
- **Dr Ping Guo** Research Associate
- **Daney Harðardóttir** Research Assistant
- **Catherine Harvey** Research Project and Coordination Assistant
- **Dr Nilay Hewitt** Research Fellow
- **Dr Mevhibe Hocaoglu** Research Associate
- **Pru Holder** Research Associate
- **Dr Kei Yan Hui** Research Associate
- **Dr Therese Johansson** Research Associate
- **Halle Johnson** Research Project and Coordination Assistant
- **Anna Johnston** Research Project and Coordination Assistant
- **Dr Duong Le** Research Assistant PhD Student
- **Dr Javiera Leniz Martelli** Research Associate
- **Dr Cheng-Pei Lin** Research Associate



Figure 10.1. Rounders game featuring the Academic Team versus the Clinical Team

- **Dr Rohan Mongru** Clinical Research Associate
- **Dr Kennedy Nkhoma** Research Fellow
- **Dr Adejoke Oluyase** Research Associate
- **Dr Anna Peeler** Research Associate
- **Clarissa Penfold** Research Assistant
- **Anna Roach** Research Project and Coordination Assistant
- **Eleanor Rochester** Research Assistant
- **Hannah Scott** Research Assistant PhD Student
- **India Tunnard** Research Project and Coordination Assistant
- **Dr Lydia Tutt** Research Associate
- **Frances Waite** Research Project and Coordination Assistant
- **Harry Watson** Research Assistant
- **Dr Lesley Williamson** Research Associate
- **Dr Deok Hee Yi** Research Fellow
- **Emel Yorganci** Research Assistant PhD Student

Clinical Staff

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- **Amy Jarvis** Team Secretary
- **Amy Kilby** CNS
- **Carolina Chiesa** CNS
- **Cathy Woollard** Service Delivery Manager
- **Charlotte Lee** SpR
- **Charoula Karpathiotaki** CNS
- **Chris Bridges** CNS
- **Cristi Sheridan-Hicks** CNS
- **Heather Holyoak** SpR
- **Helen Stephens** CNS
- **Janna Nagy** CNS
- **Katherine Sleeman** Consultant
- **Khadijah Lawrence** Service Delivery Manager
- **Leanne Boyle** CNS
- **Liam Gabb** SpR
- **Mahi Mahadevanachari** CNS
- **Margaret Boyle** CNS
- **Marilina Monti** SpR
- **Mitali Patel** Consultant
- **Nikki Larking** Social Worker
- **Paramjote Kaler** Senior Research Nurse
- **Phoebe Wright** SpR
- **Polly Edmonds** Consultant
- **Prof Irene Higginson** Honorary Consultant
- **Rachel Burman** Consultant
- **Rebecca Darge** Consultant
- **Regina Craig** Matron
- **Richard Towers** Consultant Nurse
- **Ruth Ting** Consultant
- **Sabrina Bajwah** Consultant
- **Steve Marshall** Social Worker
- **Susan Connolly** PDN
- **Theresa Tran** SpR
- **Wendy Prentice** Consultant

Guy's and St Thomas'

- **Conor Seamus Murray** Social Worker
- **Stephanie Elizabeth Russo** Social Worker
- **Bernadette Mary McDonald** Social Worker
- **Nimisha Surendra Panchmatia** Specialist Occupational Therapist
- **Marsha Dawkins** Deputy Head of Nursing – Palliative Care
- **Helen Thurkettle** Nurse Consultant
- **Joanna Louise Bate** Matron
- **Lucinda Inglis** Pal@Home Matron
- **Louise Johnina Gunn** Pal@Home Matron
- **Gemma Louise O'Driscoll** CNS
- **Abbie Cooper** CNS
- **Katherine Elizabeth Durnan** CNS
- **Georgina Anne Robb** CNS
- **Maria Gireada** CNS
- **Joanna Mary Maddicks** CNS
- **Katherine Elaine Hall** CNS
- **Mike Monypenny** CNS
- **Natalie Nabunya** CNS
- **Grainne Barbara Finnerty** CNS
- **Melissa Gwyneth Cook** CNS
- **Sarah Maeve Charters** CNS
- **Ellen Chan** CNS
- **Naomi Margaret Wells** CNS
- **Anna Hadley** CNS
- **Kimberley McCusker** CNS
- **Kelsie Reading** CNS
- **Rachel Elizabeth Meen** CNS
- **Amanda Louise Bailey** CNS
- **Louise Sara Smith** CNS
- **Jenny Wong** CNS
- **Elena Ivany** CNS
- **Marie Kamara** CNS
- **Nicola Walker** Senior Nurse Practitioner
- **Isobel Jane Newman** Deputy CNS
- **Emily Mogg** Deputy CNS
- **Katie Mew** Deputy CNS
- **James Rennie Aird** Deputy CNS
- **Lucy Elizabeth** Spike Deputy CNS
- **Charlotte Malone** Deputy CNS
- **Jasmin Amores** Deputy CNS
- **George Robert** Consultant
- **Dr Sangeetha Sathianandan** Speciality Doctor
- **Vora Vandana** Consultant
- **Dr Kate Crossland** Speciality Doctor
- **Dr Teresa Anne Beynon** Consultant
- **Dr Nicholas John Gough** Consultant
- **Dr Irene Siobhan Carey** Consultant
- **Dr Shaheen Khan** Clinical Director
- **Dr Dominique Wakefield** Consultant
- **Dr Stephanie Eileen Hicks** Consultant
- **Karen Jean Hutchinson** Advanced Nurse Practitioner
- **Peju Olokun** Advanced Nurse Practitioner
- **Binty Bridget Bangura** Senior Nurse Practitioner
- **Mary Faponle** Senior Staff Nurse
- **Jessica Olrunfumie** Theodora Konneh Senior Staff Nurse
- **Collette Rosendale** Senior Staff Nurse
- **Uloma Christian** Senior Staff Nurse
- **Mabel Chinyere Udeagha** Senior Staff Nurse
- **Marian Nyamilembe** Senior Staff Nurse
- **Tiaan Coetzee** Senior Nursing Assistant
- **Linda D'Costa-Magro** Senior Nursing Assistant

