KING'S
College
LONDON

Triennial Report
2017–20

Cicely Saunders Institute
of Palliative Care, Policy and Rehabilitation

Cicely Saunders
International
Better care at the end of life

Contents

Introduction

Professor Irene Higginson.

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.

Over the period covered by this triennial report we have strengthened our focus on high quality research that addresses the difficult questions of our field and which makes a substantial contribution to improving care for those affected by progressive illness, at the end of life and into bereavement. To achieve this ambitious programme we are aided by many local, national, and international collaborations, the leadership from Cicely Saunders International and its International Scientific Expert Panel, as well as support from key funders and partners, and the active engagement of our pioneering patient and public involvement programme. The latter includes a novel online patient and public fora, of which we are especially proud. As an independent external assessment finds, our publications are first in Europe and second in the world for citations of research in palliative care.

To respond to the new populations needing palliative care, our programme of research to evaluate and improve care has pioneered, developed, implemented and trialled novel integrated palliative care services. These services, usually short-term partnerships, respond to the needs of people such as those with multimorbidity or chronic progressive illness who hitherto missed out on the best in palliative care. Our integration extends into and beyond disease-centred specialties, and includes also rehabilitation, geriatrics, primary and social care. For example, our OPTCARE Neuro evaluation is the world's largest multicentre palliative care trial for people with long-term neurological conditions. Linked to this programme we have conducted research, partnered with the World Health Organization, to understand the essential components of high quality services for older people. We have evaluated the factors affecting the quality of care for people with dementia, transitions in care, and collaborated with others to trial palliative care and integrated rehabilitation in specific cancer and other populations.

Symptom management is essential if patients and those important to them are to make the most of their remaining life with quality. Consequently we have advanced our programme of research into relatively neglected symptoms, in particular breathlessness. Our transformative National Institute of Health Research project brought together all the international research, including our own, on the effects of holistic breathlessness support services. It found that holistic services for chronic or refractory breathlessness in people with advanced disease lead to significant improvements in psychological wellbeing and reduce the negative impact of breathlessness on quality of life.

In early 2020, the COVID-19 pandemic began. In only 93 days, what was originally a mystery illness became a pandemic. South London, where the main base of the Cicely Saunders Institute is located, was one of the areas hit early and hardest in the UK. COVID-19 has an overall case fatality ratio estimated between 1 and 4%; people with multimorbidity are at high risk of serious illness, symptoms and death. In the Cicely Saunders Institute, with the active support and help of our key funders, we were able to rapidly pivot our activity to the new challenges of COVID-19 and to conduct research to better understand and improve the quality of care for people severely affected by or dying with COVID-19.

There are many other advances highlighted in the following pages. These include understanding how to support individual patient and carer preferences for care, how to support care quality and efficiency with better outcome and assessment measures in rehabilitation and palliative care, and how to improve the access to and quality of care for those people who hitherto missed out on the best in care; including those from disadvantaged socioeconomic backgrounds, different cultures, settings, of black or minority ethnic origin and for lesbian, gay, bisexual and/or trans (LGBT) people. We have expanded our understanding of how to conduct high quality research in palliative care and rehabilitation, including among individuals who have limited capacity to make decisions, to conduct evaluations, including using big data and in economic research to truly understand societal costs at the end of life.

Palliative care will be needed for the future. Serious health-related suffering is projected to increase in all countries over the coming decades, with the most rapid rises among older people. This will impact on where people are cared for if preferences are to be met, with a need to increase community as well as hospital provision for palliative care. Consequently, we continue to build capacity, particularly for doctoral and post-doctoral researchers and clinical academics. We are delighted that we will soon be recruiting to our new endowed Professorship, the Laing-Galazka Professor of Palliative Care. We congratulate our many undergraduate and postgraduate alumni and current students for their achievements and awards. We work with the medical student undergraduate society for palliative medicine, and welcome medical students to our Institute for teaching with the clinical services on the wards and for projects. Our multi-professional MSc programme has given us the opportunity to work with many talented future leaders from across the globe. We also provide shorter diploma, certificate and single module courses. We offer bespoke PhD programmes linked to our research teams. Our success rate is very high; we congratulate our alumni from this recent period. We continue to host regular lectures, seminars and workshops and benefit from engagement with world-leading experts, especially in our vibrant Cicely Saunders International annual lectures, which we stream via live video link across the globe.

Dame Cicely Saunders and Dr Mary Baines.

We pay tribute to Dr Mary Baines OBE who died peacefully at St Christopher's Hospice this year. Mary Baines played an instrumental role in establishing hospice care, in particular she was a pioneer of home palliative care. She developed techniques that underpinned approaches that we still use today. She was a great supporter and friend to the Cicely Saunders Institute and Cicely Saunders International. We will miss her presence at seminars, workshops and meetings.

We thank the many supporters, funders and collaborators, and the teamwork of the many adept colleagues and students, working across the Institute and our partner organisations. We hope that you find aspects of interest in our report.

Clinical leads introduction

Dr Wendy Prentice and Dr Shaheen Khan.

The past three years have been exciting and challenging both clinically and academically. We are immensely proud to be part of the team at the Cicely Saunders Institute and to co-lead our Clinical Academic Group. Our strong basis of clinical and academic integration has translated into real life changes to frontline clinical care, and increased the evidence base underpinning practice locally, nationally and internationally.

Our teams across all areas of King's Health Partners continue to support multi-professional education of undergraduates and postgraduates, as well as continuing to host numerous visitors from across the world. We are committed to collecting patient outcomes across our services, and supporting our patients to participate in ongoing research, to both shape their individual care and influence ongoing development of our services. The shared expertise of our teams is of great value to our local services, but also through our many national and international links enables us to collaborate and contribute to developments on a much larger scale.

We are publishing this report in unprecedented circumstances and much uncertainty remains moving forward. Our amazing response to the COVID-19 pandemic was only possible because these strong foundations and working relationships were already in place. The close working between colleagues across all sites has never been more important. The experience of needing to rapidly adapt our clinical services, education programmes and research projects to meet the challenges of the COVID-19 pandemic will benefit us for the months and years ahead. Our key strengths are the talent and dedication of our staff, through which we are confident we will continue to provide high quality clinical care to patients and families, whilst increasing the evidence base for our specialty.

Staff at the Cicely Saunders Institute, 2017.

Our mission and key strategies

Dame Cicely Saunders, founder trustee of Cicely Saunders International, worked actively for the creation of a centre of excellence housing research, education including palliative care courses, information provision and clinical care. The **mission of the Cicely Saunders Institute** established in her name is to pioneer the very best in palliative care and rehabilitation by integrating:

- **Cutting-edge research** – committed to building new knowledge and discovering new treatments through world-leading ethical and robust clinical, applied and health services research.
- **Skilled multi-professional care** – delivering top-quality evidence-based clinical care and support to patients and carers, for life and living, and death and dying.
- **Innovation in engagement and education** – to embed change in policy and practice nationally and internationally, engage with patients and public, and inspire tomorrow's leaders in the field from around the world.

This seeks to enable ethical and robust research to quickly feed into care and practice, improving palliative care and enabling people to live better, with dignity and the least possible suffering.

Our **research strategy** is to lead the world in ethical and robust research that responds to people, families and communities affected by progressive, far advanced and life limiting conditions. We focus on understanding the needs of the most neglected and disadvantaged groups in our society, discovering and testing solutions. We find solutions that cross health and social, statutory and voluntary sectors, addressing physical, emotional, social and spiritual needs.

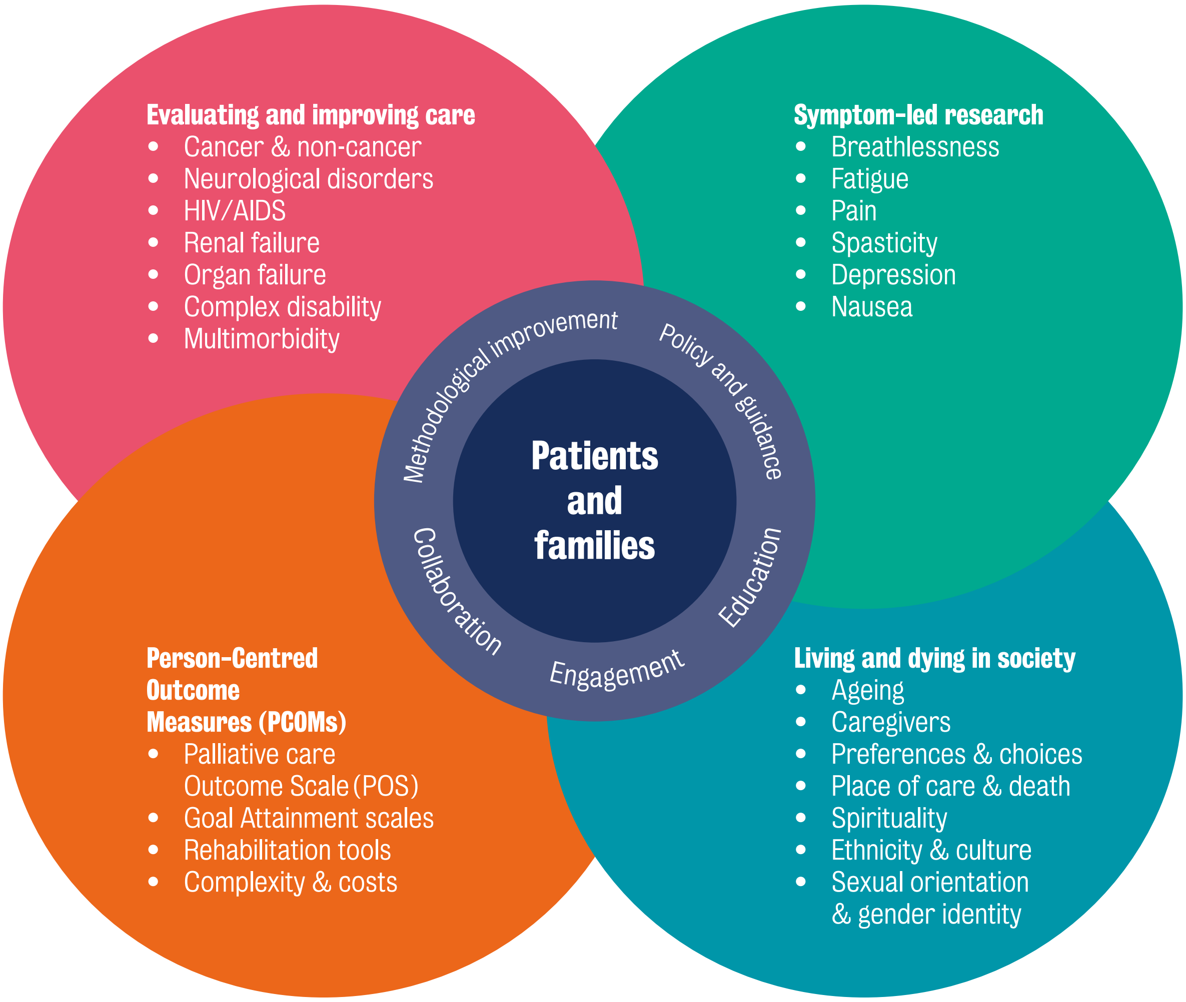
We aim to translate our research quickly into care, practice and policy so it can benefit people now.

Our research has four main strands, with improving care for patients and families at the heart of everything we do (Figure 1). These are inter-related and operate across our multi-professional staff, care settings and disease groups. Across all strands we hone research methods in our field, to improve rigour, ethical standards and ways to better support the most profoundly ill populations.

Evaluating and improving care: Studies develop, test and trial new interventions and service delivery models that are more integrated within existing health and social care, across various settings, to better meet the needs of patients and their families. Bolstered by our unique interface between palliative care and rehabilitation, we reach beyond cancer to other conditions where palliative care has been neglected, including neurological and respiratory disease, HIV/AIDS, and importantly multimorbidity and frailty.

Cicely Saunders Institute.

Figure 1. Palliative care and rehabilitation research at the Cicely Saunders Institute



Symptom-led research: Relief from distressing symptoms is a core component of palliative care and rehabilitation. Symptoms such as breathlessness, depression, pain, spasticity, weakness, fatigue and nausea are common across many diseases. Our research on symptoms includes systematic reviews, observational studies and trials to test new interventions and treatments, to manage symptoms more effectively and minimise symptom distress and impact. We always consider symptoms in the context of the person and their surroundings.

Person-centred outcome measures: Developing and implementing robust patient-centred measures of outcomes in palliative care and rehabilitation is vital. We develop and use short measures for patients, families and observers/staff that capture the highly varied, often complex circumstances of patients and provide fundamental tools for research and clinical practice. These cover physical, psychological and spiritual need, as well as social, service and rehabilitation concerns. Through global partnerships we are also transforming the evidence base and delivering culturally appropriate care.

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 rehabilitation, we study the needs and preferences of vulnerable or overlooked groups and areas, including older people, caregivers, preferences and choices, ethnicity, sexual orientation and gender identity. Our findings seek to lead the evidence response to meet the needs of an ageing multimorbid population and the diverse cultures in our society. Research in this strand underpins our other studies and bolsters our expanding health economic focus.

Our **Impact Strategy** consists of three strands:

- We embed 'impact thinking' in all that we do: from project conception throughout the project duration and beyond. We aim to effect a cultural change and raise the profile of impact within our organisation and outside by providing staff training and development, expertise, resources, guidelines and frameworks. We embed impact thinking in our teaching, e.g. MSc programmes.

- We engage with the public, patients, clinicians, policy-makers and other academics to maximise the impact of our research: We support innovative, varied and targeted stakeholder engagement, creative dissemination activity, and multi-disciplinary collaboration. This allows us to develop and scientifically study methods which enhance implementation and sustainability of underutilised evidence-based interventions.

- We capture and communicate our impact: We recognise impact in all its different forms, and record and map evidence of impact for individual projects and across themes. This enables us to articulate the value of our research to existing and future funders, collaborators and other stakeholders, and build strong Research Excellence Framework Impact Case Studies. This also enables us to evaluate and reflect on and improve our engagement and impact strategies.

Our routes to impact fall into the following categories:

- A talk, presentation or debate, including scientific and clinical conferences, study days for a variety of audiences including policy makers, clinicians and patient and public members.

- Media engagement, including dissemination of study results in newspapers through press releases, on social media platforms (e.g. Twitter @CSI_KCL and YouTube www.youtube.com/user/CSIKCL), and interviews with TV/radio broadcasters.

- Patient and Public Involvement & Engagement: embedded PPI into all our research projects and programmes with face-to-face and virtual fora.

- Including presenting findings to patient groups, and working with patients and the public on research projects.

- Implementation of Research Findings: Providing training, education and resources to healthcare professionals.

- Collaborations: Working with policy makers, clinicians, government officials nationally and internationally.

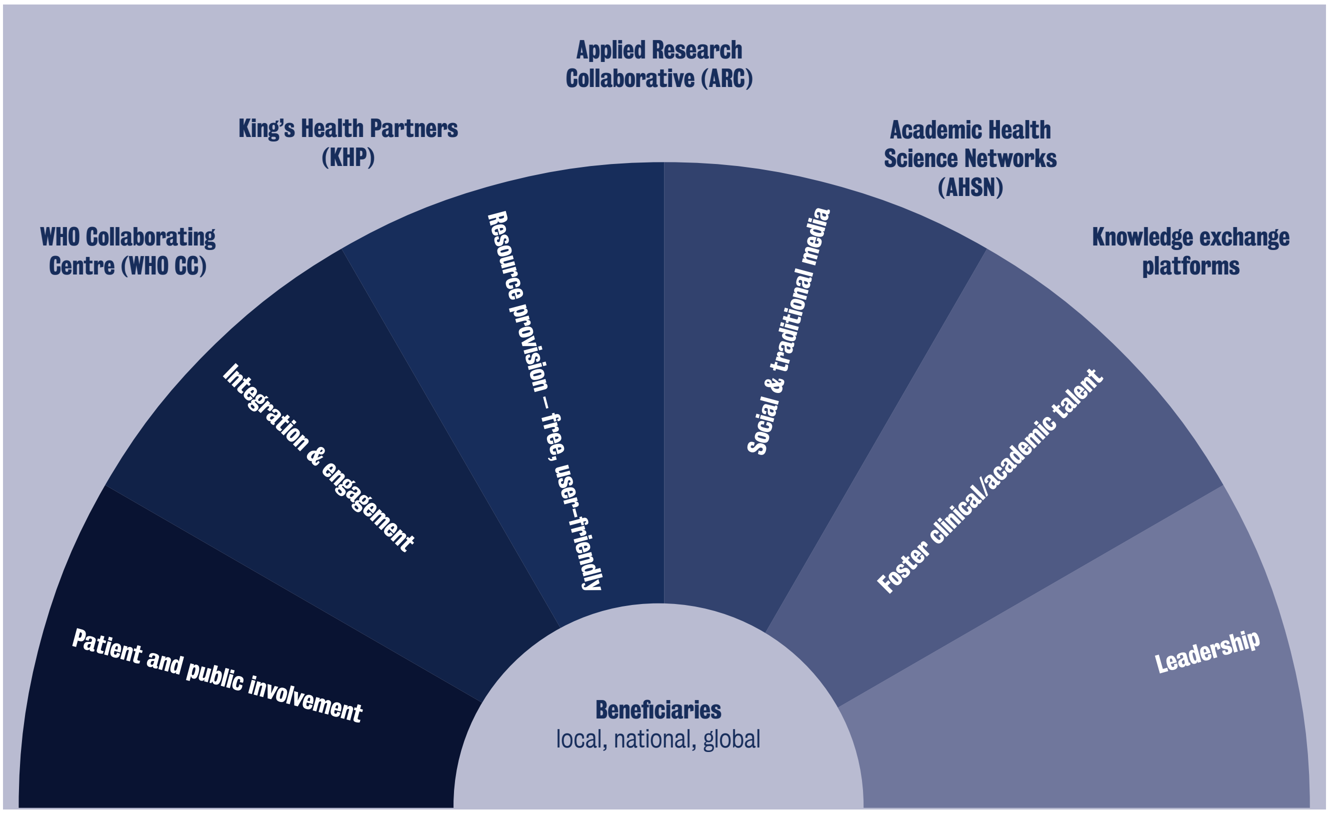
- Policy Engagement: Writing policy briefs and having conversations with policy makers. We support the End of Life Care Coalition of charities (http://endoflifecampaign.org), which has been instrumental in bringing academic and third sectors together.

We encourage everyone to think about impact from the start of study design, e.g. identifying key communities and building collaborations, right through to the dissemination phase, e.g. sharing the main narrative of the work and integrating into educational programmes.

The reach and significance of our research is enhanced by the **environment, resources and collaborations** across the Institute, King's College London and King's Health Partners (Figure 2). This includes the NIHR Applied Research Collaborative, in which we lead a theme on palliative and end of life care, and our work as a World Health Organization Collaborating Centre. We foster joint clinical-academic working to increase impact in practice. We develop leadership; many staff are board members of, and/or chair, international advisory groups, taskforces, national bodies.

We are passionate in our commitment to ensuring Diversity and Inclusion. Our aim is for all students, academic, clinical and professional services staff to be treated fairly and with equality in terms of progression, representation and working environment. We are incredibly proud of our Athena SWAN Silver Award,

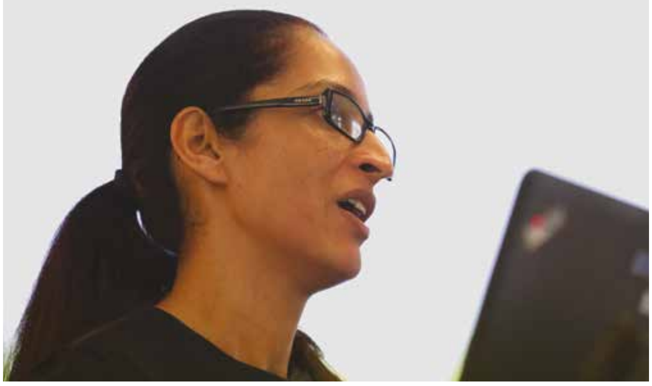
Figure 2. Strategy to enhance reach and significance of impact at the Cicely Saunders Institute



Race Equality Charter Bronze Award and the Stonewall Diversity Award, and we joined the Business Disability Forum in 2017.

Since 2018, we have conducted regular Diversity and Inclusion quantitative surveys with qualitative follow up to identify areas to focus our actions. We have made a measurable positive difference for gender equality locally, nationally and internationally. For example, our research indicated an attrition of women along the academic pipeline in palliative care (Sleeman et al, 2017). As a direct result of this work, the European Association of Palliative Care now routinely collect and analyse gender information on abstract submission and plenary presentations.

The Athena Swan charter addresses all inequality across all protected characteristics. Dr Sabrina Bajwah (Clinical Senior Lecturer and Honorary Consultant) leads our Diversity and Inclusion Committee. She was profiled for the online magazine *Womanthology* in 2017, where she discussed the need to empower women from ethnic minorities in science, technology, engineering and mathematics, and acts as a Black Asian and Minority Ethnic mentor for students and staff.



Dr Sabrina Bajwah presenting at Medical Women's Federation Gender Bias Conference November 2019.

Evaluating and improving care

This programme strives to improve the care and treatments that patients and families receive by studying and understanding opportunities to optimise services, develop and trial refined or new models of care to meet the needs of patients and families, and provide evidence about the effects of care and treatment. Our work spans cancer and non-cancer conditions, with studies conducted internationally, nationally and locally. Our study designs draw on the guidance for the development and evaluation of complex interventions from the Medical Research Council, the MORECare statement specifically for palliative care and our recent MORECare Capacity statement on the process of consent for research on end of life care (Evans et al, 2020). Our designs include: randomised multicentre trials, feasibility testing and evaluation, systematic reviews, service modelling and theory development. Collaboration with patients, families and the public are a core component in all phases.

New models of palliative care and rehabilitation

Informed by observational studies and comparative effectiveness evaluations, we seek to develop, evaluate and implement new models of palliative and end of life care suited to multimorbidity, with integration that extends into and beyond disease-centred specialties, and interfaces with specialties such as rehabilitation, geriatrics, primary and social care. Our work aims to build understanding around relevant indicators of need including symptoms, existing and new delivery models such as short-term integrated palliative care, and health and social care outcomes including evaluation of service use and costs.

Neurological conditions

The Short-term Integrated Palliative Care Neuro trial (OPTCARE Neuro) is the world's largest multicentre palliative care trial in people with long-term neurological conditions (LTNCs) (ISRCTN18337380). The trial evaluated the effectiveness and cost-effectiveness of a new integrated care model of short-term palliative care. The trial concluded that the model of short-term integrated palliative care (SIPC) can reduce costs without compromising on quality of care (Gao, Wilson et al, 2020). SIPC was well received by patients and their caregivers, perceived to build resilience, attend to function and deficits, and enable caregivers.