Royal Brompton and Harefield hospitals

- **Rachel Conway** Nursing
- **Lynn Shedden** Nursing
- **Helen Bass** Nursing
- **Zoe Kabeli** Nursing
- **Jo Griffiths** Nursing
- **Jayne Langdale** Nursing
- **Bonnie Oakley** Nursing
- **Lucia Menneghelli** Nursing
- **David Smith** Nursing
- **Sarah Wake** Nursing
- **Gilli Erez** HH Consultant



Figure 10.2. Prof Catherine Evans and Dr Clare Ellis-Smith welcome visitors to the Cicely Saunders Institute

- **Andrew Tweddle** Consultant
- **Armita Jamali** Consultant
- **Rosa Osborne** Administrator/Coordinator

Princess Royal University Hospital

- **Leena Srivastava** Consultant
- **Fiona Ring** Consultant
- **Louise Exton** Consultant
- **Natalie Webber** Consultant (Mat Leave)
- **Deborah Brown** CNS
- **Kay Casson** CNS
- **Carolym Chandler** CNS
- **Diane Farringdon** CNS
- **Lara McCarthy** CNS
- **Sarah Spencer-Adams** CNS
- **Esther Williams** CNS
- **Concepta Jackson** Matron
- **Kar Yan Kimmy Lam** Social Worker
- **Catherine Short** Administrator

Professional Services

- **Sian Best** Administrative Director, Cicely Saunders International
- **Emily Boocock** Research Administrator
- **Ryana Dhali** Research Administrator
- **Petar Lachev** Senior Programmes Officer
- **Virginie Lambertucci** Research Projects Administrator
- **Ho Yan Janet Lau** EA to Professor Higginson



Figure 10.3. The Cicely Saunders Institute's faculty, students, and staff celebrate the annual summer party

- **Isabella Millet** Research Administrator
- **Karen Murphy** EA to Professor Higginson
- **Veronica Murrey** PA to Professor Richard Harding
- **Chloe Nast** Research Administrator
- **Debbie Spreadborough** Business Manager
- **Beka Torlay** Research Administrator
- **Mark Willis** Senior Programmes Officer

Macmillan Centre Staff

- **Feyesola Banjo** Cancer Quality Improvements Manager
- **Lindsay Farthing** Cancer Quality Improvements Manager
- **Michelle Goode** Manager
- **Katheryn Hair** Interim Manager
- **Carolyn Walker** Interim Manager
- **Amber Rogers** Assistant Manager
- **Nichola Murphy** Administrator
- **Diane Sinclair** Administrator

PhD Students

- Mary Abboah-Offei
- Khulood Alyami
- Oladayo Afolabi
- Tofunmi Aworinde
- Lisa Brighton
- Megan Bowers
- Ling Hui Chen
- Lucy Coombes
- Joanna Davies
- Fei Fei
- Lucy Fettes
- Alice Firth
- Miki Fujimoto
- Nahla Gafer
- Nuhamin Tekle Gebre
- Alessandra Giusti
- Juliet Gillam
- Sameera Helal
- Megumi Kishino
- Houshen Li Cheng-Pei Lin
- Natasha Lovell
- Javiera Martelli
- Jacqueline Miller
- Yihan Mo Eve Namisango
- Carmine Petrasso
- Charlie Rogers
- Hannah Scott



Figure 10.4. Professor Matt Maddox and team celebrate the Chinese New Year

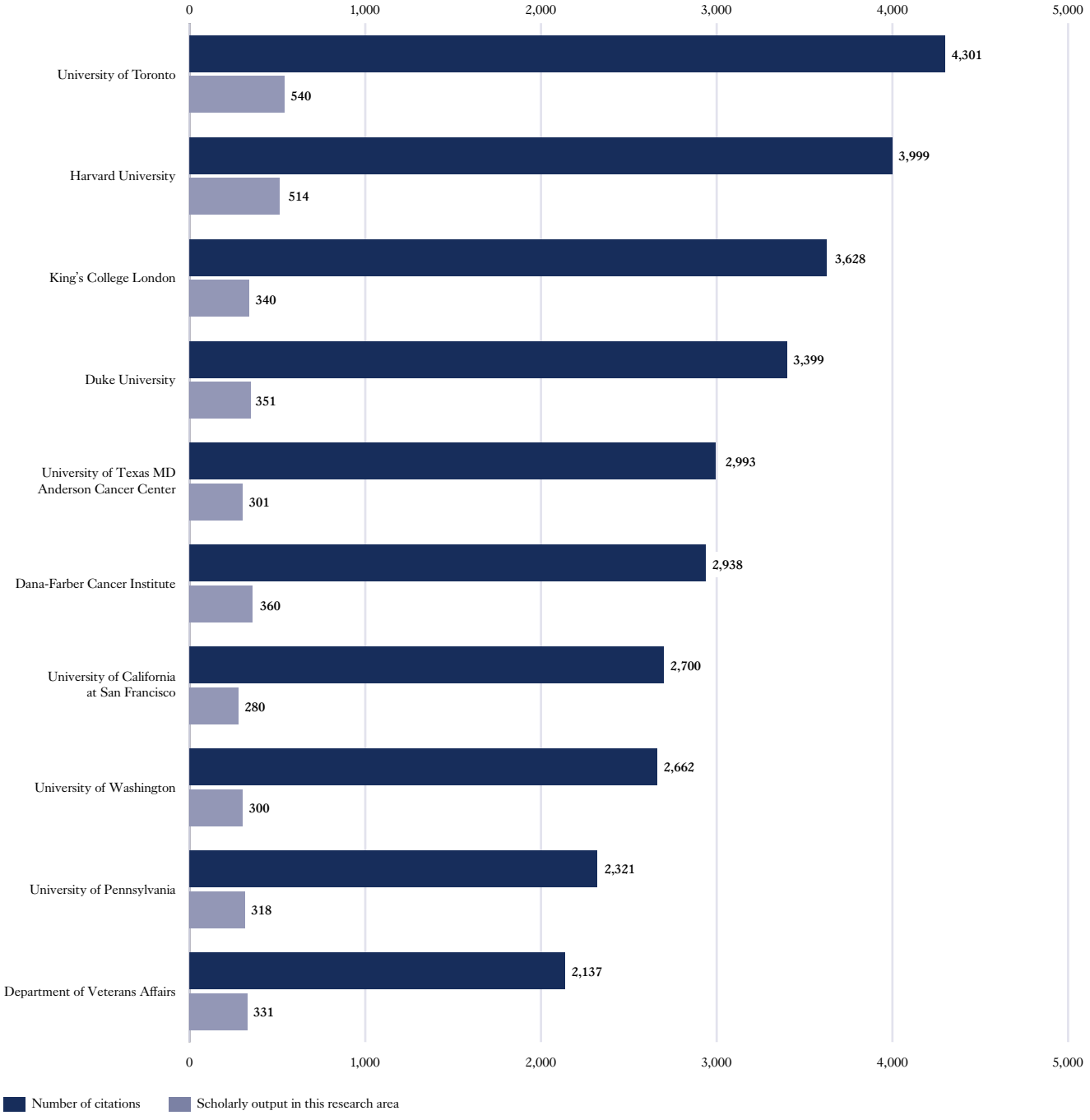
- Natalie St Clair-Sullivan
- Wilailak (Yok) Sakharang
- Emel Yorganci
- Yuxin Zhou

Visiting appointments

- **Dr Stephen Ashford** Honorary Reader
- **Dr Nicola Ayers** Visiting Research Fellow
- **Dr Tushti Bhardwaj** Visiting Senior Lecturer
- **Dr Sabah Boufkhed** Visiting Research Fellow
- **Dr Lucy Coombes** Visiting ResearchAssociate
- **Dr Massimo Costantini** Visiting Senior Lecturer
- **Marsha Dawkins** Hon research Assistant
- **Professor Julia Downing** Visiting Senior Research Fellow
- **Dr Ayaka Fujiita** Visiting Research Associate
- **Maja Furlan de Brito** Visiting Research Associate
- **Dr Barbara Gomes Da Silva** Visiting Senior Research Fellow
- **Rev Dr Andrew Goodhead** Visiting Lecturer
- **Dr Joanna Goodrich** Visiting Research Associate
- **Dr Nicholas Gough** Honorary Senior Lecturer
- **Dr Ping Guo** Visiting Senior Lecturer
- **Dr Lesley Henson** Visiting Senior Lecturer
- **Frank Jackson-Hill** Visiting Research Fellow
- **Halle Johnson** Visiting Research Assistant
- **Dr Eun Sook Kim** Visiting Research Assistant
- **Professor Jonathan Koffman** Visiting Professor
- **Sophie Law-Clucas** Visiting Research Assistant
- **Javiera Leniz-Martelli** Visiting Research Assistant
- **Dr Cheng-Pei Lin** Visiting Research Fellow
- **Dr Natasha Lovell** Visiting Research Fellow
- **Dr Samantha Lund** Visiting Senior Lecturer
- **Catthi Ly** Visiting Research Assistant
- **Dr Steve Marshall** Honorary Senior Lecturer
- **Professor Felicity Murtagh** Visiting Professor
- **Monica Oancea** Visiting Research Assistant
- **Sophie Pask** Visiting Research Associate
- **Dr Charles Reilly** Adjunct Senior Lecturer
- **Anna Roach** Visiting Research Assistant
- **Professor Steffen Simon** Visiting Research Fellow
- **Dr Peter Speck** Visting Senior Lecturer
- **Dr Margaret Dingle Spence** Visiting Associate Lecturer
- **Dr Ruth Ting** Honorary Senior Lecturer
- **Dr Richard Towers** Honorary Senior Lecturer
- **Dr Dominque Wakefield** Honorary Senior Lecturer
- **Harry Watson** Visiting Research Assistant
- **Sofia Weiss Goitiandia** Visiting Research Assistant
- **Dr Rebecca Wilson** Visiting Reearch Associate
- **Dr Deokhee Yi** Visiting Research Fellow

Publications

Figure 10.5. Research output for the top ten institutions globally from 2020–2023 based on a title-keyword-abstract search for ‘palliative care’ in the SciVal database as of 1 February 2024



Source: SciVal

Top 10 publications by Altmetrics score

Publication	Score
Ting, R., Edmonds, P., Higginson, I. J., & Sleeman, K. E. (2020). Palliative care for patients with severe covid-19. BMJ, 370, m2710. https://doi.org/10.1136/bmj.m2710	635
Koffman, J., Gross, J., Etkind, S. N., & Selman, L. (2020). Uncertainty and COVID-19: how are we to respond? Journal of the Royal Society of Medicine, 113(6), 211–216. https://doi.org/10.1177/0141076820930665	385
Ward, J. L., Harwood, R., Kenny, S., Cruz, J., Clark, M., Davis, P. J., Draper, E. S., Hargreaves, D., Ladhani, S. N., Gent, N., Williams, H. E., Luyt, K., Turner, S., Whittaker, E., Bottle, A., Fraser, L. K., & Viner, R. M. (2023). Pediatric Hospitalizations and ICU Admissions Due to COVID-19 and Pediatric Inflammatory Multisystem Syndrome Temporally Associated With SARS-CoV-2 in England. JAMA Pediatrics, 177(9), 947–955. https://doi.org/10.1001/jamapediatrics.2023.2357	275
Bone, A. E., Finucane, A. M., Leniz, J., Higginson, I. J., & Sleeman, K. E. (2020). Changing patterns of mortality during the COVID-19 pandemic: Population-based modelling to understand palliative care implications. Palliative Medicine, 34(9), 1193–1201. https://doi.org/10.1177/0269216320944810	173
Bajwah, S., Oluyase, A. O., Yi, D., Gao, W., Evans, C. J., Grande, G., Todd, C., Costantini, M., Murtagh, F. E., & Higginson, I. J. (2020). The effectiveness and cost-effectiveness of hospital-based specialist palliative care for adults with advanced illness and their caregivers. Cochrane Database Syst Rev, 9(9), Cd012780. https://doi.org/10.1002/14651858.CD012780. Pub2	159
Puthucheary, Z., Brown, C., Corner, E., Wallace, S., Highfield, J., Bear, D., Rehill, N., Montgomery, H., Aitken, L., & Turner-Stokes, L. (2022). The Post-ICU presentation screen (PICUPS) and rehabilitation prescription (RP) for intensive care survivors part II: Clinical engagement and future directions for the national Post-Intensive care Rehabilitation Collaborative. J Intensive Care Soc, 23(3), 264–272. https://doi.org/10.1177/1751143720988708	138
Etkind, S. N., Bone, A. E., Lovell, N., Cripps, R. L., Harding, R., Higginson, I. J., & Sleeman, K. E. (2020). The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the COVID-19 Pandemic. Journal of Pain and Symptom Management, 60(1), e31-e40. https://doi.org/10.1016/j. Jpainsymman.2020.03.029	138
Bajwah, S., Wilcock, A., Towers, R., Costantini, M., Bausewein, C., Simon, S. T., Bendstrup, E., Prentice, W., Johnson, M. J., Currow, D. C., Kreuter, M., Wells, A. U., Birring, S. S., Edmonds, P., & Higginson, I. J. (2020). Managing the supportive care needs of those affected by COVID-19. European Respiratory Journal, 55(4), 2000815. https://doi.org/10.1183/13993003.00815-2020	138
Chapman, E. J., Edwards, Z., Boland, J. W., Maddocks, M., Fettes, L., Malia, C., Mulvey, M. R., & Bennett, M. I. (2020). Practice review: Evidence-based and effective management of pain in patients with advanced cancer. Palliative Medicine, 34(4), 444–453. https://doi.org/10.1177/0269216319896955	137
Hussain, J. A., Koffman, J., & Bajwah, S. (2021). Racism and palliative care. Palliative Medicine, 35(5), 810–813. https://doi.org/10.1177/02692163211012887	133