This clinical trial compared a new integrated care model of short-term palliative care with standard care among patients severely affected by progressive neurological conditions and their caregivers (e.g. family members). The new SIPC model involved delivery by multi-professional palliative care teams, linked with local neurological services with emphasis on comprehensive assessment, personalised care planning, case management and care coordination. The primary outcome was change in eight key palliative care symptoms from baseline to 12-weeks, measured by the Integrated Palliative care Outcome Scale for neurological conditions (IPOS Neuro). Three hundred and fifty patients were randomised to receive SIPC (n=176) or standard care (n=174), and 229 caregivers (SIPC n=121; standard care n=108). The trial detected no between group differences in the primary outcome (effect size, -0.16; 95% CI, -0.37 to 0.05), the secondary outcomes or adverse events. There was a decrease in mean health and social care costs from baseline to 12 weeks −£1,031 (95% CI, −£1,847 to −£212) in the SIPC group and −492 (95% CI, −£1,386 to −£401) in the control group, but this difference was not statistically significant (P = .12). Our findings provide the most robust evidence to date to support service and policy developments that improve palliative care provision for people with LTNCs in the UK or in health care systems similar to the NHS. Our initial development work with specialists in palliative care and neurology demonstrated limited collaboration between the two specialties, and positive perceptions about the impact of the new SIPC model (Hepgul et al, 2018). Our next step is to explore how best to implement the new care model more widely to benefit more people.

Public involvement in the OPTCARE Neuro project

Patient and Public involvement (PPI) was an integral part of all research processes. Processes in OPTCARE Neuro were enhanced by a PPI co-applicant to support oversight of PPI, and PPI membership of trial management groups and linkage with the PPI-Trial-reference group. The PPI-Trial reference group provided expert views to enable us to prioritise the research questions and ensure the study was undertaken in a way meaningful and relevant for patients and caregivers. Active involvement of members in interpretation of the qualitative data enabled valuable insight in understanding the data and its relevance to address the needs of this patient population.

Patient-reported outcome measures (PROMs) are important for assessment in clinical practice and research. There was no generic PROM for patients severely affected by LTNCs. Along with the main trial, we developed an Integrated Palliative care Outcome Scale for neurological conditions (IPOS Neuro). We previously conducted a preliminary evaluation of the psychometric properties of the eight key symptoms subscale (IPOS Neuro-S8) and found it was acceptable to promising psychometric properties. We explored the factor structure of the symptom subscale of IPOS Neuro (IPOS Neuro-S24) and identified a reliable four-factor structure of symptom experience in people with

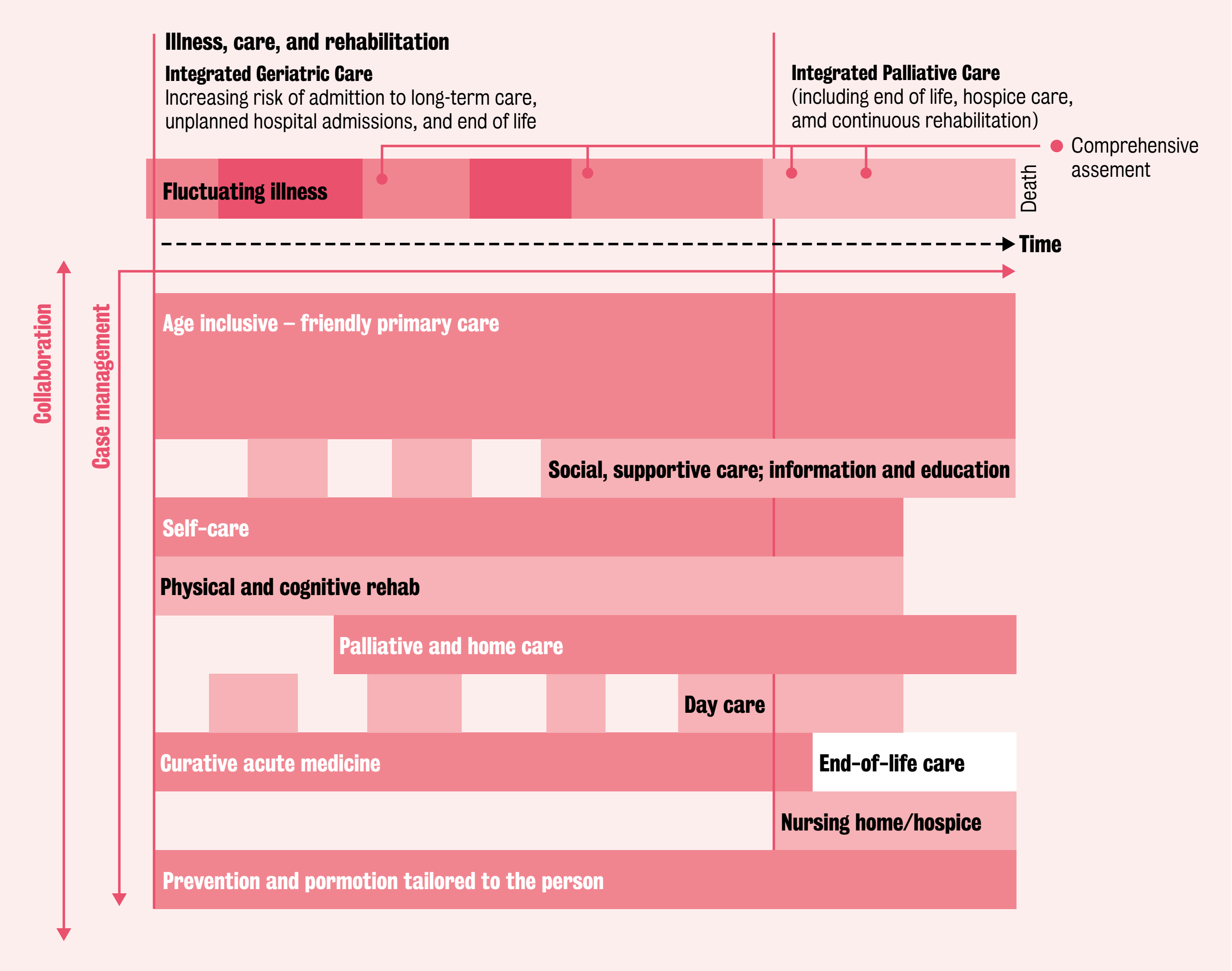
LTNCs (Wilson, Hepgul, Saha et al, 2019). The results suggest that symptom dimensions are common across LTNCs and the IPOS Neuro S-24 is an appropriate tool to measure symptoms in people with LTNCs, which may improve care.

Older people

In an era of unprecedented global ageing, a key priority is to align health and social care services for older populations to support the dual priorities of living life well while adapting to gradual decline. This rapid scoping review of systematic reviews aimed to synthesise evidence on service delivery models that optimize quality of life for older people towards the end of life across health, social care and welfare services internationally (Evans et al, 2019). The review responded to a call from the WHO, with attention to low- and middle-income countries to inform global policy and health care provision for older people across the care continuum, including end of life. This review included 72 systematic reviews, with 20 reporting meta-analyses. We identified two overarching classifications of service models both orientated to person-centred care with emphasis on multiprofessional workforce and education, but with different target outcomes. The classifications comprise Integrated Geriatric Care emphasising optimising physical function, and Integrated Palliative Care stressing management of symptoms and concerns. We identified the following overarching processes as key to integrate care and manage the continuum of care:

- Comprehensive assessment with person-centred assessment of needs across physical, psychological, social and spiritual domains.

Figure 3. Services for universal health coverage for older people nearing the end of life



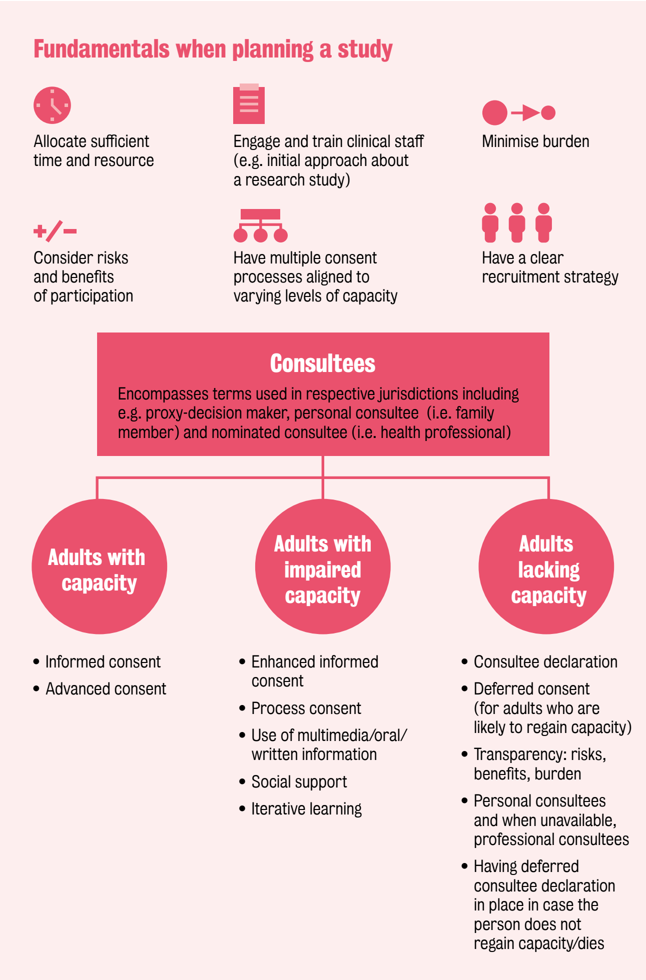
Source: Evans et al, 2019.

- Case management to coordinate care for patients and their caregivers by assigning each case to an individual and/or team.
- Collaborative working across disciplines and organisations to plan and deliver services to meet needs of the individual and their caregivers.

The reviews assessed 117 separate outcomes. A meta-analysis demonstrated effectiveness for both classifications on quality of life, including symptoms such as pain and depression. However, economic analysis and its implications were little considered. Our findings indicate the imperative for integrating services across the care continuum, with service involvement triggered by needs and likelihood of benefit. This could include a breadth of possible packages of care to deliver the continuum of care across illness trajectories, care settings, and context (Figure 3). To incorporate new models of integrated palliative care and sustain health change, we encourage greater attention to economic analyses that span health and social care and examine all sources of finance to understand contextual inequalities.

Methodological advancements in research are a key endeavour to ensure robust high-quality research to strengthen the provision of evidence-based palliative care. Recruiting and enabling participation for adults with progressive conditions across the illness trajectory is vital for our research to benefit all those using palliative care services. Our Methods of Researching End of Life Care Capacity (MORECare Capacity statement) aimed to develop evidence-based guidance on how best to include individuals with impaired capacity nearing the end of life in research (Evans, Yorganci et al, 2020). The statement details 20 solutions to recruit adults lacking capacity nearing the end of life in research, providing much needed guidance to enrol individuals with serious illness in research. The statement was generated from synthesis of systematic review and transparent expert consultations (TEC). The systematic review included 91 primary studies on involving adults with serious illness and impaired capacity in research, methods for recruitment and implementation in research, and public attitudes. Studies mainly encompassed dementia care (27%) and palliative care (18%). Recruiting adults across the capacity spectrum centred on using processes of consent tailored to individual capacity level including proxy decision-making for adults lacking capacity (e.g. severe dementia), advance consent for adults anticipated to lose capacity (e.g. progressive neurological condition), and deferred consent when anticipated regain of capacity (e.g. ICU). Studies on implementing process of consent demonstrated the role of family members as both proxy decision-makers (e.g. dying phase) and supporting decision-making for the person with impaired capacity (e.g. adult with intellectual disability). The TEC used a modified nominal group to discuss and generate recommendations on solutions, with consensus explored in a Delphi survey. Twenty-nine recommendations were considered as indicated. Key areas were

Figure 4. How ‘best’ to include adults nearing the end of life in research



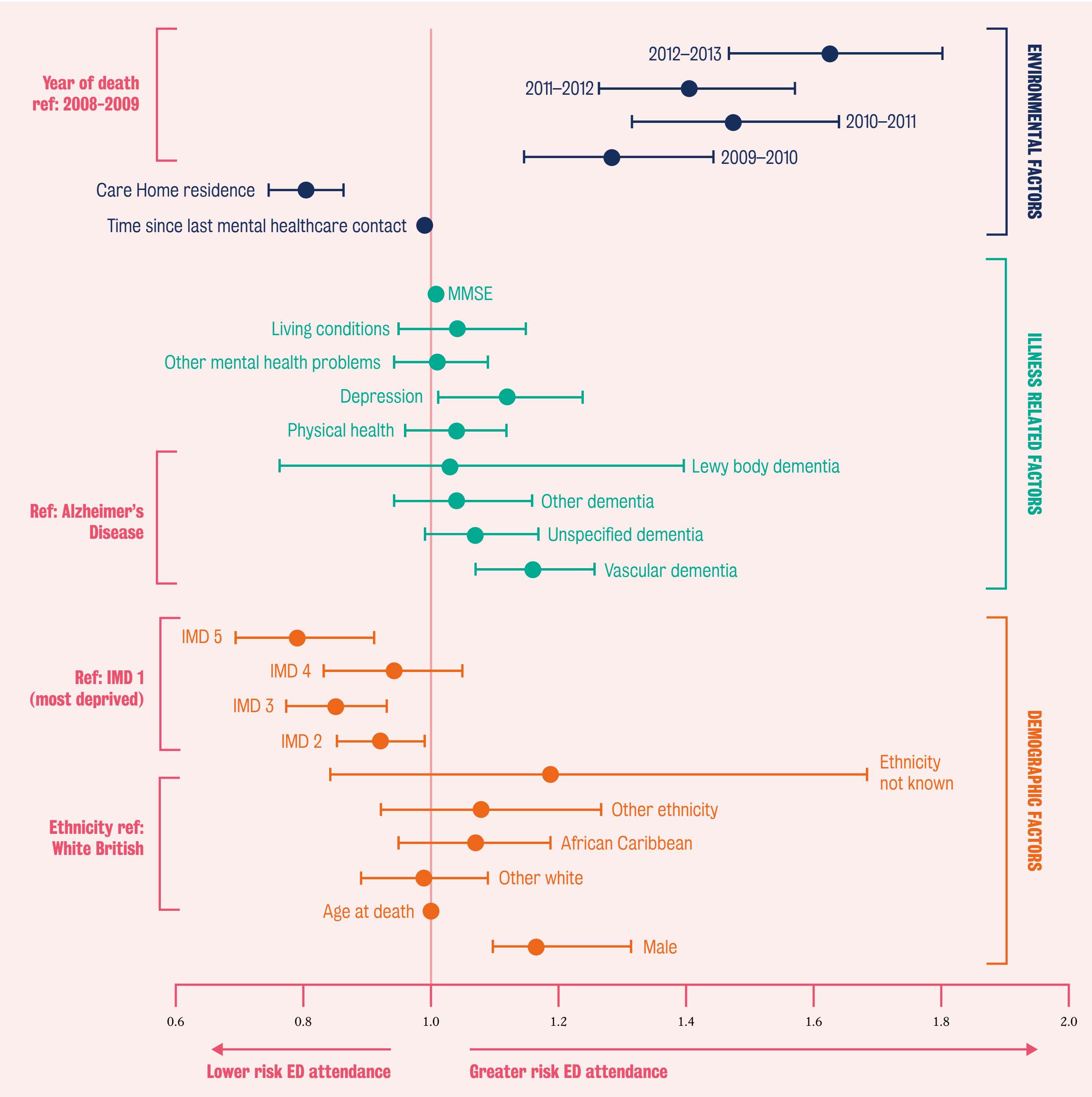
Source: Evans, Yorganci et al, 2020.

the timeliness of the consent process and maximising an individual's decisional capacity (Figure 4). A final think tank supported data synthesis to generate the statement and refine equivocal areas on supporting proxy-decision makers, training practitioners and incorporating legislative frameworks. The statement demonstrates the ethical imperative and processes of recruiting adults across the capacity spectrum in varying populations and settings.

Dementia

Dementia is the leading cause of death in the UK. Place of death has been used as an indicator of good quality end of life care by policy makers, but this does not necessarily reflect the care received in the last weeks and months of life. We examined the frequency and predictors of emergency department attendance among people with dementia in their last year of life. We analysed anonymous electronic patient

Figure 5. Environmental, illness-related, and demographic factors associated with emergency department attendance in last year of life for people with dementia



Abbreviations: ED – Emergency Department. IMD – Index of Multiple Deprivation. MMSE – Mini–Mental State Examination.

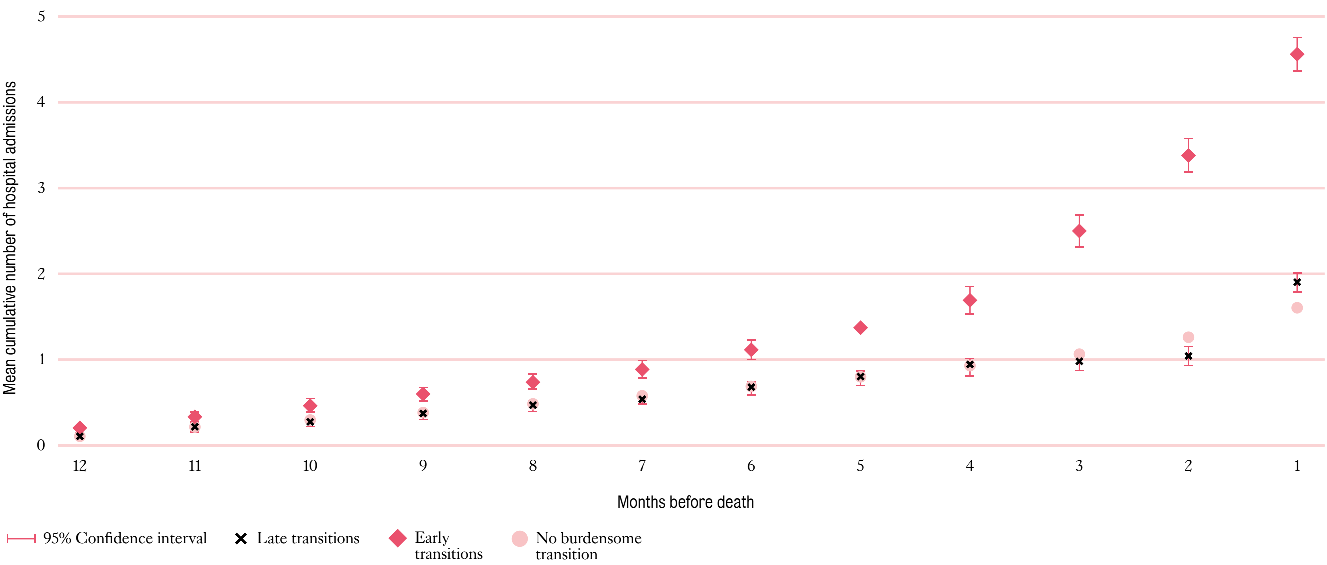
Source: Sleeman, Perera et al, 2018.

medical records from a large mental health provider, linked to national mortality and hospital use data for people with dementia who had died between 2008–2013 (n=4,867). Over three quarters of people living with dementia had at least one emergency department admission in their last year of life (mean 2.13, SD 2.34, range 0–54). Emergency department attendance also increased over the years with incidence ratio 1.62 (95% CI, 1.46-1.80) for 2012–2013 compared with 2008-2009. Our findings show the commonality of emergency department attendance for people with dementia in the last year of life (Figure 5). These findings indicate the importance of policy makers looking beyond place of death when measuring quality of care at end of life (Sleeman, Perera et al, 2018).

End of life care is often disjointed for people living with dementia. Many experience “transitions” between care settings, for example, from home to acute hospital admission. These points of transition can often precipitate decline in health and wellbeing from, for example, hospital deconditioning. We investigated the frequency and correlates of two types of end-of-life transitions among people with dementia. These included any hospital admission in the last three days of life (late transitions) and multiple transitions to hospital in the last 90 days of life (early transitions). We again analysed anonymous electronic patient records, linked to national mortality and hospital data for individuals with dementia who had died between 2007–2016 (n=8,880). We found that end-of-life transitions in people with dementia are frequent, occurring in one out of six people (n=1,421, 16%). While late transitions were more common than early transitions (8.9% verses 5.7%), they have been decreasing over time. In contrast with late transitions, early transitions were associated with increased healthcare use throughout the last year of life (Figure 6) and were more frequent among men, younger age groups, more deprived groups and people experiencing physical illness, and depressed mood. Our results suggested early transitions at the end of life are more predictable than late transitions, suggesting they can be prevented (Leniz et al, 2019).

Our population-based studies on dementia emphasised the need for improvements in end of life care for people with dementia where they live and receive care. The Empowering Better End of Life Dementia Care (EMBED-Care) project is a five-year joint research programme between the Cicely Saunders Institute, King’s College London and the Marie Curie Palliative Care Research Department, University College London. The programme aims to deliver a model of integrated palliative dementia care, enhancing communication and person-centred decision-making to improve comfort and quality of life (Sampson et al, 2019). The

Figure 6. Mean of the cumulative number of hospital admissions in the last year of life for individuals with dementia by type of end-of-life transition



Source: Leniz et al, 2019.

Above: EMBED-Care Launch conference ‘From evidence to best practice in health and social care’, April 2019. Below: EMBED-Care Team members (Dr Katherine Sleeman, Prof Liz Sampson and Dr Catherine Evans) with Professor Joan Teno, 2019.

collaboration, led by Catherine Evans and Liz Sampson, brings together expertise in old age psychiatry and dementia care and palliative care. We intend to deliver a step-change in care through a large sequential study, spanning multiple workstreams.

The programme uses mixed methods across settings where people with dementia live and die: their own homes, care homes and hospitals. Beginning with policy synthesis on priorities and opportunities for palliative care, and meta-review synthesising evidence from palliative care and dementia care, we develop our underpinning logic model of integrated palliative dementia care. We use anonymous patient record data, linked with national mortality and hospital use data to examine health service use and transitions in care settings in the last two-years of life to identify inequalities in end of life care and calculate projections for future needs. Longitudinal cohort studies of people with dementia will describe care transitions, quality of life including symptoms, care provision and costs. Data synthesis will inform and refine our model of integrated palliative dementia care with feasibility and pilot testing. The programme is guided throughout by patient and public involvement, innovative engagement and policy work with artists, policy makers and third sector organisations. This will enable us to deliver our intended societal step-change in care provision to ensure people live and die well with dementia.