Key publications 2020–2023

Evaluating and improving care

Design and Evaluation of a Novel Mobile Phone Application to Improve Palliative Home-Care in Resource-Limited Settings. Harding R, Carrasco JM, Serrano-Pons J, Lemaire J, Namisango E, Luyirika E, Immanuel T, Paleri AK, Mathews L, Chifamba D, Mupaza L, Martínez CL, Zirimenya L, Bouësseau MC, Krakauer EL. J Pain Symptom Manage. 2021 Jul;62(1):1–9. doi: 10.1016/j.Jpainsymman.2020.09.045. Epub 2020 Nov 24. PMID: 33246073

Developing a global practice-based framework of person-centred care from primary data: a cross-national qualitative study with patients, caregivers and healthcare professionals. Giusti A, Pukrittayakamee P, Alarja G, Farrant L, Hunter J, Mzimkulu O, Gwyther L, Williams N, Wannarit K, Abusalem L, Alajarmeh S, Alrjoub W, Thongchot L, Janwanishstaporn S, Edilbi A, Al-Ani R, Shamieh O, Guo P, Bashan Nkhoma K, Venkatapuram S, Harding R. BMJ Glob Health. 2022 Jul;7(7):e008843. doi: 10.1136/bmjgh-2022-008843. PMID: 35831035

Electronic palliative care coordination systems (EPaCCS): a systematic review. Leniz J, Weil A, Higginson IJ, Sleeman KE. BMJ Support Palliat Care. 2020 Mar;10(1):68–78. doi: 10.1136/bmjspcare-2018-001689. Epub 2019 May 8. PMID: 31068334

Immediate versus delayed short-term integrated palliative care for advanced long-term neurological conditions: the OPTCARE Neuro RCT. Hepgul N, Wilson R, Yi D, Evans C, Bajwah S, Crosby V, Wilcock A, Lindsay F, Byrne A, Young C, Groves K, Smith C, Burman R, Chaudhuri KR, Silber E, Higginson IJ, Gao W. Southampton (UK): NIHR Journals Library; 2020 Sep. PMID: 32902934

Implementation of eHealth to Support Assessment and Decision-making for Residents With Dementia in Long-term Care: Systematic Review. Gillam J, Davies N, Aworinde J, Yorganci E, Anderson JE, Evans C. J Med Internet Res. 2022 Feb 3;24(2):e29837. doi: 10.2196/29837. PMID: 35113029

Improving bereavement outcomes in Zimbabwe: results of a feasibility cluster trial of the 9-cell bereavement tool. Mutedzi B, Nkhoma K, Langhaug L, Hunt J, Harding R. Pilot Feasibility Stud. 2023 Jul 21;9(1):127. doi: 10.1186/s40814-023-01313-2. PMID: 37480142

Integrated Primary Palliative Care in Nigeria – Perspectives of Patients, Families and Providers. Afolabi OA, Nkhoma K, Soyannwo O, Aje A, Ogunniyi A, Harding R, Maddocks M. J Pain Symptom Manage. 2022 Oct;64(4):319–329. doi: 10.1016/j. Jpainsymman.2022.06.019. Epub 2022 Jul 11. PMID: 35835429

Mechanisms and contextual influences on the implementation of advance care planning for older people in long-term care facilities: A realist review. Zhou Y, Wang A, Ellis-Smith C, Braybrook D, Harding R. Int J Nurs Stud. 2022 Sep;133:104277. doi: 10.1016/j.Ijnurstu.2022.104277. Epub 2022 Apr 30. PMID: 35717924

Phase II mixed methods' feasibility cluster randomised controlled trial of a novel community-based enhanced care intervention to improve person-centred outcomes for people living with HIV in Ghana. Abboah-Offei M, Bristowe K, Vanderpuye-Donton NA, Ansa G, Oppong-Agyei YD, Abas M, Higginson I, Harding R. AIDS Care. 2020 May;32(sup2):107–118. doi: 10.1080/09540121.2020.1739217. Epub 2020 Mar 13. PMID: 32164440



Figure 10.6. Dr Lisa Brighton, Mino Petrasso, Emily Boocock, Dr Jo Bayly, and Megan Bowers spend a productive day at the Cicely Saunders Institute building

Resistance training in advanced cancer: a phase II safety and feasibility trial-home versus hospital. Ribeiro C, Santos R, Correia P, Maddocks M, Gomes B. BMJ Support Palliat Care. 2022 Sep;12(3):287–291. doi: 10.1136/bmjspcare-2020-002230. Epub 2020 Aug 13. PMID: 32792420

Standards, Guidelines, and Quality Measures for Successful Specialty Palliative Care Integration Into Oncology: Current Approaches and Future Directions. Kamal AH, Bausewein C, Casarett DJ, Currow DC, Dudgeon DJ, Higginson IJ. J Clin Oncol. 2020 Mar 20;38(9):987–994. doi: 10.1200/JCO.18.02440. Epub 2020 Feb 5. PMID: 32023165