Complex palliative care interventions

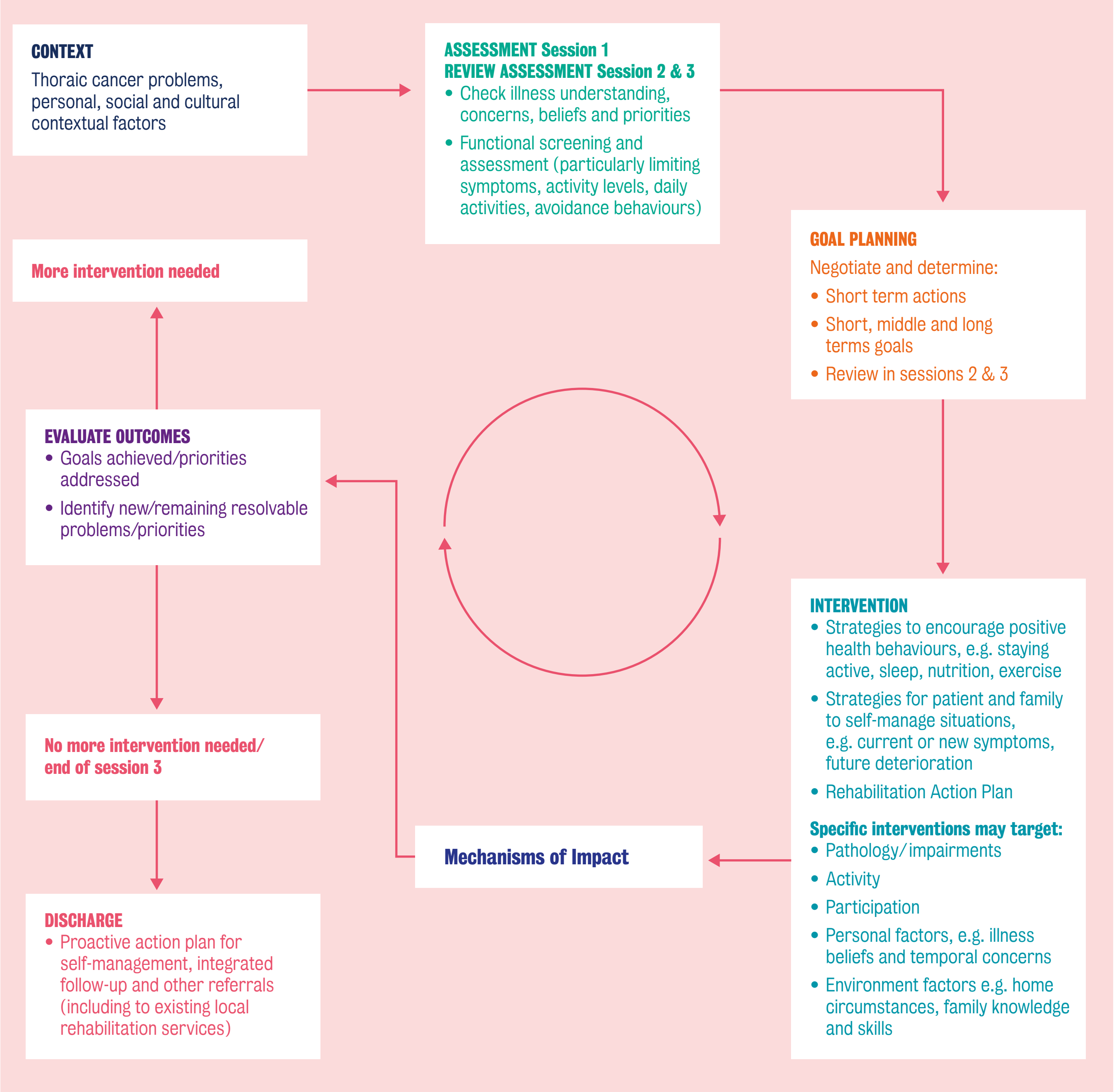
Developing and evaluating complex interventions to improve services, care and treatment for individuals with serious illness is increasingly common, but are one of the most challenging areas of research. Complexity is driven by the number of interacting components in for example a service intervention, the number and difficulty of behaviours needed for the intervention, groups or service levels involved, outcomes, and degree of tailoring the intervention to the local context allowed.

Rehabilitation for people with thoracic cancer

Worldwide, more people are diagnosed with and die from thoracic cancer (cancers of the respiratory tract, lung and pleura) than any other cancer. Most present with incurable disease and despite new oncology treatments, people experience symptoms which impact on function and daily life. Rehabilitation aims to ameliorate functional impairment and improve participation in daily life. However, while guidelines recommend provision, it is infrequently integrated within cancer core treatment pathways.

To support the integration of rehabilitation within the thoracic cancer treatment pathway, we used mixed methods to develop and assess the feasibility of testing a brief rehabilitation intervention for people in the period following diagnosis. Following the Medical Research Council guidance for the development and evaluation of complex interventions, during the development phase, a systematic review explored the application of behaviour change theory and

Figure 7. Conceptual model of short term integrated rehabilitation for thoracic cancer



Source: Bayly et al, 2020.

techniques in empirical rehabilitation studies in this population to inform behaviour change approaches in the new intervention (Bayly et al, 2018). Concurrently, focus groups, held with patients, family members and clinicians, elicited views on the aims, content and delivery of the proposed rehabilitation intervention in a randomised controlled trial (Bayly et al, 2018). The findings from this development work were integrated with theory to inform a conceptual model of brief integrated rehabilitation. The key components, processes and outcomes of the new rehabilitation intervention were used to produce an Intervention Manual to support fidelity during delivery and evaluation of the intervention in a randomised controlled feasibility trial (Bayly et al, 2020).

During the feasibility study, participants with a recent diagnosis of lung cancer or pleural mesothelioma on any treatment pathway were recruited to a parallel group 1:1 randomised controlled multicentre feasibility trial of short-term integrated rehabilitation plus standard care versus standard care. We found that it is feasible to recruit and retain people with thoracic cancer to a trial of brief integrated rehabilitation in the period following diagnosis. The trial recruited 54 of 159 (34%) eligible patients and 44/54 (82%) and 39/54 (72%) participants provided data at 30 days and 60 days respectively. Intervention fidelity was high: 25/26 participants allocated to integrated rehabilitation received a median 3 (range 1–3) sessions of rehabilitation over 32 (22–45) days. The evaluation identified that trial and intervention satisfaction were high. Participants who received rehabilitation valued practical advice and face to face contact. Feasibility challenges included integration with oncology services, for example accessing clinic space. Changes in clinical outcomes were modest but most apparent for physical activity levels and health-related quality of life as measured by FACT-L. The outcomes will support sample size calculation for a future effectiveness trial. A larger trial to examine the efficacy of integrated rehabilitation in this population is feasible, with health-related quality of life as a candidate primary outcome.

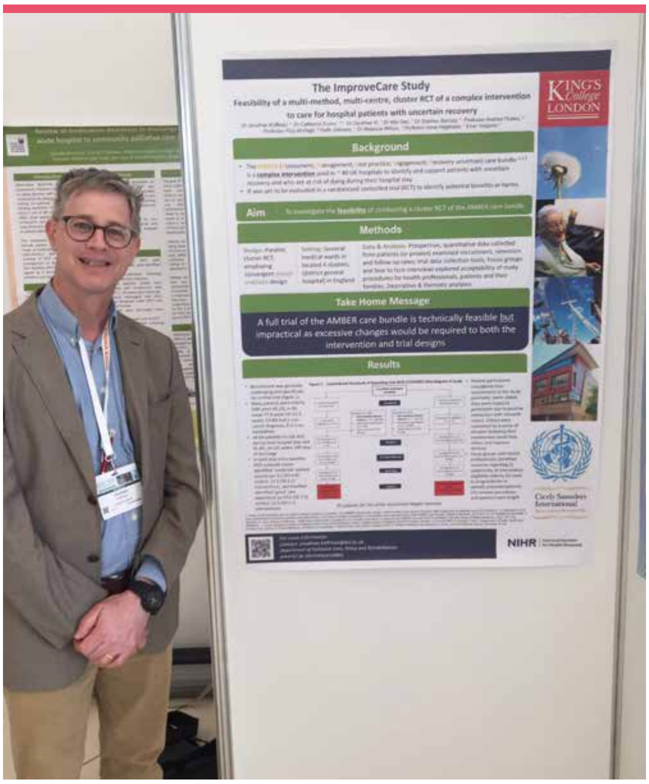
The Danish Palliative Care Trial – DanPaCT

The Danish Palliative Care Trial (DanPaCT), for which Higginson was one of the international team members, is a multicentre randomised clinical trial comparing early referral to a specialist palliative care team plus standard care versus standard care alone among patients with advanced cancer (Groenvold et al, 2017). Patients meeting predefined threshold for problems with physical, emotional or role function, or nausea/vomiting, pain, dyspnoea or lack of appetite according to the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire were recruited. The primary outcome was the change in each patient's primary need at 3- and 8-week follow-up (0–100 scale). Two hundred and ninety-seven patients were randomised to early specialist palliative care (n=145) or standard care (n=152). In the early specialist palliative care group, a coding study from health care records showed a median of 3.5 (range 0–22) new interventions were delivered from the palliative teams in the 8-week intervention-period. Pain band impaired physical function were the most frequent symptom/problems treated, most often with pharmacological intervention (Skjoedt et al, 2020). Early specialist palliative care showed no clear beneficial or harmful effect on the primary outcome of change in primary need (mean difference [95% confidence interval] -4.9 points [-11.3 to +1.5], p = 0.14). Analyses of the secondary outcomes, including survival, also showed no differences, with the exception of nausea/vomiting where early specialist palliative care may have had a beneficial effect (Groenvold et al, 2017).

A further exploratory analysis, examining outcomes using change from baseline and weighted mean of the 3-and 8-week follow-ups, similarly found no significant effect on any symptom or problem. However, specialized palliative care improved the item 'overall satisfaction with the help received from the health care system' (mean difference [95% confidence interval] 9 points [3.8 to 14.2], p = 0.0006) and three other satisfaction related items (Johnsen et al, 2020). Possible explanations for the lack of positive effect could be the low intensity of palliative care, teams prioritising more acute needs, and possible compensation in the control group. This work highlights the importance of carefully testing promising new health-care interventions in new settings.

ImproveCare

The AMBER care bundle, where AMBER stands for: Assessment; Management; Best practice; Engagement; Recovery uncertain represents a complex intervention developed to better identify and then care for patients whose situations are clinically uncertain, where they are deteriorating with limited reversibility and with risk that they might die during their hospital stay, despite receiving treatments. For these patients, health professionals develop and document a clear medical plan with patients (where possible) and families, including consideration of anticipated outcomes, cardiopulmonary resuscitation and escalation status, while acknowledging the uncertainty. This plan is revisited daily and encourages regular communication with the patient and family regarding treatment plans, place of care and any other concerns. In 2017, we led a mixed-methods, feasibility cluster randomised controlled trial to inform the optimisation and refinement of the AMBER care bundle and to evaluate the methods



Dr Jonathan Koffman with the ImproveCare Study Poster at the European Association for Palliative Care conference in Berlin, 2019.

and practicality of undertaking a full clinical trial of the intervention. The study included four UK district general hospitals (clusters) where candidate wards were selected based on the number of deaths per year. The study experienced important challenges, specifically the interpretation of the intervention eligibility criteria and the requirement to prognosticate. This resulted in a variable and unpredictable identification of potential patient participants within, and across, study sites. Health professionals' cognitive aversion to making decisions about certain patients as fulfilling this aspect of the eligibility criteria led to their potential exclusion. We concluded that whilst a full trial would be 'technically possible' it is currently not practical due to this and other intervention-based issues (Koffman, Yorganci, Yi et al, 2019).

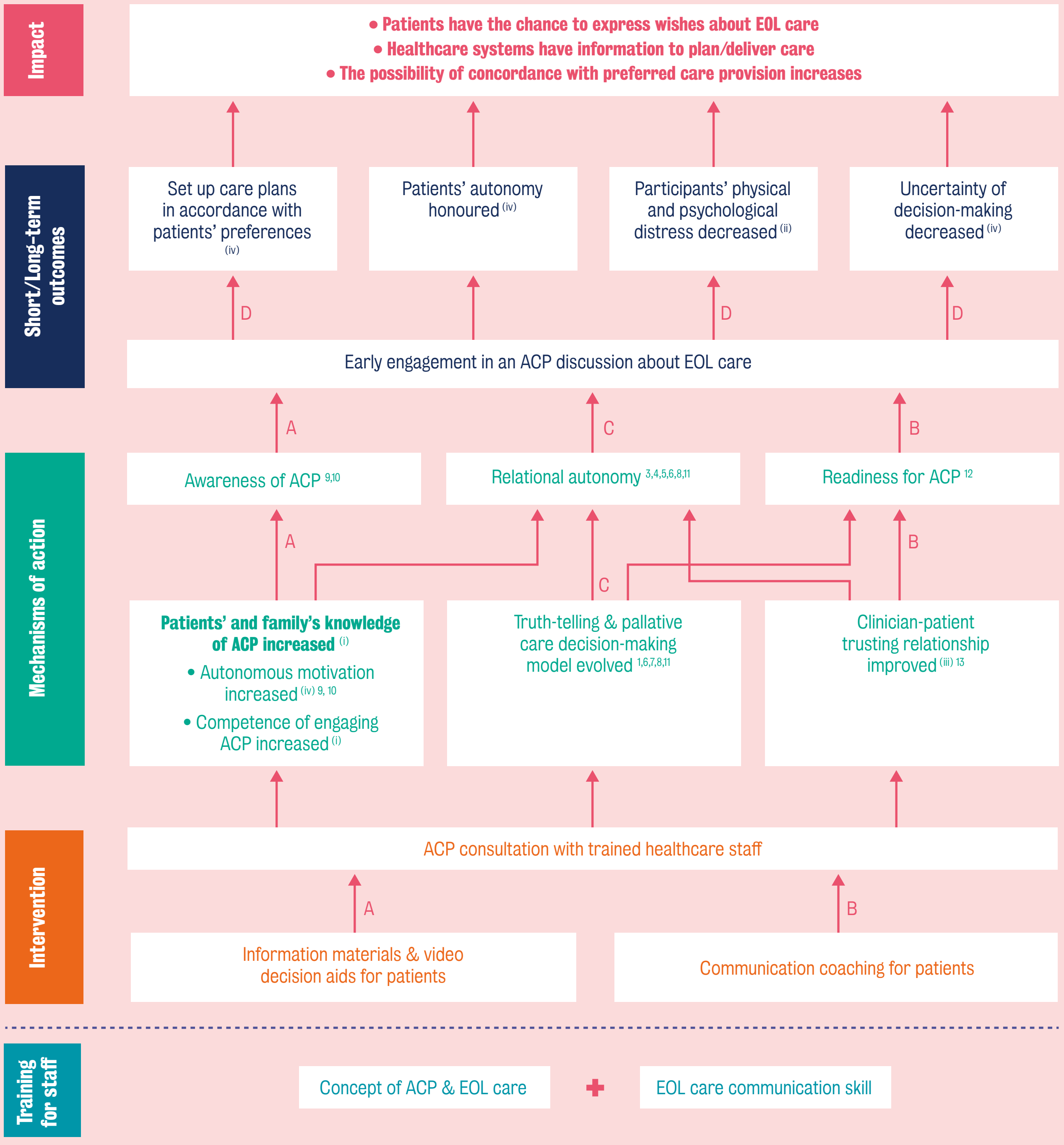
Our embedded process evaluation guided by normalisation process theory identified issues with the cognitive participation (specifically the identification of potential patients) and collective action associated with the AMBER care bundle. This included the requirement to modify the eligibility criteria, the need for a 'ward champion' to drive participation and ensure sustainability, and the requirement for all staff to feel competent and confident in undertaking difficult conversations (Koffman, Yorganci et al, 2019; Johnson et al, 2020). From a methodological perspective, the study developed a novel multi-methods approach aimed at understanding the characteristics of usual or standard care in clinical trials (Yorganci et al, 2019).

Advance Care Planning

Advance care planning (ACP) is a process that supports adults at any age or stage of health in understanding and sharing their values, life goals and preferences regarding future medical care. It includes written documentation or any type of record to reflect a patient's care preferences at the end of life. We conducted ACP-related research within and outside of the UK to improve the palliative care delivery for patients and their family caregivers. Whilst ACP is widely accepted as a component of palliative care and evidence suggests it improves patient and healthcare outcomes, most research on ACP has been developed in Western cultures, with little evidence from Asian countries. This limits the transferability of Western-oriented ACP interventions to Asian countries such as Taiwan. We conducted a sequential qualitative mixed-methods project to develop a culturally acceptable ACP intervention for use in Taiwan among cancer patients and their families. The study involved a systematic review (Lin, Evans, Koffman, Armes et al, 2019) on ACP-based randomised controlled trials for cancer patients to develop a logic model (Figure 8) that was used to inform the basis for a subsequent qualitative study (Lin, Evans, Koffman, Sheu et al, 2019) with cancer patients, family caregivers and staff to explore their perspectives on ACP to culturally adapt the logic model.

This adapted logic model was then modified through a transparent expert consultation with clinicians and evaluated by a single-group, non-controlled mixed-methods feasibility study with advanced cancer patients, family caregivers and palliative care staff in Taiwan (Lin et al, 2020). We concluded that implementing the ACP intervention in clinical practice in Taiwan is possible and acceptable. Careful use of local primary data to develop conceptual

Figure 8. Advance care planning intervention theory of change



Cultural specific factors
1. Medical staff feel discomfort discussing EOL care issues 2. Avoidance of medical dispute and uncertainty 3. Filial piety and family harmony
4. Confucian culture and religion 5. Public expectation about medicine 6. Concealing prognosis of diseases to patients
7. Misunderstanding of palliative care 8. Family involvement in the patient's decision-making process

Common factors
9. Knowledge of ACP 10. Early education 11. Patients do not want to become a burden 12. Lack of resources and competence among participants
13. Quality of EOL communication

Assumptions
A. Information sheets and video decision aids can increase patient's and families' awareness of disease prognosis and knowledge ACP, then enhancing the engagement of ACP.
B. Communication coaching can improve competence of EOL question asking and trusting relationship between clinicians and patients, then enhancing the efficacy of EOL communication and readiness of engaging ACP. C. Patients' EOL decision-making process are influenced by their relation to others. D. ACP can bring positive impact to patients and families (e.g. reduce emotional distress and uncertainty of decision-making, facilitate patient's autonomy, provide desirable care).

Potential outcome metrics
(i) Knowledge of ACP (ii) Physical and psychological distress (iii) Clinician-patient communication (iv) Experience of participating ACP

* ACP = Advacne care planning; EOL = end of life; HCPs = healthcare professionals

Source: Lin, Evans, Koffman, Armes et al, 2019.

underpinning and recruitment strategies were key to achieving these goals. This study provides valuable contributions to inform future ACP intervention development in the wider Asia-Pacific region. However, testing this conceptual model in a feasibility trial in collaboration with implementation science is required.

ACP is relevant and important for all population groups living with serious illness. Koffman and colleagues are currently undertaking a study to understand the essential elements of advance care planning relevant to people with multiple sclerosis and their families, to develop ACP educational resources for people with multiple sclerosis to identify their life goals and preferences for future care. The team have undertaken a systematic realist synthesis to develop and refine an initial theory on engagement in ACP for people with multiple sclerosis, and conducted interviews with people severely affected by their multiple sclerosis and their families to explore their perspectives about being involved in decision-making as their illness progresses. The findings will be brought to an Ethical Discussion Group where health professionals and people with multiple sclerosis and their families will discuss what they mean, what the ethical challenges might represent and how guidance may empower this group to make important decisions about future care.

> ‘How people die remains in the memories of those who live on, and for them as for the patient we need to be aware of the nature and management of terminal pain and distress’.

Cicely Saunders ‘Pain and impending death’
In: Wall P and Melzack R (eds) Textbook of pain,
Churchill Livingstone, 1984, quote from p472.

Symptom-led research

Traditionally medical research is often disease focused, rather than focusing first on the needs of people and the problems and concerns they experience. Yet, symptoms and problems are often similar across diseases, and importantly the numbers of people with multiple illnesses is increasing, meaning that a siloed approach to diseases will not serve future populations. Our symptom-led research strand places improving and relieving symptom-related distress. We research individual symptoms and symptom clusters, and always consider these in the context of the person’s holistic needs.

Our research includes systematic reviews, observational studies as well as feasibility, exploratory and pragmatic randomised controlled trials that test new interventions and treatments. Our goal is to better understand the symptoms experienced by patients with advanced illness and their families towards the end of life, and to discover and trial more effective ways to prevent and manage the impact and distress they cause. Research targets symptoms that have been neglected, especially breathlessness, and our programme extends across multiple patient groups, including those with cancer, chronic respiratory disease, heart failure and long-term neurological conditions, spanning health and social care settings.

Breathlessness triggered services

Breathlessness is a common, distressing symptom which affects over 15 million people in Europe alone. It increases as disease progresses and often becomes chronic or refractory, i.e. not responsive to treatment aimed at the underlying disease. It is frightening for patients and families, and results in reduced life expectancy and high health care costs.

Our previous work contributed to the developing and testing of holistic breathlessness services for people with advanced disease (Reilly et al, 2016, Higginson et al, 2014, Gysels et al, 2015, Gysels et al, 2016). These services provide pharmacological and non-pharmacological treatments to patients and caregivers, across settings, using multidisciplinary approaches. They emphasise self-management, and target improvements in quality of life by reducing the impact of breathlessness and related symptoms on everyday living. In light of a growing body of literature relating to holistic breathlessness services for people with advanced disease and chronic breathlessness, we conducted an evidence synthesis project to inform future practice (Maddocks et al, 2019).

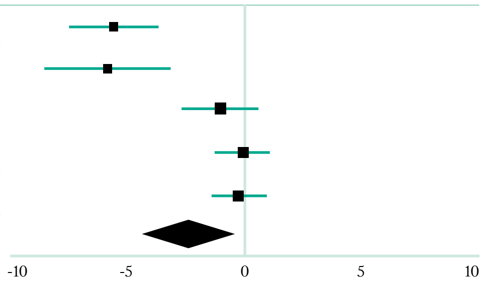
Our systematic review (Brighton, Miller et al, 2019) summarised quantitative and qualitative evidence on holistic breathlessness services up to June 2017. Thirty-seven papers were included, representing 18 different services. Most services enrolled people with thoracic cancer, involved palliative care staff, and comprised 4–6 contacts over 4–6 weeks. Common interventions were breathing techniques (14/18), psychological support (12/18), and relaxation techniques (11/18). Meta-analyses (Figure 9) demonstrated reductions in distress due to breathlessness

Figure 9. Meta-analyses for the effects of holistic breathlessness services on clinical outcomes

1. NRS distress due to breathlessness

	INTERVENTIONS			CONTROL				MEAN DIFFERENCE
STUDY OR SUBGROUP	**MEAN**	**SD**	**TOTAL**	**MEAN**	**SD**	**TOTAL**	**WEIGHT**	**IV, RANDOM, 95% CL**
Bredin et al, 1999	0.5	5	49	6	4.5	51	19.6%	-5.50 (-7.37, -3.63)
Corner et al, 1996	-4.9	3.84	11	0.88	2.22	9	16.8%	-5.78 (-8.47, -3.09)
Farquhar et al, 2014	3.43	2.95	28	4.42	3.01	26	20.4%	-0.99 (-2.85, 0.60)
Yorke et al, 2016	4.02	2.49	41	4.05	2.57	38	21.6%	-0.03 (-1.15, 1.09)
Farquhar et al, 2015	-1.07	2.07	31	-0.88	2.9	40	21.6%	-0.19)-1.35, 0.97)
Total (95% CI)			**160**			**164**	**100.0%**	**-2.30 (-4.43, -0.16)**

MEAN DIFFERENCE
IV, RANDOM, 95% CL

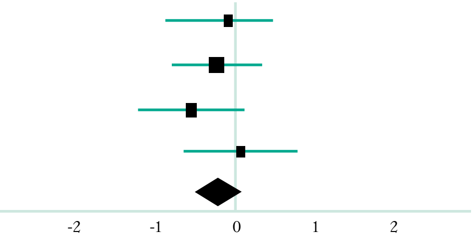


Heterogeneity: Tau^2 = 5.15; Chi^2 = 38.68, df = 4 (P < 0.00001); I^2 = 90%
Test for overall effect: Z = 2.11 (P = 0.03)

2. CRQ Breathlessness mastery

	INTERVENTIONS			CONTROL				MEAN DIFFERENCE
STUDY OR SUBGROUP	**MEAN**	**SD**	**TOTAL**	**MEAN**	**SD**	**TOTAL**	**WEIGHT**	**IV, RANDOM, 95% CL**
Farquhar et al, 2014	4.81	1.29	28	4.72	1.21	26	23.3%	0.09 (-0.58, 0.76)
Farquhar et al, 2016	4.49	1.35	41	4.24	1.17	38	33.5%	0.25 (-0.31, 0.81)
Higginson et al, 2014	4.15	1.7	42	3.57	1.4	40	22.9%	0.58 (-0.09, 1.25)
Pearce et al, 2006	0.77	1.18	22	0.83	1.24	22	20.3%	-0.06 (-0.78, 0.66)
Total			**133**			**126**	**100.0%**	**0.23 (-0.10, 0.55)**

MEAN DIFFERENCE
IV, RANDOM, 95% CL

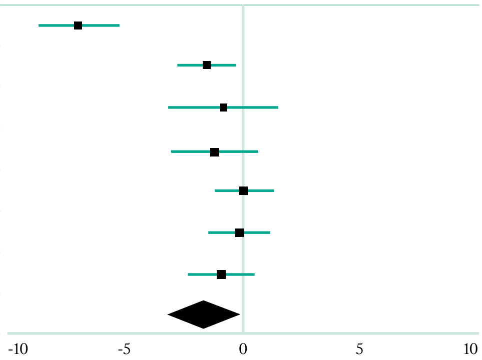


Heterogeneity: Tau^2 = 0.00; Chi^2 = 1.84, df = 3 (P = 0.61); I^2 = 0%
Test for overall effect: Z = 1.37 (P = 0.17)

3. HADS Anxiety

	INTERVENTIONS			CONTROL				MEAN DIFFERENCE
STUDY OR SUBGROUP	**MEAN**	**SD**	**TOTAL**	**MEAN**	**SD**	**TOTAL**	**WEIGHT**	**IV, RANDOM, 95% CL**
Bredin et al, 1996	-1	4.5	50	6	4.25	52	14.0%	-7.00 (-8.70, -5.30)
Corner et al, 1996	-2	1.47	11	-0.5	1.19	9	12.5%	-1.50 (-2.67, -0.33)
Farquhar et al, 2014	7.07	5.05	28	7.85	3.59	26	12.3%	-0.78 (-3.10, 1.54)
Farquhar et al, 2016	7.45	3.97	41	8.61	4.25	38	13.7%	-1.16 (-2.98, 0.66)
Higginson et al, 2014	9.2	2.8	42	9.1	2.7	40	15.1%	0.10 (-1.09, 1.29)
Yates et al, 2011	4.5	3.8	72	4.6	3.9	72	15.0%	-0.10 (-1.36, 1.16)
Yorke et al, 2015	-0.81	2.75	31	0.06	3.1	40	14.8%	-0.87 (-2.23, 0.49)
Total			**275**			**277**	**100.0%**	**-1.59 (-3.22, 0.05)**

MEAN DIFFERENCE
IV, RANDOM, 95% CL

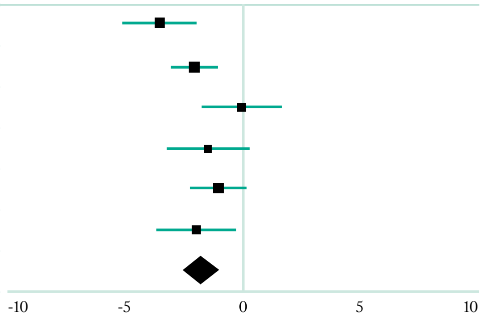


Heterogeneity: Tau^2 = 4.23; Chi^2 = 52.70, df = 6 (P < 0.00001); I^2 =89%
Test for overall effect: Z = 1.90 (P = 0.06)

4. HADS Depression

	INTERVENTIONS			CONTROL				MEAN DIFFERENCE
STUDY OR SUBGROUP	**MEAN**	**SD**	**TOTAL**	**MEAN**	**SD**	**TOTAL**	**WEIGHT**	**IV, RANDOM, 95% CL**
Bredin et al, 1996	-0.5	4.25	50	3	3.5	52	15.6%	-3.50 (-5.01, -1.99)
Corner et al, 1996	-2.5	0.87	11	-0.5	1.19	9	22.5%	-2.00 (-2.93, -1.07)
Farquhar et al, 2014	6.22	3.36	28	6.23	2.89	26	14.1%	-0.01 (-1.68, 1.66)
Farquhar et al, 2016	6.28	3.97	41	7.71	3.83	38	13.7%	-1.43 (-3.15, 0.29)
Higginson et al, 2014	10	2.8	42	11	2.5	40	19.8%	-1.00 (-2.15, 0.15)
Yorke et al, 2015	-0.7	3.14	31	1.22	3.97	40	14.3%	-1.92 (-3.57, -0.27)
Total			**203**			**205**	**100.0%**	**-1.67 (-2.52, -0.81)**

MEAN DIFFERENCE
IV, RANDOM, 95% CL



Heterogeneity: Tau^2 = 0.62; Chi^2 = 11.36, df = 5 (P < 0.04); I^2 =56%
Test for overall effect: Z = 3.83 (P = 0.0001)

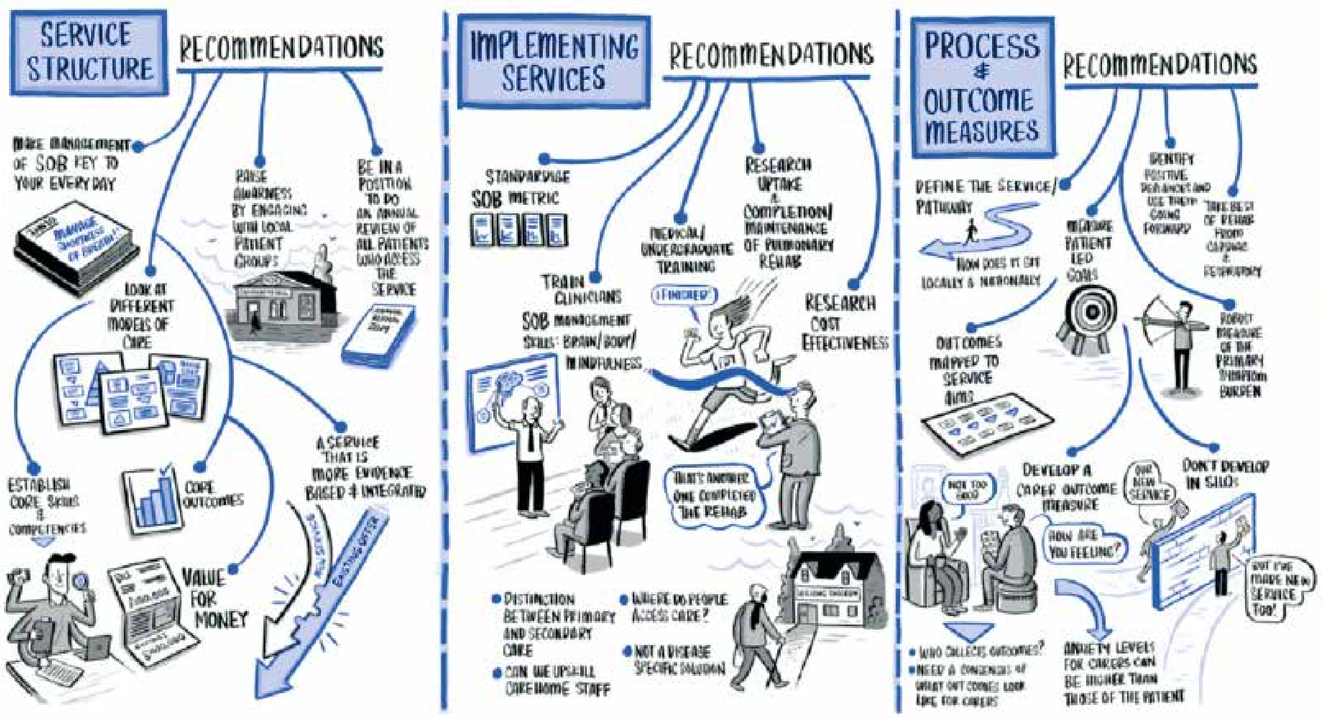
Source: Brighton, Miller et al, 2019.

(n=324; mean difference (MD) -2.30, 95% CI -4.43 to -0.16, p=0.03) and depression scores (n=408, MD -1.67, 95% CI -2.52 to -0.81, p<0.001) favouring the intervention. Statistically non-significant effects were observed for breathlessness mastery (n=259, MD 0.23, 95% CI -0.10 to 0.55, p=0.17) and anxiety scores (n=552, MD -1.59, 95% CI -3.22 to 0.05, p=0.06). There was no observable effect on overall health status or quality of life, and evidence for cost-effectiveness was inconclusive. Qualitative data illustrated that patients and their informal carers valued the provision of dignified, person-centred care from expert staff; education and information sharing; and useful self-management interventions that were simple and portable (e.g. handheld fan, breathing techniques). Holistic services for chronic or refractory breathlessness in people with advanced disease are therefore acceptable to patients and carers, and lead to significant improvements in psychological aspects of breathlessness and health.

We also conducted a secondary analysis of pooled individual patient data from three trials of holistic breathlessness services, for example predictors of treatment response (Brighton, Gao et al, 2019). The pooled dataset comprised 259 participants (118 female) with primary diagnoses of COPD (49.8%), cancer (34.7%) and interstitial lung disease (10.4%). Controlling for age, sex, and trial in the multivariate modeling, baseline Chronic Respiratory Questionnaire for first time use (CRQ) mastery remained the only significant predictor of intervention CRQ mastery response (Odds Ratio, OR 0.57, 95% CI 0.43 to 0.74; p<.001), and baseline NRS distress remained the only significant predictor of intervention NRS distress response (OR 1.64; 95% CI 1.35 to 2.03; p<.001). This illustrated that clinical response to holistic breathlessness services in terms of increased mastery or reduced distress is influenced by baseline scores for these variables, but not by breathlessness severity, patient diagnosis, lung function, health status, anxiety or depression. In the context of limited resources, this suggests prioritising patients with low levels of mastery or high levels of distress could be appropriate to direct resource to those most likely to benefit.

Alongside other relevant evidence, we presented these findings as part of a transparent expert consultation to elicit stakeholders' evidence-based priorities for clinical practice, policy, and research around holistic breathlessness services (Brighton, Tunnard et al, 2018). Stakeholders attending

Figure 10. Graphic recording of stakeholder workshop discussions



the workshop (n=37) produced 34 statements reflecting their priorities: ten for clinical practice, eight for policy, and sixteen for research. Workshop discussions were captured in a graphic illustration (Figure 10). Their priority statements were subsequently rated by 74 online survey respondents. Seven statements had strong agreement and a high level of consensus, reflecting suggestions to improve access to person-centred, multi-professional care, and support for carers to provide, or access, breathlessness management interventions. Future research in this field will therefore need to test the optimal models of care and educational strategies to address stakeholders' priorities and understand how best to embed core therapeutic components into routine clinical practice.

Matthew Maddocks and Lisa Brighton receiving a CLAHRC award for 'best stakeholder event' for the breathlessness stakeholder workshop, with Jill Lockett, Managing Director of King's Health Partners. Know Your CLAHRC awards, November 2017.

Public involvement in our breathlessness evidence synthesis project:

By including our patient and public involvement (PPI) members across all project meetings and subsequent communications, this ensured frequent opportunities to relate emerging findings to their real-life experiences of having breathlessness or caring for someone with breathlessness. This ranged from highlighting inconsistencies in clinical practice, to raising important issues related to breathlessness (e.g. relationships, including intimacy).

"Including PPI members as we first considered our study findings, not once we had digested and interpreted them, meant their views went beyond simply endorsing our view; it ensured a more collaborative research process" – Matthew, Project Lead.

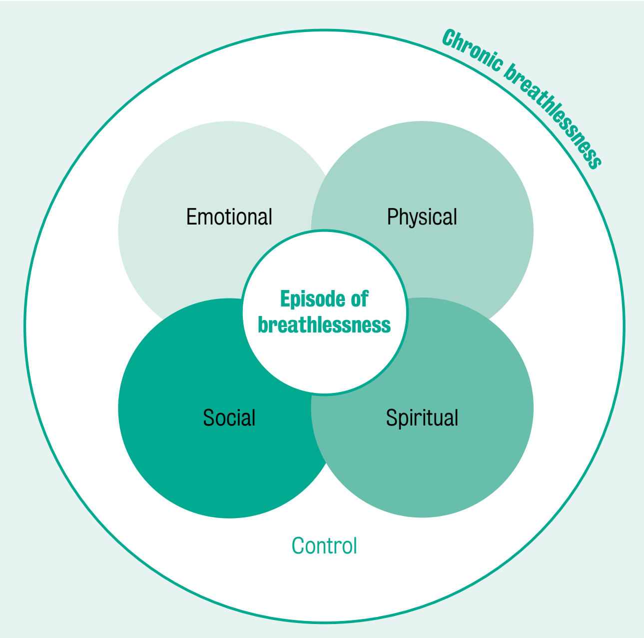
Our PPI members valued the opportunity to get involved in a variety of tasks, and appreciated that the researchers took time to explain and respond to questions during and outside of meetings and workshops. Overall, they commented that they felt valued as part of the project team, leading to more rewarding and satisfying involvement.

"I felt I could add value being able to test the questionnaire, make suggestions for wider dissemination of the survey etc. I realised what an extensive network I have as a resource" – Colleen, PPI Representative.

Repurposing drug treatments for breathlessness

Chronic or refractory breathlessness has few effective drug treatment options. New treatments need to be developed and trialled. Conducting clinical trials in advanced illness can be challenging, with difficulties recruiting and retaining participants. Outcome measures that capture changes important to people living with breathlessness are also necessary, and a systematic review has shown that people with advanced illness experiencing breathlessness describe concerns across six domains of 'total breathlessness': physical, emotional, spiritual, social, control, and context (Lovell et al, 2019a) (Figure 11).

Figure 11. Total breathlessness. Adapted from Abernethy and Wheeler (2008)

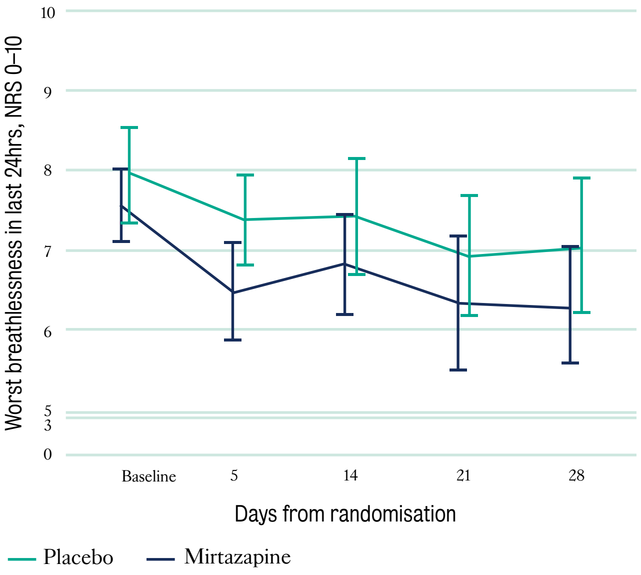


Source: Lovell et al, 2019a.

Central nervous system mechanisms are important in respiratory sensation and control. Consequently, drugs which may modify processing and perception of afferent information in the brain may have a role. Of potentially suitable antidepressants, mirtazapine is an attractive option given its tolerability profile, low cost, and wide availability, along with additional potential benefits. Our initial review provided an overview of the physiology of breathlessness, with an emphasis on central mechanisms, particularly the role of fear circuits and the associated neurotransmitters. It highlighted a potential rationale for how mirtazapine may improve chronic breathlessness in patients with advanced disease (Lovell, Wilcock et al, 2019).

We conducted a multi-centre randomised controlled feasibility trial of mirtazapine as a treatment for chronic or refractory breathlessness. Using a mixed-methods approach we explored the feasibility of, and ways to optimise recruitment, retention, and outcome measures in a double blind randomised controlled trial of mirtazapine for chronic or refractory breathlessness. Sixty-four patients were randomised achieving our primary feasibility endpoint of recruitment.

Figure 12. Mean (95% CI) breathlessness at worst and average over 24 hours during the 28 days of the study, by study arm



Mean (95% CI data) at each time point

Placebo	8.0 (7.4–8.6)	7.4 (6.8–8.0)	7.5 (6.7–8.2)	7.0 (6.2–7.7)	7.1 (6.2–7.9)
Mirtazapine	7.6 (7.1–8.1)	6.5 (5.9–7.1)	6.9 (6.2–7.5)	6.4 (5.5–7.2)	6.3 (5.6–7.0)

Source: Higginson, Wilcock et al, 2020.

Most patients had COPD or interstitial lung disease; 52 (81%) completed the trial. There were no differences between placebo and mirtazapine in tolerability or safety, and blinding was maintained. Worst breathlessness ratings at day 28 (primary clinical activity endpoint) were, 7.1 (SD 2.3, placebo) and 6.3 (SD 1.8, mirtazapine) (Figure 12). The intervention was well tolerated during the trial with few adverse effects reported. Twelve patients (six per arm) discontinued treatment prematurely. There was 100% completion of questionnaires at baseline and few missing data throughout the trial.

Prioritisation of the relationship between the patient and professional; person-centred processes including home visits, assistance with questionnaires, and involvement of the carer; and enabling people to participate by having processes in line with individual capabilities appeared to support recruitment and retention in the trial. Themes were considered in relation to person centered care and a model of the person-centred trial was developed (Lovell, Etkind et al, 2020). Participants described change in experience across all domains of 'total breathlessness' during the trial. Changes in the qualitative data were commonly captured in the Numerical Rating Scale (worst and average) and CRQ. However, agreement was highest with the NRS worst, which despite being a single item measure appeared to capture changes across multiple domains (Lovell et al, 2019b).

On the basis of this work, we secured European Commission funding for the BETTER-B programme, (https://betterbreathe.eu/) which aims to significantly improve the treatment of severe breathlessness in patients with advanced disease by establishing whether mirtazapine is an effective treatment to reduce severe breathlessness even when people are not depressed. The BETTER-B main trial lies at the heart of the project and consists of a large-scale randomised controlled trial, which will study the effects of mirtazapine on patients, their families or caregivers, as well as treatment and care costs. This patient-centred trial could result in reduced symptom burden and significant improvements in quality of life and well-being for patients and their family and friends. The trial is supported by a thorough period of preparation,

in which the research consortium will be focussing on setting up the trial and researching views, usual practice and experiences of European clinicians usually involved in the treatment of chronic breathlessness on the main medications to alleviate breathlessness. The results of the BETTER-B main trial will be used to facilitate the development of easily accessible and multi-lingual guidance on the management of breathlessness in advanced disease.
The consortium will additionally focus on communicating preliminary findings and results to the general public as well as the scientific community to make sure that BETTER-B actually reaches the people it's meant for. The study website is already sharing the best practice in breathlessness management and we have surveyed clinicians from respiratory medicine and palliative care to understand their practice and sources of information.

Breathlessness PPI group

At the end of 2018, researchers from the Cicely Saunders Institute were awarded a small grant from Collaboration for Leadership in Applied Health Research Collaborative (CLAHRC) South London to launch a Breathlessness Patient and Public Involvement (PPI) group. This new group would support our portfolio of breathlessness research at the CSI, enabling breathlessness researchers and PPI members to collaborate on and champion the increasing and vital breathlessness related work taking place.

The group, consisting of 8 patient, carer and family members with lived experience of chronic/refractory breathlessness, have to date held two face-to face workshops. These workshops gave a chance for patient representatives to meet some of the breathlessness researchers and learn about our breathlessness projects. It also provided an opportunity for them to give feedback on aspects of various projects. One of the main projects under discussion in the workshops has been the EU-funded BETTER-B project, with patients and caregivers reviewing key public-facing documents that will be used in the project. As a result of the workshop, significant changes to the language and layout were made to the materials.

PPI members and researchers reported that the workshops to date had been hugely valuable, informative and an inclusive forum to work across projects to tackle the debilitating symptom. While COVID-19 meant that we had to postpone our breathlessness PPI workshop in Spring 2020, we are continuing to gain valuable feedback from this group via email.