The effectiveness and cost-effectiveness of hospital-based specialist palliative care for adults with advanced illness and their caregivers. Bajwah S, Oluyase AO, Yi D, Gao W, Evans CJ, Grande G, Todd C, Costantini M, Murtagh FE, Higginson IJ. Cochrane Database Syst Rev. 2020 Sep 30;9(9):CD012780. doi: 10.1002/14651858.CD012780. Pub2. PMID: 32996586

Symptom-led research

"I have failed to separate my HIV from this pain": the challenge of managing chronic pain among people with HIV. Baker V, Nkhoma K, Trevelion R, Roach A, Winston A, Sabin C, Bristowe K, Harding R. AIDS Care. 2023 Aug;35(8):1164–1172. doi: 10.1080/09540121.2020.1869148. Epub 2021 Jan 14. PMID: 33443450

A randomised, controlled, feasibility trial of an online, self-guided breathlessness supportive intervention (SELF-BREATHE) for individuals with chronic breathlessness due to advanced disease. Reilly CC, Maddocks M, Chalder T, Bristowe K, Higginson IJ. ERJ Open Res. 2023 Apr 11;9(2):00508-2022. doi: 10.1183/23120541.00508-2022. eCollection 2023 Mar. PMID: 37057089

Depressive Symptoms and Palliative Care Concerns Among Patients With Non-communicable Diseases in Two Southern African Countries. Namisango E, Powell RA,



Figure 10.7. Colleagues gather for the BETTER-B Consortium meeting in November 2023

Taylor S, Radbruch L, Freeman R, Haufiku D, Mwagomba BM Dr, Acuda W, Thambo L, Kambiya I, Luyirika EBK, Mwangi-Powell FN, Harding R. J Pain Symptom Manage. 2023 Jan;65(1):26–37. doi: 10.1016/j.Jpainsymman.2022.09.008. Epub 2022 Sep 24. PMID: 36162705

Disability in Basic Activities of Daily Living Is Associated With Symptom Burden in Older People With Advanced Cancer or Chronic Obstructive Pulmonary Disease: A Secondary Data Analysis. Fettes L, Bone AE, Etkind SN, Ashford S, Higginson IJ, Maddocks M. J Pain Symptom Manage. 2021 Jun;61(6):1205–1214. doi: 10.1016/j. Jpainsymman.2020.10.012. Epub 2020 Oct 21. PMID: 33096219

Effect of listening to breathing recordings on self-reported breathlessness: a public experiment. Lovell N, Etkind SN, Davies JM, Prentice W, Higginson IJ, Sleeman KE. Eur Respir J. 2023 Jul 20;62(1):2201439. doi: 10.1183/13993003.01439-2022. Print 2023 Jul. PMID: 37105574

Experiences of Pulmonary Rehabilitation in People Living with Chronic Obstructive Pulmonary Disease and Frailty. A Qualitative Interview Study. Brighton LJ, Bristowe K, Bayly J, Ogden M, Farquhar M, Evans CJ, Man WDC, Maddocks M. Ann Am Thorac Soc. 2020 Oct;17(10):1213–1221. doi: 10.1513/AnnalsATS.201910-800OC. PMID: 32644823

High Prevalence and Burden of Physical and Psychological Symptoms in a Chronic Obstructive Pulmonary Disease Population in Primary Care Settings in South Africa. Nkhoma KB, Farrant L, Mzimkulu O, Hunter J, Higginson I, Gao W, Maddocks M, Gwyther L, Harding R. Int J Chron Obstruct Pulmon Dis. 2023 Aug 2;18:1665–1679. doi: 10.2147/COPD.S395834. eCollection 2023. PMID: 37554921

Improving Exercise-Based Interventions for People Living with Both COPD and Frailty: A Realist Review. Brighton LJ, Evans CJ, Man WDC, Maddocks M. Int J Chron Obstruct Pulmon Dis. 2020 Apr 20;15:841–855. doi: 10.2147/COPD.S238680. eCollection 2020. PMID: 32368030

Meditative movement for breathlessness in advanced COPD or cancer: a systematic review and meta-analysis. Nolan CM, Brighton LJ, Mo Y, Bayly J, Higginson IJ, Man WD, Maddocks M. Eur Respir Rev. 2023 Jun 21;32(168):220243. doi: 10.1183/16000617.0243-2022. Print 2023 Jun 30. PMID: 37343961

Optimising breathlessness triggered services for older people with advanced diseases: a multicentre economic study (OPTBreathe). Yi D, Reilly CC, Wei G, Higginson IJ;



Figure 10.8. A welcome for prospective students

OPTBreathe collaborators. Thorax. 2023 May;78(5):489–495. doi: 10.1136/thoraxjnl-2021-218251. Epub 2022 Aug 15. PMID: 35970540

Pharmacological and nonpharmacological interventions to improve symptom control, functional exercise capacity and quality of life in interstitial lung disease: an evidence synthesis. Bajwah S, Colquitt J, Loveman E, Bausewein C, Almond H, Oluyase A, Dzingina M, Maddocks M, Higginson IJ, Wells A. ERJ Open Res. 2021 Jan 25;7(1):00107-2020. doi: 10.1183/23120541.00107-2020. eCollection 2021 Jan. PMID: 33532482

Randomised, double-blind, multicentre, mixed-methods, dose-escalation feasibility trial of mirtazapine for better treatment of severe breathlessness in advanced lung disease (BETTER-B feasibility). Higginson IJ, Wilcock A, Johnson MJ, Bajwah S, Lovell N, Yi D, Hart SP, Crosby V, Poad H, Currow D, Best E, Brown S; BETTER-B Feasibility Trial Group. Thorax. 2020 Feb;75(2):176–179. doi: 10.1136/thoraxjnl-2019-213879. Epub 2020 Jan 8. PMID: 31915308

Social dimensions of chronic respiratory disease: stigma, isolation, and loneliness. Brighton LJ, Chilcot J, Maddocks M.Curr Opin Support Palliat Care. 2022 Dec 1;16(4):195–202. doi: 10.1097/SPC.0000000000000616. Epub 2022 Sep 13. PMID: 36102929