> "Having stopped working a few years ago due to my health, I felt devalued and I try to seek ways to change this. Having the opportunity to be part of a group such as this can only be empowering as I discover something positive from having this condition. If my condition and the experiences connected to it can be of benefit to someone else, I am empowered!" – Breathlessness PPI member

Symptom management in interstitial lung disease

Progressive fibrotic interstitial lung diseases (ILDs) are characterised by major reductions in quality of life and survival and have similarities to certain malignancies. In a systematic review of 23 studies we described symptom prevalence in this group (Carvajalino et al, 2018). The highest symptom prevalence range was that for breathlessness (54–98%) and cough (59–100%) followed by heartburn (25–65%) and depression (10–49%) highlighting the urgent need for effective assessment and clinical intervention to meet these needs.

Previously, working in collaboration with others, a needs assessment tool to identify the supportive/palliative needs of people with ILD (NAT-ILD) has been developed. We have now adapted, validated and tested the reliability of the NAT-ILD in a psychometric validation showing that it had adequate reliability and construct validity (Johnson et al, 2017). We have also identified training needs for the clinical implementation which include improving communication skills and local service knowledge (Reigada et al, 2017). We continue to develop validated and reliable outcome measures which meet the needs of those living with ILD.

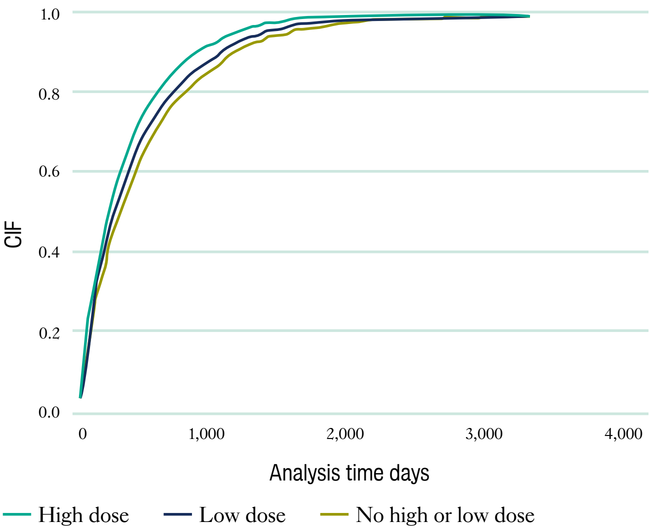
In our work, we have found breathlessness and anxiety are significant symptoms in ILD which impact on quality of life. Benzodiazepines and opioids may be used to manage these symptoms. However, safety concerns are a barrier to prescribing. In a population-based longitudinal cohort study, we examined data from 1603 ILD patients starting long term oxygen therapy and looked at the association between benzodiazepines and opioid prescribing and risk of admission to hospital and death (Bajwah et al, 2018). We found there was no association between benzodiazepines and increased admission. Treatment with high- versus low-dose benzodiazepines was associated with increased mortality (subdistribution hazard ratio (SHR) 1.46, 95% CI 1.08-1.98 versus 1.13, 95% CI 0.92-1.38). Opioids showed no association with increased admission. Neither low-dose opioids (≤30 mg·day-1 oral morphine equivalent) (SHR 1.18, 95% CI 0.96-1.45) nor high-dose opioids (>30 mg·day-1 oral morphine equivalent) (SHR 1.11, 95% CI 0.89-1.39) showed association with increased mortality (Figure 13). This first ever study to examine associations between benzodiazepine and opioid use and harm in ILD supported the use of opioids and low-dose benzodiazepine in managing ILD patients' symptoms safely.

Within ILD, there is an incorrect perception that palliative care is synonymous with end-of-life care and has created a culture of neglect. In an international position statement (Kreuter et al, 2017) we clearly delineate palliative care needs of those living with ILD. We usefully direct health professionals on how to address the unmet patient and carers needs including effective pharmacological and psychosocial interventions to improve quality of life throughout the disease course, sensitive advanced care planning, and timely patient-centred end-of-life care.

Managing frailty in respiratory disease

Frailty is a multidimensional syndrome characterised by decreased reserve and diminished resistance to stressors. Our review of recent evidence highlighted increasing understanding of the interconnectedness of respiratory disease and frailty (Brighton, Bone et al, 2020), resulting from both age- and disease-related factors (e.g. sedentary behaviour, mobility impairments, sarcopenia and malnutrition). Recognition of frailty in respiratory disease offers advantages over measures of disease severity, particularly in the context of multimorbidity, in that it incorporates a more holistic understanding of a persons' health and limitations.

Figure 13. Cumulative incidence function (CIF) plot of benzodiazepine treatment on mortality

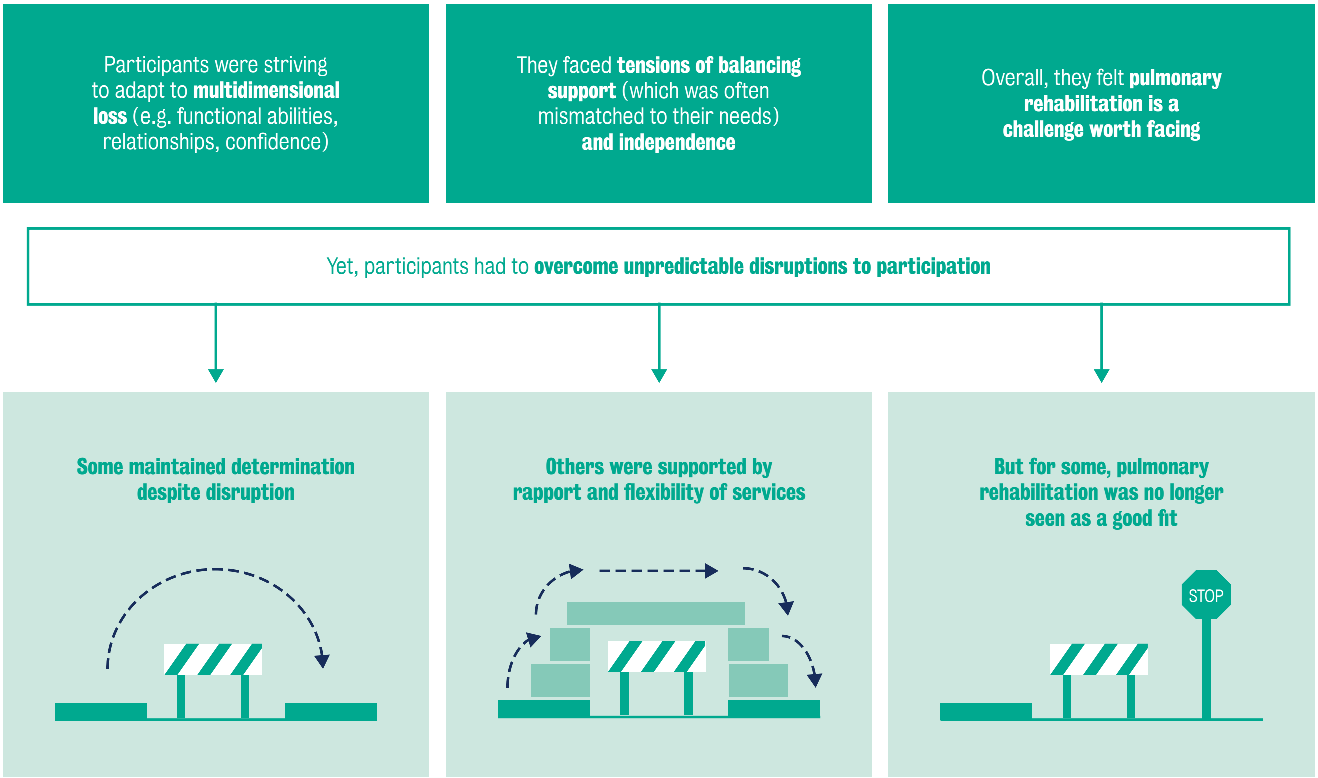


Source: Bajwah et al, 2018.

Older person being supported into standing.

Our previous work showed that about 1 in 4 people attending pulmonary rehabilitation services are living with frailty (Maddocks et al, 2016). These individuals show improved health outcomes on completing pulmonary rehabilitation, but faced a difficult time doing so: they are less than half as likely to complete a programme compared those who are not frail. Work to increase the value of pulmonary

Figure 14. The different pulmonary rehabilitation journeys for people living with COPD & frailty



Source: Brighton, Bristowe et al, 2020.

rehabilitation for people with COPD and frailty is therefore essential.

To inform development of an adapted approach, we conducted qualitative interviews with people living with both COPD and frailty referred for pulmonary rehabilitation (Brighton, Bristowe et al, 2020). Purposive sampling ensured representation of people who did (n=10) and did not (n=9) complete their pulmonary rehabilitation programme. Participants in our qualitative study described how they continually strive to adapt to multidimensional losses associated with living with COPD and frailty, and how support received is variable. While all have an initial motivation to engage in pulmonary rehabilitation, their changeable health and disruptions can interfere with, and in some cases erode, their motivation to attend (Figure 14).

We then conducted a realist review to unpick how exercise-based interventions for people with COPD might better address the context of frailty (Brighton, Evans, Man et al, 2020). Findings of our review suggested that successful exercise-based interventions for people with respiratory disease and frailty might need to foster trusting relationships with participants and a shared understanding of their priorities, be able to individualise content to match priorities, have capacity to address multidimensional losses, and take a flexible approach to service delivery. Several strategies to work towards these mechanisms were identified, including a potential role for Comprehensive Geriatric Assessment. We are currently undertaking a randomised controlled feasibility trial, ‘Breathe Plus’, introducing a Comprehensive Geriatric Assessment at the start of pulmonary rehabilitation for people with COPD and frailty. This will test the feasibility of the intervention and trial design for a future effectiveness study.

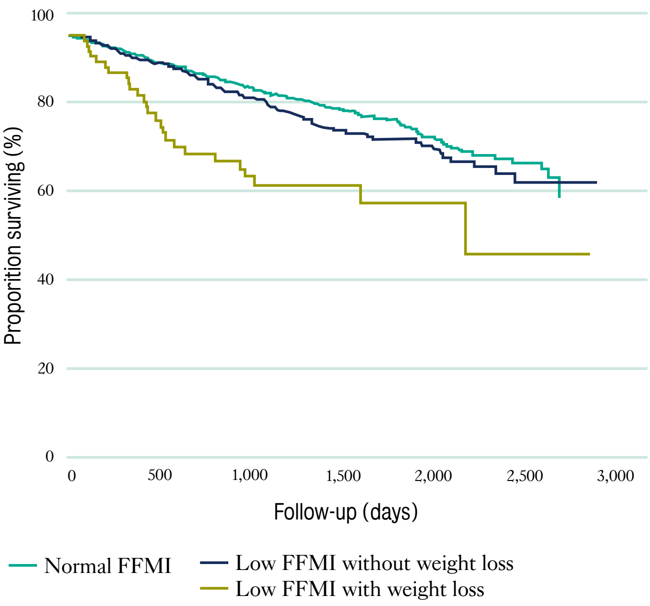
New endpoints for symptoms in respiratory disease

Surrogate endpoints that can predict adverse outcomes are required to help develop and evaluate new treatments. Our work establishing the psychometric properties and predictive value of measures of usual walking speed and exercise capacity have extended their potential utility beyond COPD, to also include people with idiopathic pulmonary fibrosis (IPF).

The four-metre gait speed (4MGS) test measures usual walking speed and can consistently predict adverse outcomes in older people. We conducted a series of four prospective cohort studies to evaluate the inter-observer (n = 46) and test-retest (n = 46) reliability, concurrent validity (n = 65 and n = 62) and responsiveness (n = 60) of the 4MGS test in people with IPF (Nolan et al, 2018). Intra-class correlation coefficients for inter-observer and test-retest reliability were high: 0.996 and 0.983, respectively (n=46). The 4MGS test was reliable (n=46) and showed concurrent validity in two independent cohorts (n=65 and n=62) with established IPF measures including walking exercise capacity, respiratory disability, health status and a multi-dimensional prognostic index. The 4MGS test was also responsive to pulmonary rehabilitation (mean change: 0.16m/s; 95% CI 0.12-0.20; effect size 0.65). Having established the psychometric properties of the 4MGS for people with IPF, we conducted a prospective cohort study to investigate the ability of the 4MGS to predict all-cause mortality and nonelective hospitalisation in this population (Nolan et al, 2019). The 4MGS test and lung function were measured at baseline in 130 people newly diagnosed with IPF, and then survival status and nonelective hospital admissions were recorded over one year. After adjusting for confounding variables, 4MGS was associated with a significantly increased risk of all-cause mortality (HR 0.03, 95% CI: 0.01 to 0.25) and non-elective hospitalisation (HR 0.03, 95% CI: 0.01 to 0.18) at one year. Multivariable models incorporating 4MGS had better discrimination for predicting mortality than either the gender, age and lung physiology index, or the Composite Physiologic Index. Altogether, these findings support the psychometric properties and predictive value of the 4MGS test in people living with IPF.

Cachexia is an important extra-pulmonary manifestation of COPD, presenting as unintentional weight loss and altered body composition. In a prospective cohort study (n=1755) from 2012 to 2017, we aimed to determine the prevalence of cachexia and pre-cachexia phenotypes in COPD, and examine the associations between cachexia and its component features with all-cause mortality (Kwan et al, 2019). Participants were stratified according to European Respiratory Society Task Force defined cachexia [unintentional weight loss >5% and low fat-free mass index (FFMI)], pre-cachexia (weight loss >5% but preserved FFMI), or no cachexia. We found a prevalence of 4.6% (95% CI 3.6-5.6) for cachexia and 1.6% (95% CI: 1.0-2.2) for pre cachexia in people with stable COPD. Both cachexia (HR 1.98, 95% CI: 1.31-2.99, P = 0.002) and pre cachexia (HR 2.79, 95% CI: 1.48-5.29, P = 0.001) were associated with increased mortality risk. However, contrary to our hypothesis, low FFMI did not add prognostic value to unintentional weight loss alone (Figure 15). Based on this work we advocate for unintentional weight loss to be regularly monitored in practice and considered in COPD management.

Figure 15. The prognostic significance of weight loss in chronic obstructive pulmonary disease related cachexia



Number at risk							
Normal FFMI	1,054	850	631	403	186	54	0
Low FFMI without weight loss	620	472	274	167	83	28	0
Low FFMI with weight loss	81	51	34	16	6	1	0

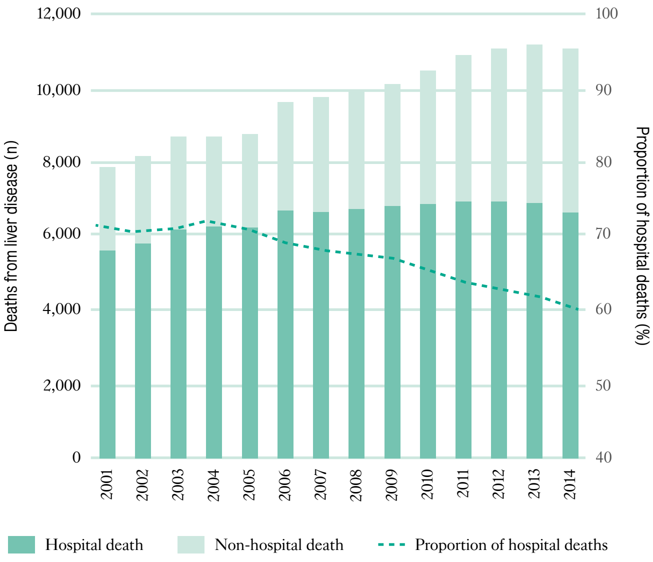
Source: Kwan et al, 2019.

Symptoms of End-stage liver disease (ESLD)

End-stage liver disease (ESLD) is a common cause of morbidity and mortality worldwide. In a systematic review of 80 studies we described symptom prevalence and health-related quality of life in this group (Peng et al, 2018). Frequently reported symptoms included pain (prevalence range 30%–79%), breathlessness (20%–88%), muscle cramps (56%–68%), sleep disturbance (insomnia 26%–77%, daytime sleepiness 29.5%–71%), and psychological symptoms (depression 4.5%–64%, anxiety 14%–45%), which resembled that of patients with other advanced conditions. Given the diversity of symptoms and impaired health-related quality of life, a multidisciplinary approach and timely intervention are crucial.

Liver disease has high numbers of hospital deaths worldwide. In a national population-based, observational study using the National Death Registration Database from the Office for National Statistics we examined the place of death and factors associated with hospital death for people who died from liver disease 2001–14 (Peng, Higginson et al, 2019). 135,953 decedents were included of whom 56,065 (41%) died from alcohol-related liver disease. Hospitals were the main place of death (66·9% [95% CI 66·6-67·1]). After adjusting for sociodemographic factors, patients who died from alcohol-related liver disease had the highest chance of hospital death; people who died from liver cancer were less likely to die in hospital (adjusted PR 0·61 [95% CI 0·60-0·61]). Patients with sepsis (1·24 [1·23-1·25]), hepatorenal syndrome (1·22 [1·21-1·22]), and peritonitis (1·18 [1·17-1·20]) had higher chances of hospital death than those without these contributory causes (Figure 16). These findings warrant further investigation and prevention strategies plus end-of-life care services are urgently needed to prevent and tackle harms from liver disease (Peng, Higginson et al, 2019).

Figure 16. Number of deaths and proportion of hospital deaths in decedents who died from liver disease in England in 2001–14



Source: Peng et al, 2019.

In another Population-based cohort study using the National Health Institute Research Database of Taiwan, we aimed to understand the utilization of intensive care and its associated factors in patients with ESLD during terminal hospitalization 2010–13. Of the 14,247 patients with ESLD, the majority (60·8%) were comorbid with hepatocellular carcinoma. The intensive care utilization by patients with ESLD in their terminal hospitalization was substantial. Compared to patients with comorbid HCC, relatively more patients with ESLD only were admitted to intensive care (59·6% vs 22·3%), or received CPR (11·1% vs 4·3%) and mechanical ventilation (36·3% vs 12·5%) during terminal hospitalization. Prior palliative care was associated with lower probability of intensive care admission (aRR range: 0·24-0·38). We suggest this group need more attention, especially in terms of their palliative care needs, choices regarding intensive care, and their healthcare utilization (Peng et al, 2020).

Troublesome symptoms in advanced cancer

We have provided practical evidence-based guidance based on reviews of current evidence to support health care professionals provide effective symptom management for people with advanced cancer (Henson, Maddocks et al, 2020). Most patients with advanced cancer experience symptoms throughout the disease trajectory, often with greater intensity as death approaches. If poorly managed, such symptoms, such as pain, fatigue, breathlessness, nausea and vomiting can have a considerable impact on patients' ability to function, quality of life, ability to comply with anticancer treatments, and use of health care resources. Multidisciplinary palliative care teams' use of symptom assessment tools can improve patient outcomes and possibly even survival (Henson, Maddocks et al, 2020). Our practice review around pain (Chapman et al, 2020) identified that after comprehensive assessment of patients with advanced cancer, a strong opioid remains the drug of choice for treating moderate or severe pain. Treatment with bisphosphonates, radiotherapy or both for bone pain is effective. Optimal management requires a tailored approach, support for self-management and regular review of treatment outcomes. The review found that interventions commonly recommended by international guidelines are not always supported by a robust evidence base. Oral paracetamol should not be used in patients already taking a strong opioid to manage moderate or severe pain. Cannabis-based drugs are not recommended due to evidence of lack of effect. Data are needed to support the appropriate selection of patients who might benefit from third-line approaches, such as lidocaine and ketamine (Chapman et al, 2020).

Our research has explored symptom burden and impact in under-researched populations. For example, in advanced soft tissue sarcomas (STS), a rare cancer type. Our mixed methods longitudinal study identified that people with advanced STS experience a considerable physical and psychological symptom burden during different treatment approaches. Symptom prevalence and severity were recorded before treatment commenced in 113 people with sarcoma. The most common physical symptoms were pain (77%; 95% CI 68-84), lack of energy (73%; CI 63-81), difficulty sleeping (56%; CI 46-65), feeling bloated (49%; CI 39-58), and dyspnoea (49%; CI 39-58). Distress levels were commensurate with prevalence except for dyspnoea, which was disproportionally less distressing. Psychological distress was moderate but higher than comparative cancer data (Gough et al, 2017). Quantitative and qualitative longitudinal data from sixty-six patients identified that STS had a profound impact on several physical, psychological and functional aspects of patients' lives that were not captured using the generic EORTC QLQ-C30 tool. Furthermore, functional EORTC QLQ-C30 domains did not change longitudinally in line with qualitative data suggesting poor content validity or response to change in some of the EORTC QLQ-C30 scales. This supports the need for the development and testing of a disease specific tool (Gough et al, 2019).

Symptoms and anxiety were also found to predict declining HRQoL in people with multiple myeloma (Ramsenthaler et al, 2019). Multiple myeloma patients from 14 hospitals in England were recruited to a prospective, longitudinal cohort study, the first to describe and compare the longitudinal patterns of change in QoL and palliative care concerns in this population. In addition to clinical information and standardised HRQOL and psychological aspects, the Myeloma Patient Outcome Scale (MyPOS) measured palliative care concerns. A total of 238 patients were recruited, on average 3.5 years (SD: 3.4) post-diagnosis. Latent mixture growth models identified four HRQoL trajectories: improving, stable QoL, stable, poor QoL and deteriorating QoL. The strongest predictors of poor outcome at the end of follow-up were general symptom level (odds ratio (OR): 1.3, 95% CI: 1.0–1.6, p = 0.028), presence of clinically relevant anxiety (OR: 1.2, 95% confidence interval (CI): 1.0–1.4, p = 0.019), and presence of pain (OR: 1.02, 95% CI: 1.0–1.1, p = 0.018), all being more predictive than demographic or clinical characteristics. The findings indicate that early identification of patients with palliative care needs should focus on assessing patient-reported symptoms and psychosocial well-being to identify those at risk of deterioration (Ramsenthaler et al, 2019).

Our work has shed light on the functional impact of symptoms. Our systematic review of 43 observational studies with 19,246 patients (Neo et al, 2017), reveals that about one-third of adults with cancer respectively require assistance to perform basic activities of daily living (ADLs) and about one-half require assistance to perform instrumental ADLs. Across the activities studied, the most frequently affected basic ADLs were personal hygiene, walking and transfers, and instrumental ADLs were housework, shopping and transportation. These findings highlight substantial need for rehabilitation services that focus on maintaining functional independence.