The association between socioeconomic position and the symptoms and concerns of hospital inpatients seen by specialist palliative care: Analysis of routinely collected patient data. Davies JM, Sleeman KE, Ramsenthaler C, Prentice W, Maddocks M, Murtagh FE. Palliat Med. 2023 Apr;37(4):575–585. doi: 10.1177/02692163221115331. Epub 2022 Aug 10. PMID: 35949141

What influenced people with chronic or refractory breathlessness and advanced disease to take part and remain in a drug trial? A qualitative study. Lovell N, Etkind SN, Bajwah S, Maddocks M, Higginson IJ. Trials. 2020 Feb 22;21(1):215. doi: 10.1186/s13063-020-4129-2. PMID: 32087745

Person-centred outcome measures (PCOMs)

"The whole of humanity has lungs, doesn't it? We are not all the same sort of people": patient preferences and choices for an online, self-guided chronic breathlessness supportive intervention: SELF-BREATHE. Reilly CC, Bristowe K, Roach A, Chalder T, Maddocks M, Higginson IJ. ERJ Open Res. 2022 Jul 11;8(3):00093-2022. doi: 10.1183/23120541.00093-2022. eCollection 2022 Jul. PMID: 35821758

A systematic review of impact of person-centred interventions for serious physical illness in terms of outcomes and costs. Nkhoma KB, Cook A, Giusti A, Farrant L, Petrus R, Petersen I, Gwyther L, Venkatapuram S, Harding R. BMJ Open. 2022 Jul 13;12(7):e054386. doi: 10.1136/bmjopen-2021-054386. PMID: 35831052

Are patient outcomes improved by models of professionally-led community HIV management which aim to be person-centred? A systematic review of the evidence. Abboah-Offei M, Bristowe K, Harding R. AIDS Care. 2021 Sep;33(9):1107–1117. doi: 10.1080/09540121.2020.1798865. Epub 2020 Aug 3. PMID: 32741201

Concerns and priority outcomes for children with advanced cancer and their families in the Middle East: A cross-national qualitative study. Boufkhed S, Yurduşen S, Alarjeh G, Ahmed F, Alrjoub W, Guo P, Alajarmeh S, Şengelen M, Cemaloğlu M, Aydın B, Alnassan A, Al-Awady S, Kutluk T, Shamieh O, Harding R. Front Oncol. 2023 Mar 14;13:1120990. doi: 10.3389/fonc.2023.1120990. eCollection 2023. PMID: 36998436

Face and content validity, acceptability, feasibility, and implementability of a novel outcome measure for children with life-limiting or life-threatening illness in three sub-Saharan African countries. Namisango E, Bristowe K, Murtagh FE, Downing J, Powell RA, Atieno M, Abas M, Ali Z, Luyirika EB, Meiring M, Mwangi-Powell FN, Higginson IJ, Harding R. Palliat Med. 2022 Jul;36(7):1140–1153. doi: 10.1177/02692163221099583. Epub 2022 Jun 2. PMID: 35656638



Figure 10.9. Collaborative output from participants at the Science Museum Late on dying with dementia

Goal-setting and attainment in prolonged disorders of consciousness – development of a structured approach. Turner-Stokes L, Rose H, Lakra C, Williams H, Ashford SA, Siegert RJ. Brain Inj. 2020;34(1):78–88. doi: 10.1080/02699052.2019.1682190. Epub 2019 Oct 30. PMID: 31661982

How can we achieve person-centred care for people living with HIV/AIDS? A qualitative interview study with healthcare professionals and patients in Ghana. Abboah-Offei M, Bristowe K, Koffman J, Vanderpuye-Donton NA, Ansa G, Abas M, Higginson I, Harding R. AIDS Care. 2020 Dec;32(12):1479–1488. doi: 10.1080/09540121.2019.1698708. Epub 2019 Dec 4.

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Figure 10.11. Professor Katherine Sleeman gives a talk at St Martins in the Fields

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Figure 10.12. Clinical team members from the Guy's and St Thomas' NHS Foundation Trust

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Figure 10.13. CSI colleagues welcome Professor Eduardo Bruera during his visit to accept the Fellowship of King's College

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Figure 10.14. MSc students participate in the HyFlex Research Methods module

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Contributions to the discipline

We **collaborate globally** across six continents. Our staff have active collaborations with more than 100 universities and research institutions and all UK universities with palliative care programs. Examples include:

- UK: Hull York Medical School, Imperial College London, Manchester University, National Collaborative for Post-Intensive Care Rehabilitation, University College London, University of Cambridge, University of Leeds, University of Liverpool, University of Nottingham, University of Sheffield
- Europe: European Association for Palliative Care, European Respiratory Society, Fonden for Almen Praxis (Denmark), Ludwig-Maximilians-Universität München (Germany), Lyon Ingénierie Projets (France), Universita Cattolica Del Sacro Cuore (Italy), Universitet i Bergen (Norway), Uniwersytet Mikolaja Kopernika (Poland), Trinity College Dublin (Ireland) Africa: African Palliative Care Association, Makerere University (Uganda), University of Cape Town (South Africa), University of Zimbabwe
- Americas: Harvard Medical School (USA), Johns Hopkins University (USA), Memorial Sloan Kettering (USA), University of California at San Francisco (USA), University of São Paulo (Brazil) Asia-Pacific: Auckland University of Technology (New Zealand), University of Medicine and Pharmacy in Ho Chi Minh City (Vietnam), University of Melbourne (Australia), University of Technology Sydney (Australia), University of Wollongong (Australia)

Members of the Institute staff serve on numerous **editorial and advisory boards** and regularly review for top international journals within and beyond palliative care and rehabilitation. Examples include:

- BMJ Open
- Clinical Academic Roles Implementation Network (CARIN)
- Disability and Rehabilitation
- European Association for Palliative Care Paediatric Task Force
- European Journal of Paediatrics
- Frontiers in Rehabilitation
- Journal of Palliative Medicine
- Journal of Clinical Oncology
- NIHR Research Design Service
- Palliative and Supportive Care
- Palliative Medicine

We undertake **advisory and consolatory roles** for discipline specific, professional, and health and social care organisations across government, charities, and industry in the UK and internationally. Examples include:

- Asthma and Lung UK's Lung Research Innovation Group
- European Association for Palliative Care LGBT+ Inclusive Palliative and End-of-Life Care Taskforce
- National Institute for Health and Care Excellence (NICE) guidelines development groups
- NHS England Clinical Reference Group for Rehabilitation and Complex Disability Specialised Services
- Royal College of Physicians' Medical Specialties Board

- Scottish Government Strategy Steering Group for Palliative Care
- World Health Organization

Several **prizes and honours** have been awarded to Institute staff during this report period, including:

- CovPall Team – Know Your ARC Award for "Most successful response to the Covid-19 pandemic informed by applied research"
- Catherine Evans – Honorary Nurse Consultant Palliative Care, Sussex Community NHS Foundation Trust
- Irene Higginson – Top 30 female scientists in the UK by Research.com
- Irene Higginson – King's Fellow
- Matthew Maddocks – European Respiratory Society Mid-Career Gold Medal for Allied Health Professionals
- Public Involvement Strategy Group – Know your ARC Award for "Most Innovative Patient, Public Involvement and Engagement Activity"
- Stephen Ashford – Fellow, Society of Physiotherapy

MSc alumni 2020 and their research dissertations

Ella Abramovich The bereavement experience of partners from the LGBT+ community: A secondary thematic analysis of in-depth interviews

Emily Adam The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review

Visikili Archontaki The involvement of ketamine in the treatment of complex regional pain syndrome

Thomas Banfi A chance to make somebody's life better: Patients and caregivers experiences of specialist palliative care for people severely affected by long-term neurological conditions: a secondary analysis of qualitative interviews



Figure 10.15. Dr Mevhibe Hocaoglu engages with colleagues in Brazil

Kim Barlow The motivations and experiences of hospice volunteers undertaking physical rehabilitation programmes with people with life-limiting illness in the community: A qualitative study

Carina Trejo Castro Insights from Twitter about public perceptions of palliative care: A comparison between Mexico and the United Kingdom

Karina Catley Paramedics' experience and perception of the integration of 'Coordinate My Care' into prehospital healthcare practice: Qualitative interviews

Tatiana Chavouzi Bereavement experiences through culture: A secondary qualitative analysis of free text in a mortality follow-back survey

Huei Chung Palliative care needs, models, interventions and outcome measures in greater China region

Parisa David Exploration of communicative strategies in disclosing and exploring sexual orientation and gender identity in consultations with healthcare professionals

Tara Dehpour Assessment of anticipatory grief in caregivers of patients with dementia: A systematic review

Nisachol Dejkriengkraikul Palliative care in Thailand: A survey of the views of palliative care physicians and physicians from other specialities on the future direction of the specialty

Miao Wei Roxanne Foo How much is too much? Physical activity and exercise prescription and outcomes in patients with end stage liver disease: A mixed methods review

Pei Qi Goh Barriers and facilitators to rehabilitation in advanced diseases: A systematic review

Sophie-Anne Gorniewicz Does death anxiety and terror management theory impact on palliative healthcare professionals' attitudes towards patients end of life care?

Jessica Gutjahr Prevalence and factors associated with unfavourable interventions in the last year of life of people with dementia: A systematic review

Lisa Hentsch Changes in the use of formal and informal health services following a Breathlessness Support Service for patients with advanced disease and refractory breathlessness: Secondary data analysis of a randomised controlled trial

Stephanie Hicks The effectiveness and cost-effectiveness of palliative care interventions in patients with chronic heart failure and their caregivers: A systematic review of evidence

Natasha Hill Death anxiety amongst nursing staff/students: A scoping review with implications for further research and suggestions for practice management

Netalie Kemp A systematic review and critical discourse analysis of the reporting of the specialty of paediatric palliative care in UK national broadsheet and tabloid newspapers

Jasmine Lee Is dementia care a priority for Sustainability and Transformation Plan (STP) policy makers? A qualitative documentary analysis of regional STP policies

Liang Xin Liu The conceptual models and mechanisms of action that underpin spiritual interventions in end-of-life care: A systematic review

Nicola Lochrie Palliative Care and Stroke Medicine: where are we now? A systematic review of the barriers and enablers to the delivery of palliative care within stroke medicine and an exploration of existing interventions.

Ines Mendes Patient experiences of using muscle stimulation for rehabilitation in advanced disease: a qualitative study

Jennifer Mullin How do carers' experience "truth-telling" by healthcare professionals in the first 12 months following major stroke? How do these carers process uncertainty? Do experiences of truth-telling and uncertainty influence hope?

Rubayat Rahman A scoping review and narrative synthesis Meaning and sustainability in palliative care

Isabelle Santana A systematic review of the use of Palliative Sedation at the end of life for patients in Intensive Care Units

Nural Ahmad Sudirman A scoping review of assistive technology to support independence in palliative and end of life care



Figure 10.16. Dr Sarah Crabtree, Prof Catherine Evans, and Emel Yorganci receive a King's Engaged Research award



Figure 10.17. Emel Yorganci accepts the King's Engaged Researcher Award for "Transforming research culture or public life" on behalf of the EMBED-Care team

Irma Villagomez Valdez Communicating frailty to patients and carers, an integrative review

Anna Weil The Second Conversation Model: A Qualitative Interview Study

Melissa Fong Shi Yun Patterns of primary and secondary healthcare service use among frail elderly: Secondary data analysis of a prospective cohort study (IARE II Study)

MSc alumni 2021 and their research dissertations

Annabelle Mondon-Ballantyne Assessing the efficacy of remote consultations and experiences of patients and staff involved in a palliative care setting: a quantitative systematic review and qualitative evidence synthesis.

Mina Cha A palliative care needs assessment tools for people with dementia: a systematic review of measurement properties of assessment tools

Christina Chu How healthcare professionals make decisions about the immediate treatment and care for palliative care patients: a mixed-methods systematic review.