The final strand of research in this period is on cancer cachexia, which is particularly disabling. Cachexia criteria were directly compared in terms of their relationship with measures of body composition and physical function (Dolan et al, 2020). Eastern Cooperative Oncology Group-Performance status (ECOG-PS) and modified Glasgow Prognostic Score (mGPS) were consistently associated with low skeletal muscle mass and function and therefore can be used as criteria to define cancer cachexia. Our systematic review examined current evidence for rehabilitation combining exercise and nutritional support in patients with incurable cancer (Hall et al, 2019). Studies to date report improvements in multiple domains, most notably physical endurance, and depression scores. This supports the concept that multi-modal rehabilitation incorporating principles of cachexia management may be appropriate for the wider group of patients with incurable cancer. Following a successful phase II trial, the phase III MENAC trial (Multimodal-Exercise, Nutrition and Anti-inflammatory medication for Cachexia) of a multimodal cachexia intervention is under way and we are a collaborating site (Solheim et al, 2018).

> ‘The care of the dying demands all that we can do to enable patients to live until they die’.
>
> **Cicely Saunders ‘The last stages of life’ American Journal of Nursing, March 1965.**

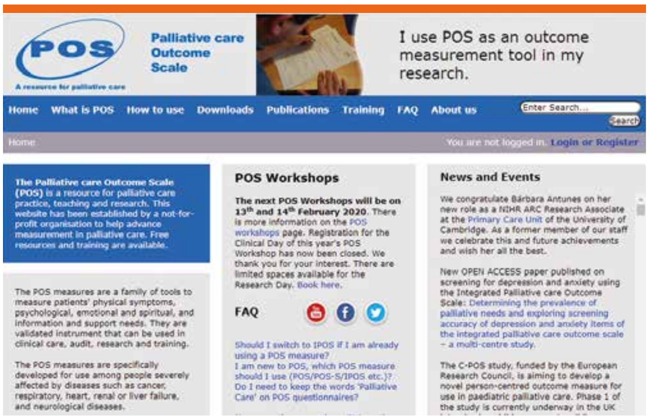
Person-Centred Outcome Measures (PCOMs)

Person-centeredness means respect for persons, their values and individuality; providing holistic care covering physical, psychosocial and spiritual aspects of life; involvement of family and friends; and doing things with people rather than for them. Person-centred care empowers people to make decisions about their own care and focuses on the whole person rather than the disease, taking into consideration their preferences and wider social and cultural context. Health services and professionals must increasingly demonstrate that they meet the needs of individual patients and their families, and that they do this in an effective and efficient way. To achieve this, and strive towards better care, services and staff must show that they are making a measurable and positive difference to patients and families receiving care. The Institute is at the forefront of the development of patient-centred outcome measures for palliative care.

Palliative care (Patient) Outcome Scale (POS) family of measures

The Institute has been at the forefront of person centred outcome measurement in life-limiting and advanced illness as the evidence-based means to put the patients and families at the centre of their care and measures aspects of health and wellbeing most important to patients and their families. The Palliative care Outcome Scale (POS) since its development and validation is one of the most widely used measures with diverse patient populations living with life-limiting and advanced illnesses.
It is used in more than 135 countries worldwide to help improve care and for assessment in clinical practice (see www.pos-pal.org). Our research has discovered ways to use POS to advance patient centred care (Kane et al, 2018), for screening patients for depression and anxiety and determining palliative care needs (Antunes et al, 2020) to assess quality of life (Ramsenthaler et al, 2019) and to audit practice (Kinley et al, 2019), and in training and research, such in clinical trials (Koffman, Yorganci, Yi et al, 2019).

Through our project C-CHANGE, we found that routine outcomes data collection is important to patients and those important to them. It found that policy, national drivers, information technology infrastructure, support from peers and leadership, clear rationale and training were all important to them (Pinto et al, 2018). The Integrated Palliative care Outcome Scale (IPOS) is now an integral part of a casemix classification in many countries to capture and reflect complexity faced by people with serious conditions (Guo et al, 2018).



The Palliative care Outcome Scale (POS) is a resource for palliative care practice, teaching and research. This website has been established by a not-for-profit organisation to help advance measurement in palliative care. Free resources and training are available.

The POS measures are a family of tools to measure patients' physical symptoms, psychological, emotional and spiritual, and information and support needs. They are validated instrument that can be used in clinical care, audit, research and training.

The POS measures are specifically developed for use among people severely affected by diseases such as cancer, respiratory, heart, renal or liver failure, and neurological diseases.

The next POS Workshops will be on 13th and 14th February 2020. There is more information on the POS workshops page. Registration for the Clinical Day of this year's POS Workshop has now been closed. We thank you for your interest. There are limited spaces available for the Research Day. Book here.

Should I switch to IPOS if I am already using a POS measure?
I am new to POS, which POS measure should I use (POS/POS-S/IPOS etc.)?
Do I need to keep the words 'Palliative Care' on POS questionnaires?

We congratulate Bárbara Antunes on her new role as a NIHR ARC Research Associate at the Primary Care Unit of the University of Cambridge. As a former member of our staff we celebrate this and future achievements and wish her all the best.

New OPEN ACCESS paper published on screening for depression and anxiety using the Integrated Palliative care Outcome Scale: Determining the prevalence of palliative needs and exploring screening accuracy of depression and anxiety items of the integrated palliative care outcome scale – a multi-centre study.

The C-POS study, funded by the European Research Council, is aiming to develop a novel person-centred outcome measure for use in paediatric palliative care. Phase 1 of the study is currently underway in the UK

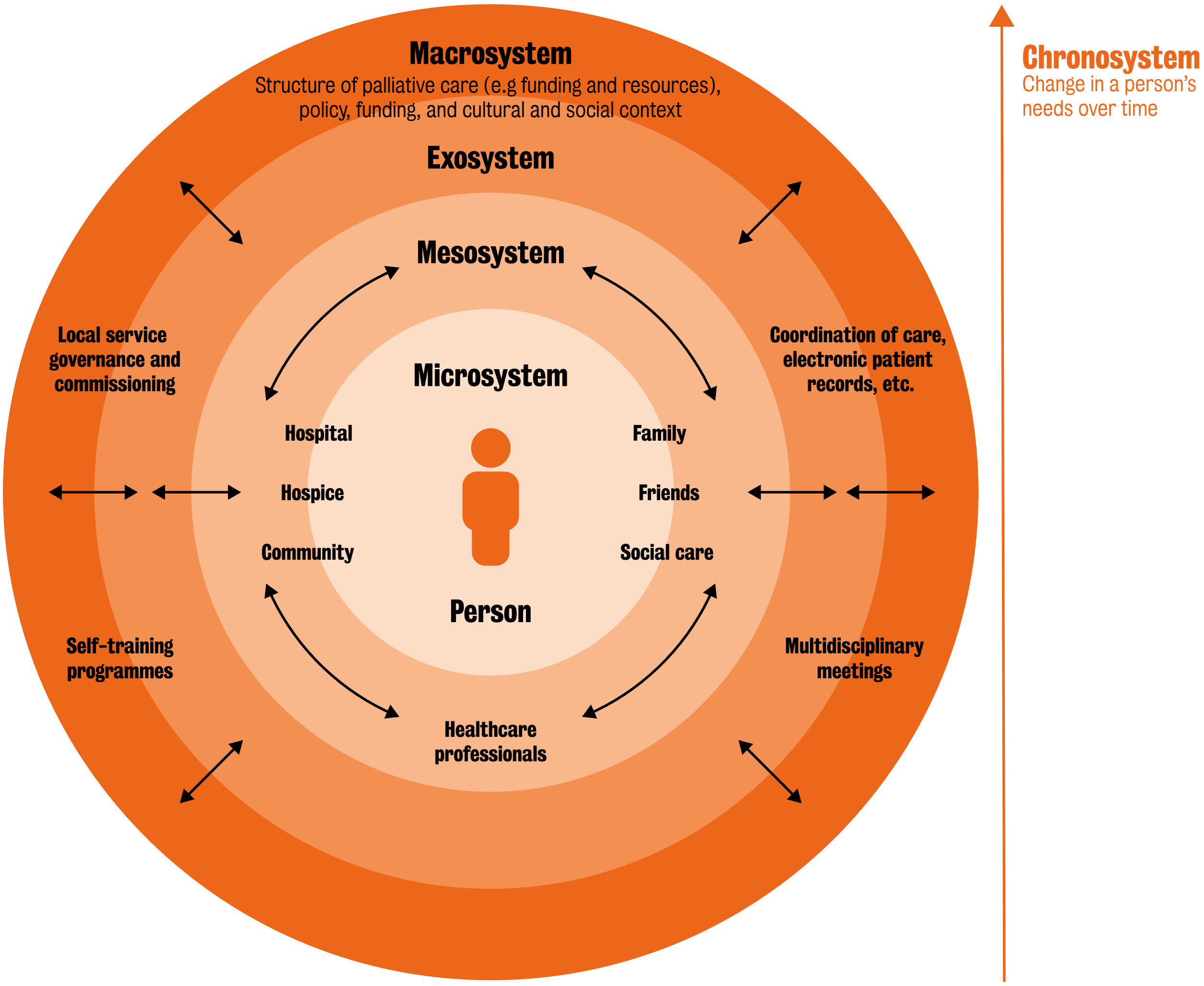
Palliative Care Outcome Scale Website, 2020. The POS is freely available for download from this site.

Above: Panel on Clinical Day of the POS Workshop, February 2018.
Below: POS Workshop, February 2020.

To explore palliative care stakeholders' views on what makes a case complex and insights on capturing complexity at patient-level. Complexity included how patients interact with family/ professionals and how services respond to needs and societal perspectives on care. Our conceptual framework of complexity (Figure 17) advances systematic understanding of complexity within the context of palliative care, and helps capture patient-level complexity and target resource provision in specialist palliative care.

We have also developed and validated condition specific versions of POS. This enables palliative care to be offered to more people who need it but previously missed out; POS enables doctors and nurses, and patients themselves, to assess and explain their concerns. These include versions of POS for people with long term neurological illnesses (Wilson, Hepgul et al, 2019) and multiple myeloma (Ramsenthaler, 2019). POS and its family of measures are available in most

Figure 17. A framework of complexity in the palliative care context



Source: Pask et al, 2018.

world languages, more recently in Turkish (Hocaoglu et al, 2020), Czech (Vlckova et al, 2020), Japanese (Sakurai et al, 2019) and French (Sterie et al, 2019) versions.

POS has also been central in evaluation of the management of symptoms and outcomes in the COVID-19 pandemic, including with our MRC, NIHR Applied Research Collaborative South London and Cicely Saunders International funded research on rapid evaluation of the COVID-19 pandemic response in palliative and end of life care 'CovPall' (www.kcl.ac.uk/cicelysaunders/research/evaluating/covpall-study). This has enabled better addressing of symptoms, complexities and most importantly palliative care needs and concerns.

Supporting clinicians, educators and those developing palliative care services has also been one of the key aspirations, and we organise Royal College of Physician accredited annual workshops, which are attended by more than 200 delegates to support use of patient-centred outcome measures in routine practice, research, quality improvement, economic evaluation and education.

IPOS for Dementia

The Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem) has been developed in our research at the Cicely Saunders Institute. It aims to support assessment and management of the palliative care needs in older people living in care homes. Our research made sure it was acceptable and feasible for care home staff, incorporating common symptoms and concerns affecting people with dementia and multi-morbidities, such as swallowing problems or depression (Ellis-Smith et al, 2016; Ellis-Smith et al, 2018).

Since its publication in 2016, IPOS-Dem has had international impact. Teams in Germany, Italy, Japan, the Netherlands, Sweden, Switzerland and Taiwan have commenced translation and cross-cultural validation. Multiple sites in England have participated in an audit of the implementation of IPOS-Dem into routine clinical practice (Kinley et al, 2019).

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 palliative dementia intervention across settings and tests it in a feasibility and pilot trial (Sampson et al, 2019).

Children's POS

We committed to leading cutting-edge research in the development, and psychometric evaluation of person-centred outcome measures. We are expanding this initiative to children and young people. To inform the psychometric evaluation of the novel children's palliative care outcome scale (C-POS-African version), we conducted a systematic review (Namisango et al, 2018) and then a large multi-country study in sub-Saharan Africa (Uganda, Kenya, Namibia and South Africa) (Namisango et al, 2020), to identify symptoms and concerns that matter to children and young people with life limiting and life threatening Illnesses. The studies found that burdensome symptoms and concerns affect young people with malignant and non-malignant conditions, and occur across the disease trajectory. We identified physical, social, psychological, psychosocial, existential/spiritual, and quality of care domains as important parts of a child–family-centered framework to inform service development (Figure 18).

Young People's Patient and Public Involvement group

With a grant from the NIHR Enabling Involvement Fund, we set up a Young People's Advisory Group, led by three researchers with experience working with children. The group ran as a "Health and Social Research Methods" after-school club at a local boys secondary school and was attended by students ranging from 11–13 years old. The group offered a unique combination of both education and consultation. Our 11-week programme was flexible and adapted as the group progressed. Researchers delivered five weeks of teaching, with sessions where students devised their own research project, and gave feedback to visiting researchers and clinicians on research studies. Young people reviewed and critiqued pre-existing material and provided valuable insight for dissemination ideas. Children were interested in learning about research methods, being exposed to new topics and enjoyed providing feedback, while visiting researchers received valuable input from the group. Sharing our research with this audience ensures the unique voices of children and young people are considered and valued in future palliative care research. We plan to deliver the programme at other secondary schools and share with younger children.

Work of a member of the Young People's Patient and Public Involvement group, 2020.

We support the adaptation and testing of POS measures in different settings, provided partners follow the standard POS guidelines. The C-POS has been adapted for the Belgian setting, based on findings from qualitative interviews conducted with children aged 8–18 and their caregivers. The following quality of life dimensions were added to the measure; social, emotional, and administrative health-care related issues, leading to a 22-item C-POS. The C-POS-Belgium has acceptable face and content properties and is feasible for use in clinical settings. (Friedel et al, 2020). Work has begun to develop a UK version of the C-POS, funded by the European Research Council.

Figure 18. A framework of domains on symptoms, concerns and health outcomes in young people with life-limiting and life-threatening conditions

	MAIN DOMAINS				
	Physical	**Psychological**	**Social**	**Existential/Spiritual**	**Quality of care and practical concerns**
Role of health professionals	• Impeccable identification, assessment and management of symptoms and any associated distress	• Identify and address child and family fears and concerns • Provide interventions that enhance positive coping, resilience and self efficacy	• Provide support for relationship building and management • Provide avenues for children to engage in age-appropriate social activities across the socio-ecological layer • Provide teenage- and adolescent-friendly social services	• Assess spiritual wellbeing (consider issues relating to meaning, relationships with supernatural power, beliefs and practices, outlook on self and death, and search for indicators of spiritual wellbeing) • Refer child and family to their preferred spiritual care provider	• Establish appropriate means of providing information and communication • Coordinate across multiple care teams • Avail useful information in appropriate formats • Provide care in a preferred child/family environment • Link child and family to available social support services
THEMES					
Key themes	• Physical symptoms • Symptom distress • Physical Function • Treatment-related concerns • Procedure-related pain • Physical needs • Normalcy	• Emotional, positive and negative • Behavioral • Cognitive	• Relationships • Perspective of others • Social function • Life values • Sexuality	• Worry about death • Existential concerns • Meaning of illness • Connectedness • Spiritual growth • Resilience and coping	• Communication and information • Decision-making • Care provision • Financial concerns • Care environment that is strange compared to home
Illustrative examples	**Physical symptoms** • Pain • Nausea • Vomiting • Fatigue **Symptom distress** • Suffering • Feeling wiped out • Crying due to pain **Physical function** • Self-care • Mobility • Doing usual things • Normalcy **Treatment-related concerns** • Procedural- and treatment-associated • Pain • Effects of opioids • Fertility concerns after cancer treatment • Treatment-related anxiety and worry	**Emotional** • Fear • Worry • Sadness • Anxiety • Happiness **Cognitive** • Declining in performance at school** • Feeling stupid • Orientation skills • Reduced concentration • Lack of self-worth **Behaviour** • Aggression • Adherence/ non-adherence **Self-image** • Impact of loss of hair, changes in skin, or facial lipodystrophy on self-image **Illness experience** • Hard • Illness is tough	**Relationships** • Family • Friends • Community • Others • Teasing • Bullying • Stigma **Perspective of others** • Concerns about family • Being a burden to family **Activities of daily living** • School** • Feel joy • Feel happy • Have fun • Play • Being with friends **Life values** • Equal opportunities like normal children* • Achieve life goals* • Live as normal **Sexuality** • Initiate and maintain sexual relationships* **Perspective of others** • Wish to protect others from bad experiences • Being a burden to others	**Worry about death** • Worried about death • Will I be remembered after death? • Am I dying? **Existential concerns** • Loss of future* • Threat to values* • Life devoid of meaning* • Suffering as educator* **Meaning of illness** • Illness is tough • Horrible experience • Personal experience of discovering diagnosis **Connectedness** • Connection with God or something larger than self **Spiritual growth** • Appreciate life as a gift **Resilience and coping** • Keeping the Spirit alive • Must survive the hard bits of illness	**Communication and information** • Lack of access to information on disease and treatment* • Breaking bad news* **Decision-making** • Advance care planning* • Shared decision-making* **Care provision** • Availability of doctors* • Point of contact care* • Provision* • Help with care transition* • Transitioning into adult care* **Financial concerns** • Foregoing leisure* • Can't afford medication* **Care environment that is strange compared to home** • Hospitalization is seen as imprisonment • Missing home • Longing for play during hospitalization to cope with strange environment

* More dominant in 10–14, 15–17 year age group
**More dominant in children of school-going age

Source: Namisango et al, 2018.

Economic value of services

Our research has also tested ways to study the economic value of palliative care services. For palliative care to fully be considered in some economic analyses, it needs outcome measures that can measure quality adjusted life years (QALYs). The types of outcome measures that do this, are called preference-based outcome measures. However, the commonly used preference-based outcome measures do not measure the changes important to patients and those close to them in palliative care (Dzingina et al, 2017a).

We developed, refined and validated the Palliative care Outcome Scale-Economics (POS-E), a new palliative-care health state classification system (Dzingina et al, 2017b). Preference weights for POS-E to be used in health economic analysis were estimated. This palliative care specific preference-based measure can be used to calculate QALYs for cost-utility analysis of palliative care interventions. In addition, mapping IPOS onto EQ-5D and valuations to generate preference weights are currently planned and will be implemented soon.

Rehabilitation, treatment planning and evaluation for spasticity

We developed national guidelines on management of spasticity incorporating our research in the process of goal setting and person-centred outcome measurement. (Ashford, Siegert, Williams et al, 2019; Euawongyarti et al, 2018; Ashford et al, 2019a; Ashford, Siegert, Handcock et al, 2019a; Ashford, Siegert, Handock et al, 2019b) and the approach has also been taken up in an international consensus for recommended practice (Turner-Stokes et al, 2018). Resulting in an international programme, which uses our tools to collect data in over 1,000 patients across 84 centres in 14 countries (Turner-Stokes, Ashford, Siegert, Williams et al, 2019; Turner-Stokes, Fheodoroff et al, 2019). With national and international colleagues, we have worked to produce a practical evidence-based approach to improving person-centred outcomes for the management of spasticity within rehabilitation in three areas.

Royal College of Physicians

2nd edition

Spasticity in adults: management using botulinum toxin

National guidelines 2018

Published with:

The Association of Chartered Physiotherapists in Neurology

British Society of Rehabilitation Medicine

Promoting quality through education and standards

Chartered Society of Physiotherapy

Royal College of Occupational Therapists

Specialist Section Neurological Practice

Spasticity in adults: management using botulinum toxin. National guidelines 2018.

UK-Rehabilitation Outcomes Collaborative

We have developed and validated a robust set of tools that are practical for use in routine clinical care to match rehabilitation inputs to individual patient needs, to measure outcomes and demonstrate value for money. Our research has shown that specialist in-patient rehabilitation for profoundly disabled patients is highly cost-efficient, leading on average to net life-time savings in care costs exceeding £670,000 for each patient treated (Turner-Stokes, Dzingina et al, 2019). Our tools are now incorporated into the NHS England national mandated clinical database, which provides on-going quarterly benchmarking on quality and outcomes for all specialist rehabilitation services in England. This work has underpinned

NHSE's approach to planning and provision of specialist rehabilitation leading to a demonstrable increase in service capacity to improve access to rehabilitation for this most vulnerable group of patients.

King's Brief Interstitial Lung Disease Questionnaire

We continued our work on the King's Brief Interstitial Lung Disease (KBILD), a 15-item validated health-related quality of life questionnaire for people with fibrotic lung conditions. Two consistent estimates of the minimal clinically important difference were generated.

In the first study patients with interstitial lung disease (n=57) completed the KBILD questionnaire at two outpatient clinics and, at the second, a global rating of change of health status questionnaire. The minimal clinically important difference was calculated as the mean of: change in KBILD for patients indicating a small global change, patients with a 7%–12% change in forced vital capacity, one standard error of baseline KBILD and effect size of 0.3. There was a significant change in KBILD total score in those patients reporting a global change in health status and the mean KBILD total score minimal clinically important difference was 5 (Sinha et al, 2019).

In a second study using pulmonary rehabilitation as a model (n=209), we combined distribution-based approaches with anchor-based approaches that mapped KBILD scores against change in breathlessness, exercise capacity, and generic health status measures. KBILD improved following rehabilitation with effect sizes by domain and total scores from 0.28 to 0.38. Using anchor-based estimates, the minimal clinically important difference estimates for KBILD-Psychological, KBILD-Breathlessness and activities, and KBILD-Total were 5.4, 4.4 and 3.9 points, respectively (Nolan et al, 2019). These data will help design and interpret clinical trials using KBLID as an end-point.

> 'You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die'.
>
> **Cicely Saunders 'Care of the dying–1 The problem of euthanasia' Nursing Times July 1, 1976 p1003–1005.**

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 rehabilitation, we study the needs and preferences of vulnerable, disadvantaged or overlooked groups and areas: older people, caregivers, preferences and choices, inequalities, identity and culture. Our findings lead the evidence response to questions around how to meet the needs of the growing ageing population, the diverse cultures in our society, and different preferences and priorities, including location of dying, population ageing and future projections.