Mairead Doherty The palliative care needs of patients with Multiple Sclerosis, Parkinson's Related Diseases and Motor Neurone Disease: a secondary analysis of the OPTCARE Neuro trial data

Inge Dufva Early palliative care for patients with pancreatic cancer-health care service use and quality of life- a quasi-experimental study

Jenny Du Feu Symptom Burden and Factors Associated with Severe Symptoms in the Last Week of Life in Older Adults and their Families Accessing Palliative Care: An International Mortality Follow-back Study

Faith Kyemba The nature and role of social support networks of people living with dementia in long-term care settings: a systematic review

Bang Ling Liu What factors influence the recites of palliative care for Asian patients with end stage renal disease managed by hemodialysis: A systematic review

Miu Leng Phoon A systematic review and narrative synthesis of the evidence underpinning the theoretical perspectives and cultural influences on forgiveness in palliative care

Mellisa Sim Effects of a home-based palliative care service in addressing needs and concerns of breast cancer patients taking into account patient specific factors: A secondary data analysis of a longitudinal cohort study

MSc alumni 2022 and their research dissertations

Ghadeer Alarjeh Communication and information sharing with paediatric patients with advanced cancer, caregivers, and health care providers: A secondary analysis of face-to-face semi-structured interviews in Jordan

Rita Ventura Coelho Vieira Alves The experience of children and young people living with a parent with an oncological life-limiting illness

Andrea Perez De Acha Chavez Association between polypharmacy and hospitalisation among people with dementia approaching the end of life: A Systematic Review

Nitzan Ben Dov Palliative Care for Frail Older Adults with Chronic Noncancer Conditions: A Qualitative Study

Ulrike Gillon Estimating the palliative care need of care home residents in England and Wales, 2010 to 2019

Sheryl Horton Needs and Concerns of Adults with Advanced Multi-Morbidity: A Systematic Review using Narrative Synthesis

Alexander Hughes Parenteral diuretics to improve breathlessness and peripheral oedema in advanced heart failure patients with palliative care requirements: a systematic review of the literature

Bin Xuan Andy Lee Cancer Home Palliative Care in Northern Cyprus – An In-Depth Descriptive Study of Patient Characteristics and Symptom Burden

Philippa McFariane Advance Care Planning for our "living", not just our "dying"; Findings from a retrospective study of a large Electronic Palliative Care Co-ordination in a diverse urban area during the COVID-19 pandemic.

Bethan Phillips The role of palliative care for people with long-term neurological conditions in supporting family caregivers: A qualitative study exploring the impact on caregiver experiences and priorities.

Caroline Phillips Educational Needs of Paramedics Providing End of Life Care: a systematic review

Asako Saji A Thematic Synthesis to Appraise Primary Evidence Underpinning the Concept of Self-Perceived Burden to Others among Adult Patients with Life-threatening Illness

Ayaka Uchida The role of the AMBER care bundle on Advance Care Planning for patients with uncertain recovery: Multi-method secondary analysis of qualitative data from patients, families and healthcare professionals

Lotte Voets Happiness and severe multiple sclerosis: A human quest to live life to the full

Van Tzu-Wu Models of care in primary care for individuals with dementia at the end of life: a systematic review



Figure 10.19. Professors Katherine Sleeman and Catherine Evans celebrate their inaugural lectures

MSc alumni 2023 and their research dissertations

Sarah Almousa Experiences of Parents from Ethnic Minority Groups of Paediatric Palliative Care: A Systematic Review and Qualitative Synthesis

Sophie Bond Invisible patients and caregivers in palliative care: Examining the sociodemographic characteristics of research participants in a Cochrane Review

Lee Winter Dean A scoping review of the literature of interventions to enable community members to support the dying

Rowena Eason The Responses Study – A qualitative exploration into psychological responses to, and potential influences of, Advance Care Planning discussions

Zoe Faggetter Systematic review: informal caregivers' perspectives on unplanned hospital admissions for individuals with dementia who are approaching the end of life

Jeannine Gambin Evaluating the Impact of An Existing Specialist Pain Team Service in A Hospice – Mixed Methods Evaluation

Anna Gray Mapping the Specialist Palliative Care Workforce and Services in London's Acute Hospital Trusts

Jamie Gross A realist review examining how goals of care communication is conducted between doctors and patients with severe acute illness in hospital settings

Man Yan Audrey Ho Health inequality in palliative and end-of-life care: A qualitative documentary analysis of health policies in the United Kingdom

David Holland A systematic review evaluating the evidence for simulation training with High Fidelity Mannequins in Teaching Adult Palliative Care Skills in Healthcare Workers who are not Specialists in Palliative Care

Lisa Kelly The impact of COVID-19 on the management teams of Irish Specialist Palliative Care Services

Xin Yi Lam Symptoms and Their Relationship to Function Overtime in Frail Older Adults: A Secondary Analysis of a Prospective Cohort Study (IARE II)

Ofelia Leiva Opioids prescribing patterns in Latin America: A systematic review

Rebecca Lewis Experiences and views of Multi-Disciplinary Team (MDT) health care professionals regarding the end-of-life care (EOLC) and withdrawal of Extra Corporeal Membrane Oxygenation (ECMO) for Severe Respiratory Failure across the UK National ECMO Network.

Anna Melon The phenomenon of caregiver burden in palliative care across six countries with different socio-economic backgrounds: a qualitative secondary data analysis

Nicola Ngiam Evaluation of the comprehensibility and feasibility of the Children's Palliative Care Outcome Scale in Singapore

Amanda Roberts A qualitative enquiry into the potential of storytelling to support patient-led change across the palliative care ecosystem, using a systematic review approach

Marie Rousseau A systematic review to explore the mortality disparities and barriers to accessing palliative care in HIV positive individuals in minority groups

Natasha Stoodley Carer burden at the end of life among patients with cancer and non-cancer: secondary analysis of mortality follow-back survey

Alexandra Woods An evaluation of the use of tools to support palliative and end of life care in Care Homes during the Covid-19 pandemic from the perception of Care Home staff.

Wenying Xu Implementation of eHealth to support assessment and decision making for informal caregivers of people with dementia living at home: a systematic review

Nami Yoshimura Exploring the healthcare support for bereaved family caregivers of older adults living at home and its effect on grief: A Secondary Analysis of the IARE II Bereavement Follow-back survey

Research support

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- Marie Curie Cancer Care
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- Medical Research Council (MRC)
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- National Institute for Health and Care Research (NIHR)
- Open Society Foundation
- Pfizer Ltd
- Public Health England
- Royal Marsden Partners
- Sussex Community NHS Foundation Trust
- The Sir Halley Stewart Trust
- Thomas Deane Trust
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