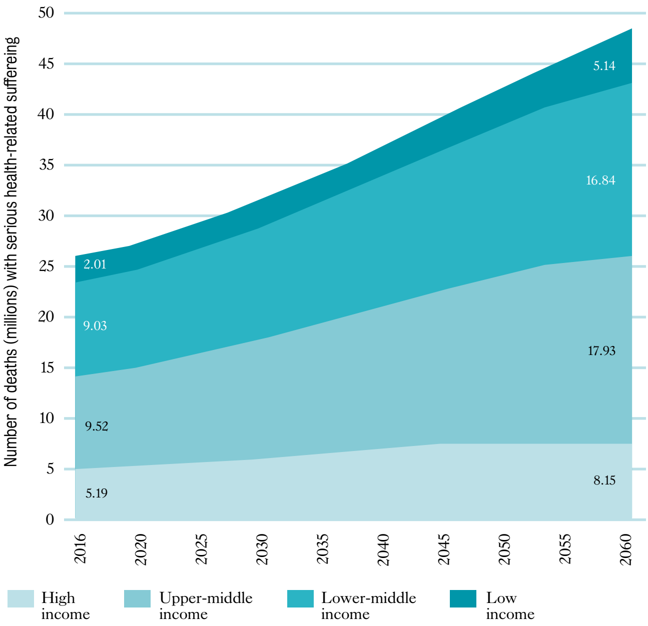
Population ageing and future projections

Serious life-threatening and life-limiting illnesses place an enormous burden on society and health systems. In 2017 The Lancet Commission on Palliative Care and Pain Relief found that 25 million people worldwide who died in 2015 experienced serious health-related suffering, 80% of whom were in low and middle income countries. To inform policies that alleviate suffering it is necessary to understand not just current levels of need, but how this will change in the future. We produced worldwide projections of the future need for palliative care by combining WHO mortality projections with estimates of physical and psychological suffering in 20 different conditions (Sleeman, de Brito et al, 2019). We found that the number of people dying with palliative care needs is set to almost double over the next four decades. By 2060, an estimated 48 million people each year (47% of all deaths globally) will die with serious health-related suffering, an 87% increase compared to 2016. Serious health-related suffering will increase in all world regions, with the largest proportional rise in low-income countries (155% increase between 2016 and 2060) (Figure 19).

The increase in serious health-related suffering will be driven by rises in cancer deaths (16 million people dying each year with serious health-related suffering by 2060, 109% increase 2016–2060). The condition with the highest proportional increase will be dementia (6 million people dying each year with serious health-related suffering by 2060, 264% increase 2016–2060). Globally, serious health-related suffering will increase most rapidly among older people (183% increase in those aged 70+ 2016–2060) (Figure 20).

Palliative care and the relief of suffering have been described as some of the most neglected dimensions of global health today. It has been estimated that just 14% of people who could benefit from palliative care worldwide actually receive it. These findings call for global policies to strengthen health care systems through availability of essential drugs, staff training and public education, with a focus on the populations that will experience the fastest rise of suffering and need.

Figure 19. Projected evolution of burden of serious health-related suffering in World Bank income regions until 2060

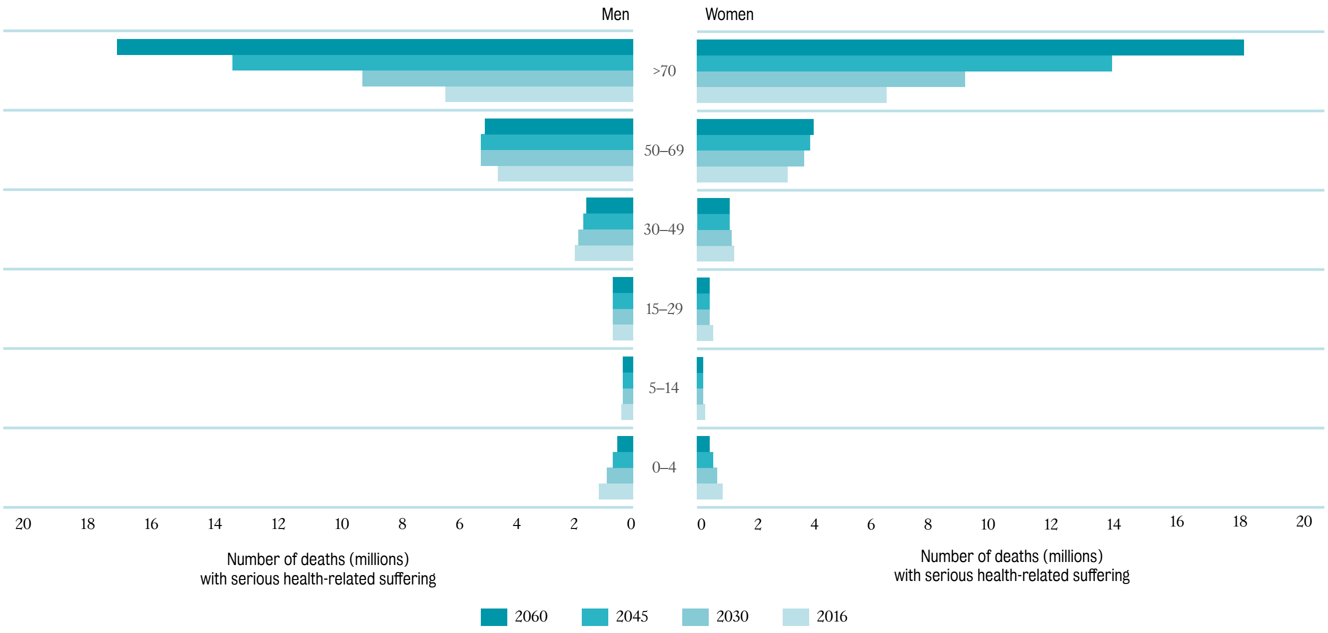


Source: Sleeman, de Brito et al, 2019.

Population ageing brings complex challenges for living and dying well in all countries. In England and Wales, we are expecting 25% more deaths by 2040, over half of whom are expected to be aged 85 years and above.(Bone, Gomes et al, 2018). We examined where people might die in the future, based on recent national trends. We found that if trends continue, care home and home deaths will rise while hospital deaths decline, and care homes would become the most common place to die in England and Wales by 2040 (Bone, Gomes et al, 2018). The headline findings were subject to extensive media coverage including in *The Express*, *The Guardian*, *The Mirror*, and *The Times*. We found similar trends in Scotland, where two-thirds of all deaths would be expected to occur in settings outside of hospital by 2040 (Finucane et al, 2019) (Figure 21). A consultation with stakeholders concluded that this scenario is very unlikely without additional investment in community-based care including care home capacity. Stakeholders advocated increasing and upskilling the community workforce; improving support for informal carers and encouraging community engagement in end-of-life care initiatives.

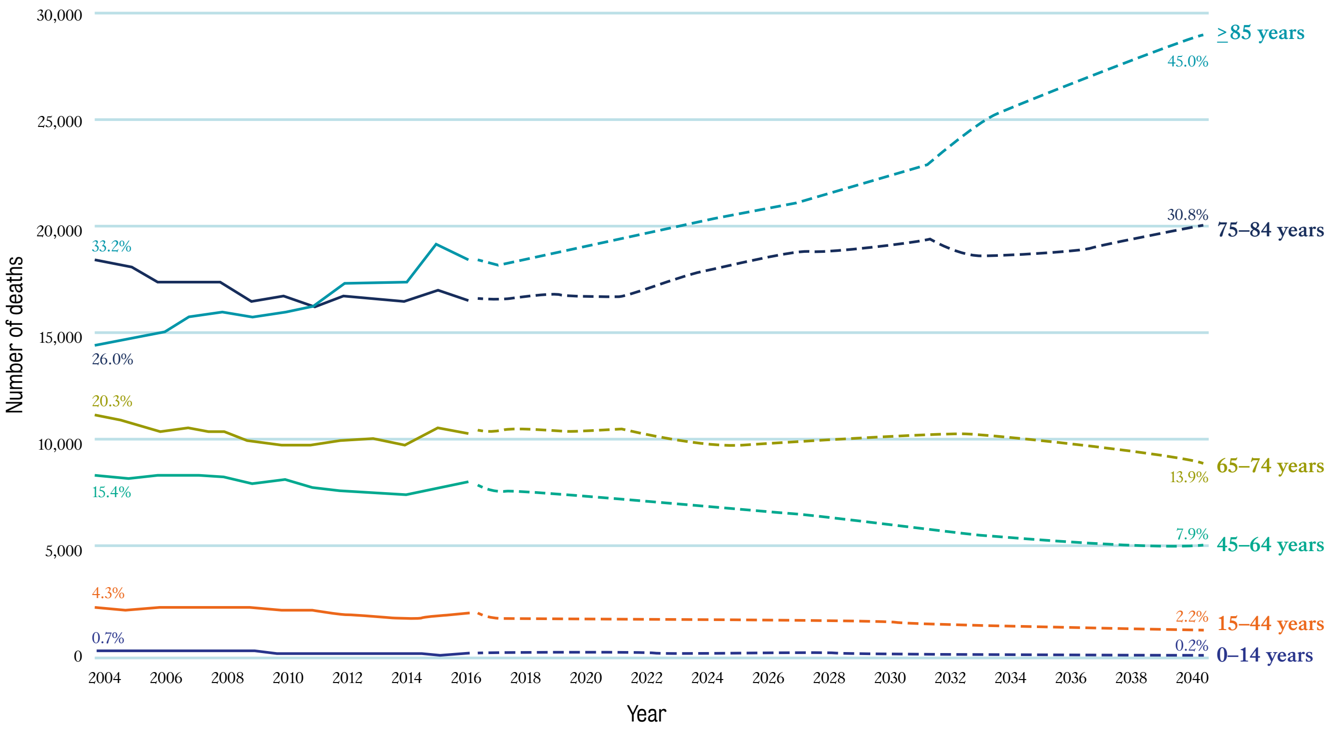
Population ageing has significant implications for palliative care services. Using death registration data we estimated how many people might need palliative care in the future (Etkind, Bone et al, 2017). We estimated that there will be between 92,000 and 172,000 more people with palliative care needs in England and Wales by 2040. This is in part due to a steep rise in deaths to people aged 85 and over, and projected increases in cancer and dementia deaths. The palliative care needs are also likely to be increasingly complex due to the rise in multiple

Figure 20. Changes in the number of people dying with serious health-related suffering for global population stratified by age group and sex



Source: Sleeman, de Brito et al, 2019.

Figure 21. Number of past deaths (2004–2016) and projected future deaths in Scotland by age group (2017–2040)



Source: Finucane et al, 2019.

coexisting conditions. Healthcare systems must now start to adapt to the age-related growth in deaths from chronic illness, by focusing on integration and boosting of palliative care across health and social care disciplines.

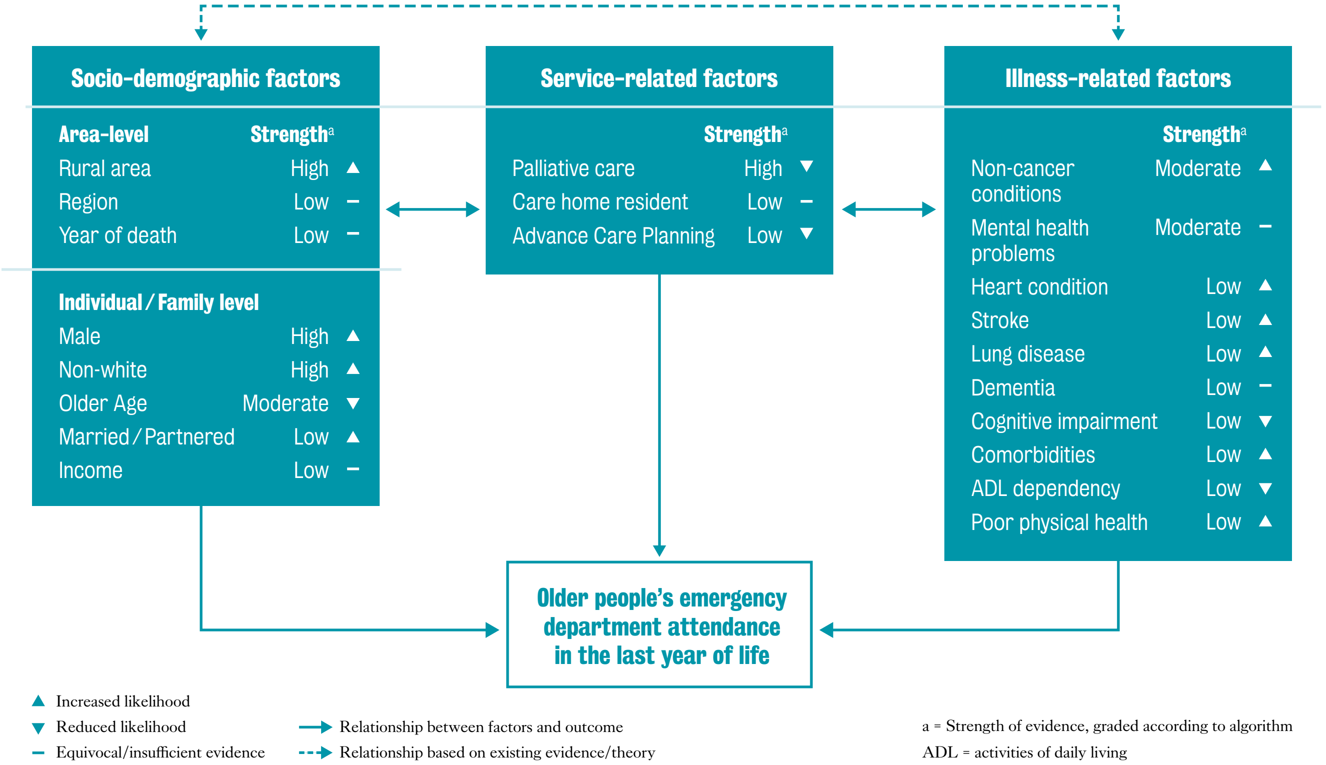
Older people's health care utilisation and care preferences

Emergency department attendance for older people towards the end of life is common and increasing, despite most preferring home-based care. Our systematic review found high strength evidence that emergency department attendance in the last year of life was lower among those who received palliative care services (Bone, Evans et al, 2019). We also found that attendance was higher among non-white ethnicity, male gender and people living in rural areas (Figure 22).

Building on this work, results of a bereavement survey found that frequent emergency

Mrs Kay Ridgeway, 91 years, during a hospital stay.

Figure 22. Model of factors related to emergency department attendance by people aged 65+ years in the last year of life



Socio-demographic factors

Area-level	Strength[a]	
Rural area	High	▲
Region	Low	–
Year of death	Low	–

Individual / Family level		
Male	High	▲
Non-white	High	▲
Older Age	Moderate	▼
Married / Partnered	Low	▲
Income	Low	–

Service-related factors

	Strength[a]	
Palliative care	High	▼
Care home resident	Low	–
Advance Care Planning	Low	▼

Illness-related factors

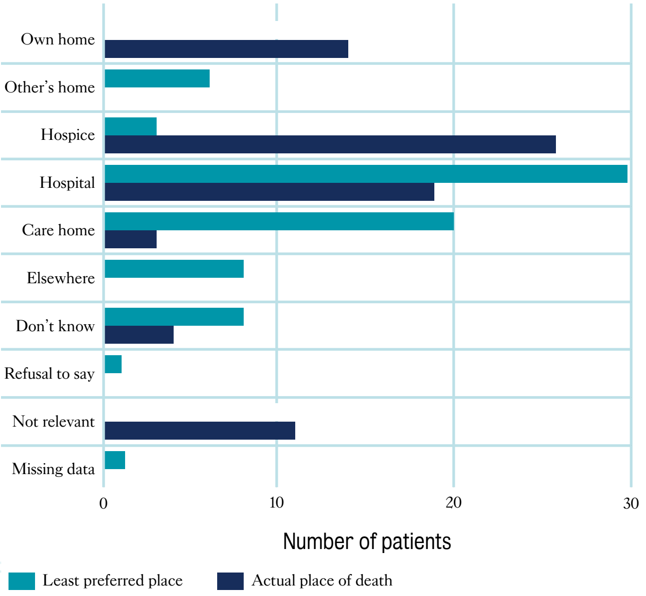
	Strength[a]	
Non-cancer conditions	Moderate	▲
Mental health problems	Moderate	–
Heart condition	Low	▲
Stroke	Low	▲
Lung disease	Low	▲
Dementia	Low	–
Cognitive impairment	Low	▼
Comorbidities	Low	▲
ADL dependency	Low	▼
Poor physical health	Low	▲

a = Strength of evidence, graded according to algorithm
ADL = activities of daily living

Source: Bone, Evans, Etkind et al, 2019.

department attendance (3+) in the last 3 months of life among older people was associated with respiratory disease, multimorbidity and higher number of community nursing contacts (Bone, Evans, Etkind et al, 2019). Conversely, those who had a key health professional who coordinated care were significantly less likely to have frequent end of life attendances to the emergency department. Assigning a key health professional to older people at increased risk of frequent end of life emergency department attendance, e.g. those with respiratory disease and/or multiple comorbidities, may reduce emergency department attendances by improving care coordination.

Figure 23. Least preferred and actual place of death for those people who declared they most preferred to die at home (N = 77)

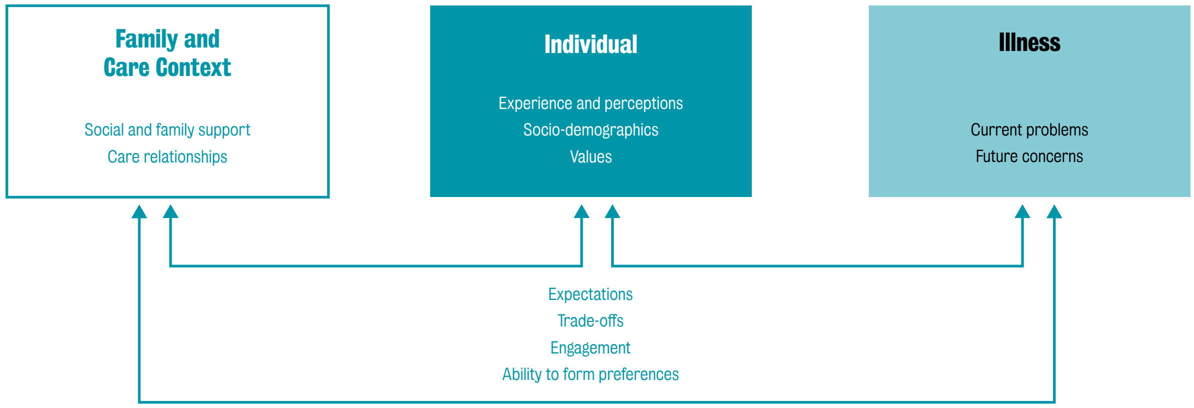


Source: Higginson et al, 2017.

Aligning care provision to individual preferences is an important goal for patient-centred care, and achieving choice is proposed as a quality marker. In our multinational BuildCARE study we examined the preferences of older adults with advanced disease. Home was consistently the most preferred place and hospital the least preferred place, with no differences between countries adjusting for age, gender and cancer diagnosis (Higginson et al, 2017). Unfortunately many people died in their least preferred place (Figure 23). Although home is the most common first preference, it is polarising and for 16% it is the least preferred. In the USA, patients had the highest preference for hospital palliative care units – an option not commonly available to those in the UK or Ireland, where the closest option is usually an inpatient hospice. Having a cancer diagnosis and living with someone else were independently associated with preferring to die at home. A preference for involving partners or spouses in healthcare decisions was also associated with preferring home. In contrast, diagnosis and living status were not associated with place of death, and instead functional status and preferring treatments aimed to improve quality of life were associated with dying at home.

Preferences can change as people's health deteriorates. Our systematic review of influences on older people's care preferences found that support from and burden on family and loved ones were prominent influences

Figure 24. Model of influences on care preferences (extension of Gomes model)



Source: Etkind et al, 2018.

on care preferences (Etkind et al, 2018) (Figure 24). Mechanisms by which preferences are influenced include the process of trading-off between competing priorities, making choices based on expected outcome, level of engagement, and individual ability to form and express preferences. To support preferences, clinicians should consider older people with illnesses and their families together as a unit of care.

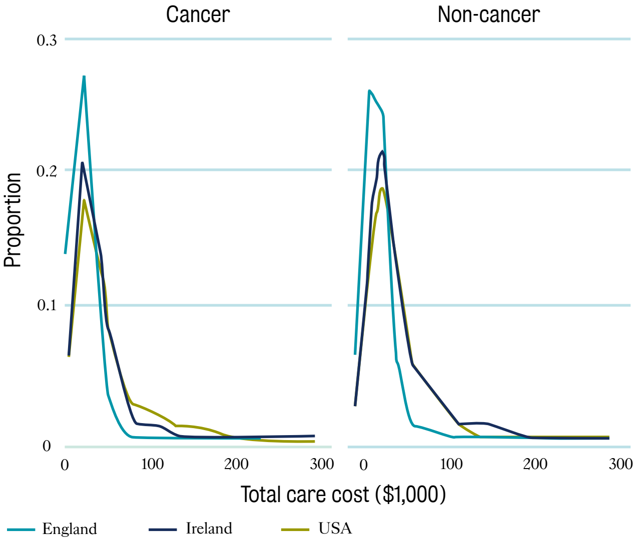
Our qualitative study of frail older people found that participants focused on the outcomes of their care, for example whether care was likely to help them 'get back to normal', or alternatively 'find a new normal' influenced preferences. Following acute illness, clinicians should discuss preferences and care planning in terms of an achievable normal, and carefully consider the social context.

Costs of caring for older adults at the end of life

Care costs are known to rise towards the end of life, but the type and volume of services have not been well studied, nor has the relationship between care costs and the quality of services. As part of the International Access, Rights and Empowerment (IARE) study, we compared health and social care costs, quality and their drivers in the last 3 months of life for older adults across countries. A mortality follow-back survey was conducted in Palliative care services in England (London), Ireland (Dublin) and the United States (New York, San Francisco) (Yi et al, 2020).

In England, total care costs were $15,347 and $16,631 for cancer and non-cancer patients respectively (Table 1). On average more than 80% of the total health and social costs were attributable to hospital care and the costs of palliative care were only around 10%, despite the fact that all patients had accessed specialist palliative care and reported high satisfaction with these services.

Figure 25. Distribution of hospital care costs in the last 3 months of life for older patients who had access to specialist palliative care in England, Ireland and the United States



Source: Yi et al, 2020.

Table 1. Hospital and total Health and Social Care Costs in the three countries

		Hospital care Cost (Unit: $)	Total care cost (Unit: $)	Percentage of total care cost spent on hospital care (%)
England	Cancer	13,206	15,347	86
	Non-Cancer	13,844	16,631	83
Ireland	Cancer	22,851	29,065	79
	Non-Cancer	25,898	29,411	88
USA	Cancer	30,684	37,250	82
	Non-Cancer	31,691	37,376	85

Notes: Hospital care was defined as the services provided in hospitals (intensive care units, inpatients and outpatients), emergency room visits, ambulance services and day case treatments. Costs were calculated by combining the service use in the Client Service Receipt Inventory with country specific unit costs. All costs were translated into the United States dollar using purchasing power parity index.
Source: Yi et al, 2020.

Table 2. Informal care (IC) costs and formal care costs of patients at the end of life in the last three months (US$)

	Informal care costs I			**Informal care costs II***			**Formal care cost ($)**		**Percentage of total care costs that are informal care costs**	
	Mean	**s.d.**	**Median**	**Mean**	**s.d.**	**Median**	**Mean**	**s.d.**	**Informal care costs I**	**Informal care costs II**
England	36,170	31,104	31,192	22,132	22,527	13,254	15,756	15,036	69.7%	58.4%
Ireland	43,760	36,930	36,398	26,767	25,477	18,604	29,210	24,231	60.0%	47.8%
USA	32,468	28,578	28,847	19,973	19,679	12,521	37,327	37,234	46.5%	34.9%
All countries	37,802	32,956	32,185	23,160	22,998	14,163	27,452	28,203	57.9%	45.8%

* Informal care cost II excludes the cost of “Time spent ‘being on call’.”
$ Formal care costs were calculated by combining resource use data with unit costs.
Source: Higginson, Yi et al, 2020.

In England costs were more homogeneous, many patients had lower per user cost than in the United States and Ireland (Figure 25). In the United States and Ireland, more patients, especially with non-cancer, had higher cost. Mean per patient costs were lowest in England; the United States had more than double English care costs.

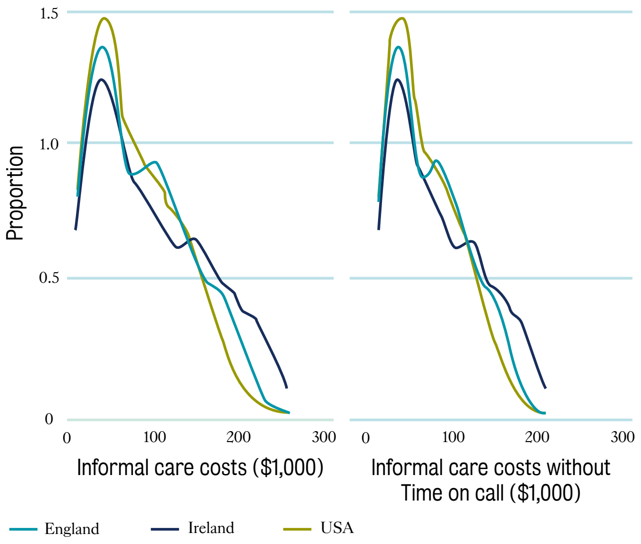
Across the three countries, the mean total costs were US$76,919 per patient in the highest 10% and US$19,865 in the rest: a small number – 25, 28 and 25 patients – used 29%, 30% and 34% of the total costs in England, Ireland and the United States, respectively. These highest cost patients (10%) spent 3.9-fold the total costs and 4.3-fold the hospital costs of the remaining 90%. Poverty, increased age and poor home care were drivers of high costs and should be a target for future interventions to improve care quality and value at the end of life. Improving palliative care access and intensity is an essential priority for health care policy, especially for non-cancer patients who had least access.

In palliative care, those important to the patient, such as family members and informal carers are part of the unit of care. They often provide high levels of demanding care and support willingly because they see this as part of their relationship with the patient and are ambivalent to considering their own needs. As part of the International, Access, Rights, and Empowerment (IARE I) study of palliative care in three countries, we aimed to determine and compare the informal care costs and their associations with self-reported caregiver burden, rewards and subsequent caregiver grief, taking account of care quality, as reported by informal carers (Higginson et al, 2020).

More than half of the patients were helped with personal care and medical procedures during the last three months of the patient’s life. On average, patients received 19–21 hours of informal care per week from friends or family for personal care, 15–18 hours for medical procedures, 7–10 hours for appointments, 17–21 hours for household tasks. Friends and/or family spent 66–76 hours per week on ‘being on call’ and 52–55 hours with patients. The contribution of informal carers is considerable, accounting for around 50% of total care costs (Table 2). These costs are similar across countries. Median informal care costs in the last 3 months of life were $28,847 (USA), $31,192 (England) and $36,930 (Ireland), with right skewed distributions that were similar for all countries. Removing the ‘being on call’ element reduced the costs, although the distributions remained unchanged (Figure 26) (Yi, Johnston, Ryan, McQuillan et al, 2020).

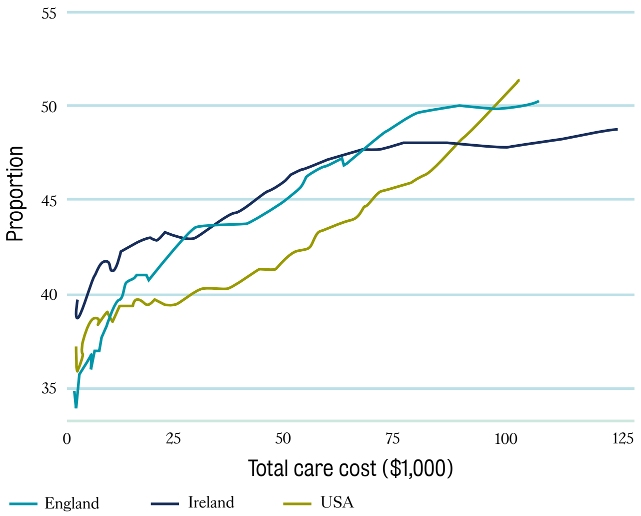
The inverse relationship between informal care costs and subsequent grief surprised us (Figure 27). It appears that providing more

Figure 26. Distribution of costs of informal care provided for older patients in their last 3 months of life, with and without 'time being on call' in three countries



Source: Higginson, Yi et al, 2020.

Figure 27. Relationship between subsequent grief and informal care costs in the last 3 months of older patient's life in three countries



Source: Higginson, Yi et al, 2020.

hours of informal care to patients protected the carers during bereavement, although the effect was small and varied. More hours of informal care was associated with a more positive feelings about caregiving. It may be that providing support protected informal carers from guilt in later bereavement. It may also be that more hours of informal care support were provided by larger families and groups, and so the informal carers were not required to do so much individually, and possibly also gained from mutual support from other family members and friends.

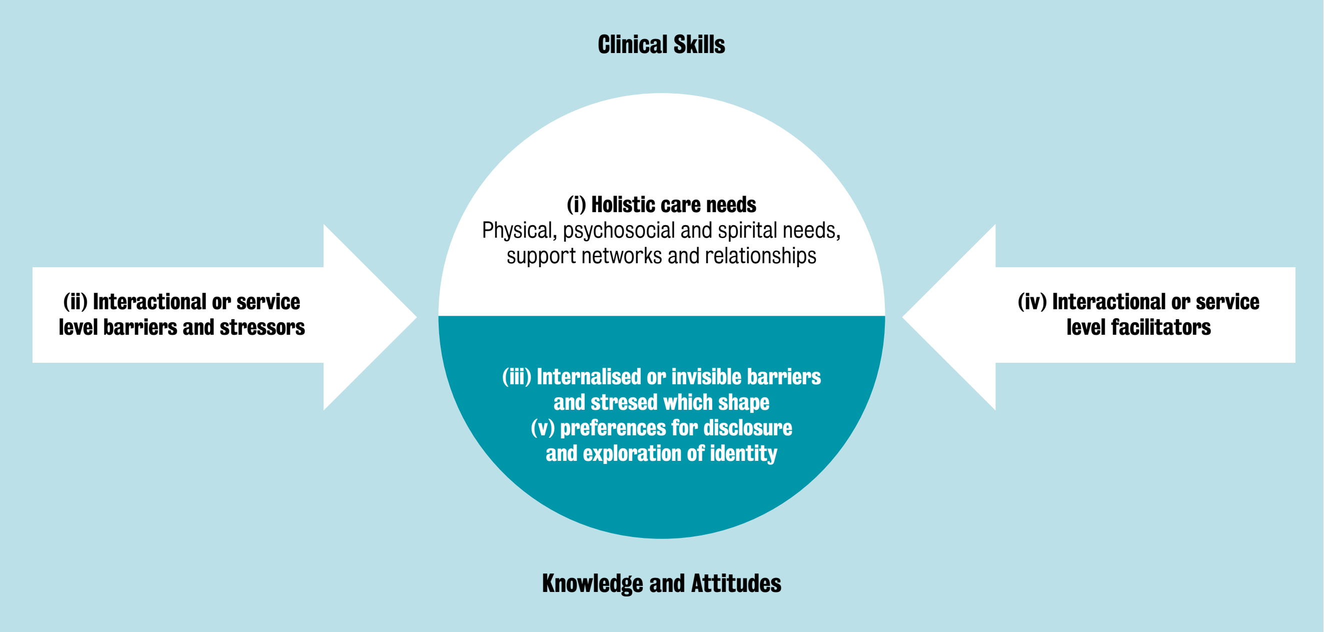
Training and support interventions for informal carers should target the wide range of activities that they undertake. Increased informal care hours and costs can lead to more rewards and lesser subsequent grief. Improving community palliative care may improve care value, the care experience for patients and informal carers, increase informal care rewards and reduce informal care burden and formal care costs, and should be a focus for investment, including and importantly during the COVID-19 pandemic.

Geographical variation in place of death

In our previous research we found geographical variation in place of death in England, which was only partly explained by individuals' characteristics. This suggests that health services may also play a part in the geographical variation in place of death. We conducted a large national population-based evaluation of health-care service factors and place of death in our GuideCARE Services study (Gao et al, 2019). We examined >430,000 adult deaths in England and found that nearly 50% of the deaths occurred in hospitals, about 20% each occurred in care homes and at home, and <10% occurred in hospices. Approximately 30% and 70% of the deaths were due to cancer and non-cancer, respectively. Almost all the service factors studied contributed to the geographical variation in the PoD. The type and capacity of services explained between 14% and 74% of this variation, while service location explained 11–34% of the variation.

We found an inverse association between drive time to hospice and hospice death, with a dose-response relationship. The effects were larger in rural areas compared to urban areas. (Chukwusa et al, 2019). The independent association of health services with place of death was weak but consistent. The further someone lived from a care facility, the less likely it was that they would die there. Higher hospice capacity

Figure 28. LGBT experiences when facing advanced illness: considerations for the clinical encounter



Source: Bristowe et al, 2018.

was also associated with a higher chance of dying in a hospice in non-cancer diseases. As part of the work, we examined regional differences in the association between geographic access to inpatient hospice and hospice deaths, using records of patients aged ≥ 25 years (n=123,088) who died from non-accidental causes in 2014 (Chukwusa et al, 2020). The percentage of deaths varied across region and we found wide differences in geographic access to inpatient hospices across regions. Median drive times to hospice varied from 4.6 minutes in London to 25.9 minutes in the North East. We found a dose-response association in several regions indicating that decedents who lived further away from hospices locations (≥ 10 minutes) were less likely to die in a hospice. This work underscores the importance of regional specific initiatives to improve and optimise access to hospices.

The GuideCARE Services study demonstrates that health services relate to where people die. The effects of health services were also found to be interacting with sociodemographic characteristics, which suggests that high-quality end-of-life care provision needs to be designed with each person's circumstances in mind. The findings highlight the need for the formulation of end of life care policies/strategies that consider differences in settlement types. Finally, the study also unveiled a large data gap, partly due to a lack of attention and investment in this area. We recommend more comprehensive, national collection of service data relevant to palliative and end-of-life care (Gao et al, 2019).

Sexual orientation and gender identity

LGBT people experience higher rates of a range of serious illnesses including mental ill health, increased isolation, reduced likelihood of attending routine screening, delayed presentation for treatment, and experiences and anticipation of discrimination from healthcare providers. Owing to these inequalities, LGBT people are a continuing focus at policy level, as reflected by the National LGBT Survey and the LGBT Action Plan from the UK Government Equalities Office. In the later stages of life-limiting illnesses and during bereavement, LGBT people face barriers to accessing care at multiple levels. As such, the palliative care needs of LGBT people warranted our focus.

In ACCESSCare A we explored health-care experiences of LGBT people facing advanced illness using in-depth interview to elicit their views regarding health-care experiences including sharing identity (sexual

ACCESSCare Team with EAPC Task Force members at the EAPC Congress in Berlin, 2019.

orientation/gender history), accessing services, discrimination/exclusion and best-practice examples (Bristowe, Hodson et al, 2018). Forty LGBT people from across the United Kingdom took part and described barriers to accessing care, in the context of advanced illness, at multiple levels: internalised; interactional (in clinical encounters) and service level. LGBT people also faced further stressors at societal levels, increased isolation and family estrangements and additional legal concerns (Figure 28). We also identified facilitators to good care at a service and interactional level, including overtly acknowledging and including partners in critical decisions. From the data we made recommendations for health-care professionals and services/institutions providing simple, low cost gains in access to, and outcomes of, care for LGBT people.

We have worked to progress the experiences of LGBT+* people by sharing our findings widely. The team organised and hosted the first ACCESSCare conference to advance knowledge and improve care for LGBT+ people facing serious or advanced illness and bereavement. With over 85 healthcare professionals, researchers, policy makers and community representatives in attendance, Dr Michael Brady, the National Advisor for LGBT Health began the day. Amongst research presentations across all ACCESSCare projects, our valued PPI members also shared their experiences of working on these studies. The ACCESSCare A study informed a Marie Curie information booklet to support LGBTQ+ people living with terminal illness in planning ahead for care. Our research informed a submission to the Women and Equalities Committee for their inquiry into the health and social care of LGBT communities, which was published and referenced in the House of Commons report. The team have also launched an international Task Force through the European Association for Palliative Care (EAPC) to improve palliative and end of life care for LGBT+ people. This professional network, including 30 members across 13 countries, is working together to identify and share best local practice to inform collaborative evidence-based guidance for better care for LGBT+ people.

In ongoing studies, ACCESSCare B, our population-based cross-sectional mixed methods project, aims to compare the bereavement experiences for LGB and heterosexual people who have lost a partner to understand if needs, experiences and access to bereavement services differ. Over 500 people in England who had registered the death of their partner or spouse responded to our survey 6–10 months after bereavement and 21 interviews with LGBT people have been conducted to gain a deeper understanding of experiences. ACCESSCare C aims to identify preferences and best practices in communication relating to sexual orientation, gender identity and gender history. We have interviewed 74 participants, including LGBT+ patients with serious illness, their significant others, and health and social care professionals.

Dr Michael Brady, the National Advisor for LGBT Health opening the ACCESSCare Conference 2019.

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* The '+' in LGBT+ was utilised to include anyone who has a minority sexual orientation, gender identity, gender history or biological sex.

Evidence-based communication guidelines for clinicians were developed and tested with stakeholders, offering practical direction for conducting interactions in an LGBT+ inclusive way.

Building on these successful national studies, we supported a sister project in Zimbabwe which aimed to examine the accessibility to, and experiences of, palliative care for lesbian, gay, bisexual, trans and intersex (LGBTI) people and sex workers (key populations) in Zimbabwe. Sixty people from these key populations and twelve health professionals shared their experiences, highlighting barriers to accessing basic palliative and thus multiple unmet needs. A minimal understanding of and access to palliative care for these key populations was linked to increased risk of painful and undignified deaths; and discriminatory beliefs and practices from healthcare providers, family members and community presented barriers for people with life-limiting illness from key populations from diagnosis, throughout illness and to end of life (Hunt et al, 2019). Enhanced clinical interviewing skills and palliative care training are recommended to ensure practitioners understand the health risks of key populations, the additional challenges faced, related health and human rights, and the importance of person-centred care for key populations living with life-limiting illnesses.

Socioeconomic position

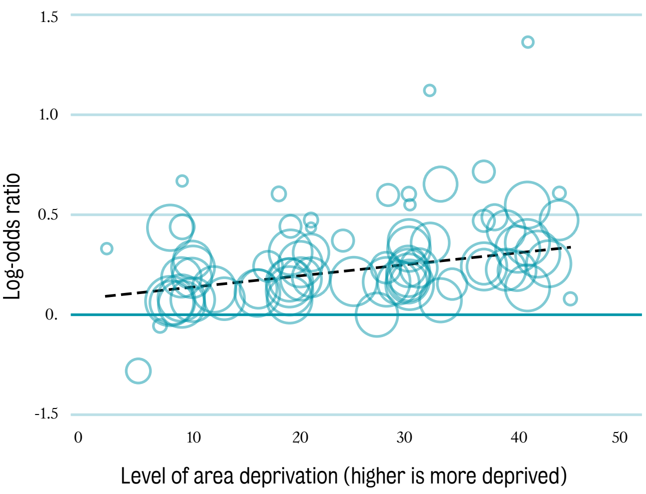
Socioeconomic inequality in health is a global phenomenon; people with lower socioeconomic position (lower wealth, less education or living in a more deprived area) tend to experience earlier onset of disease and have reduced life expectancy. In end of life care there is growing recognition that low socioeconomic position may be a risk factor for poorer care outcomes, in particular people who live in more deprived areas are significantly more likely to die in hospital.

We carried out an extensive systematic review of studies from high-income countries that reported an association between a measure of socioeconomic position (including income, education, occupation, private medical insurance status, housing tenure, housing quality, or area-based deprivation) and healthcare received by adults in their last year of life (Davies et al, 2019).

Combining evidence from 209 international studies, we found consistent evidence that low socioeconomic position was a risk factor for hospital death as well as other indicators of potentially poor quality end of life care including being more likely to receive acute hospital-based care in the last three months of life, and to not receive specialist palliative care before death (Figure 29). Compared to people living in the least deprived neighbourhoods, people living in the most deprived neighbourhoods were more likely to die in hospital versus home (Odds Ratio 1.30, 95% CI 1.23–1.38) and to not receive specialist palliative care (OR 1.13, 95% CI 1.07–1.19). For every quintile increase in area deprivation, hospital versus home death was more likely (OR 1.07, 95% CI 1.05–1.08), and not receiving specialist palliative care was more likely (OR 1.03, 95% CI 1.02–1.05).

The results of the review identified a need for more detailed research to understand the mechanisms that lead to socioeconomic inequality in end of life care. Using data on a cohort of 737 deceased participants from the English Longitudinal Study of Ageing

Figure 29. Dose analysis of area deprivation on log-odds of hospital versus home death, compared to the least deprived group



Source: Davies et al, 2019.

(ELSA), we have investigated potential mediating pathways between socioeconomic position and receipt of hospital-based care towards the end of life. Preliminary results from this observational cohort study suggest that health substantially mediated the effect of wealth on hospital admissions, highlighting the importance of socioeconomically driven health differences in explaining patterns of hospital use towards the end of life.

We also contributed to a prospective cohort study of advanced cancer patients in Singapore; the Cost of Medical Care of Patients with Advanced Serious Illness in Singapore (COMPASS). This study investigated the association between self-reported financial difficulties and measures of total pain and suffering, including: physical, psychological, social and spiritual outcomes and perceived quality of healthcare. Greater financial difficulties were associated with worse pain and suffering after adjusting for demographical characteristics, highlighting patients with financial difficulties as a particularly vulnerable group (Malhotra et al, 2020).

Serious mental illness

Patients with serious mental disorders have shorter lives compared with the general population. Although the gap in mortality is largely because of increased risk of premature death from natural causes, rates of deaths from unnatural (or external) causes are also higher in this group than the general population. Using routinely collected data from the Clinical Record Interactive Search (CRIS) system, developed by the South London and Maudsley Biomedical Research Centre, we explored place of death and correlates of unnatural causes of death in 1029 patients with serious mental disorders. Deaths from unnatural causes were high and more likely to occur at home and non-healthcare settings. Unnatural causes of death were higher in younger patients with non-schizophrenia spectrum disorder diagnoses (Wilson, Gaughran et al, 2019). Our findings also suggested that younger patients and those with diagnoses other than schizophrenia spectrum disorder are less likely to die from natural causes, although the mechanisms behind these associations could not be elicited. This study highlighted the benefits of using routinely collected clinical data in research.

Beyond mortality risk, people with serious mental illness may also experience health care inequalities throughout life. In a systematic review we assessed evidence describing end-of-life care and place of death for this group (Wilson, Hepgul, Higginson et al, 2019). From 23 studies reporting hospital admissions, emergency department care, palliative care, and general practitioner visits at end of life, we found conflicting evidence for the association between serious mental illness and end-of-life care. We found people with serious mental illness were more likely to die in care homes than the general population, though no other patterns for place of death could be understood. This gap in the knowledge around end-of-life care outcomes is concerning and we intend to further develop this stream of research (Wilson, Hepgul, Higginson et al, 2019).

> ‘We must somehow give everything we can to these people that says “you matter because you are you,” everything to enable the patient to live up until he dies, and the family to go on living afterwards.’

Cicely Saunders ‘A death in the family: a professional view’ British Medical Journal, 6 January, 1973, p30–31.

Partnerships and engagement

Cicely Saunders International

Cicely Saunders International is a worldwide charity dedicated to research and improvement in palliative care, and to ensuring that everyone has access to the best care at the end of life, no matter where they are cared for.

The charity was established in 2002 towards the end of her life by Dame Cicely Saunders, the founder of modern palliative care and the modern hospice movement. Dame Cicely recognised the specialty needed robust evidence-based research to translate quickly into practice for the benefit of patients.

The charity joined with academic partner King's College London to raise £10m for an Institute of Palliative Care – an international hub uniting research, education, clinical services and patient support. Since the Institute opened in 2010, Cicely Saunders International has continued to support the work of the Institute through direct funding of research programmes and in partnership with other funders. Particular areas of interest are education and capacity building, empowering patients, care for older people, and research to manage challenging symptoms such as breathlessness.

Cicely Saunders International fund research to improve the care and treatment of all patients with progressive illness to make high-quality palliative care available to everyone who needs it, wherever they are cared for. In 2018, we launched a major fundraising effort to establish a new Professorship in Palliative Care for Older People, and create a step change in care for older people with advanced illness and transform treatment and care. Thanks to generous donations from our partner funders, Kirby Laing Foundation, The Atlantic Philanthropies, and the Hospice Education Institute, in 2019 we were pleased to announce the new professorship will take forward the following work focussing on palliative care for older people:

- At least five scientifically robust new therapies for an older population with multiple co-morbidities which have been taken to full trial.
- A step-change in knowledge about patient choice and how to meet this in order to ensure adequate resources are in place for a rapidly ageing population, with influence on policy.
- Greater awareness of what palliative care is, and improved access to this.
- Expanded clinical, research and teaching capacity within the field to develop palliative care leaders of the future with at least six PhDs completed, and a wider range of opportunities for development.

Cicely Saunders International is also part of a coalition of 6 charities campaigning for better care and support towards the end of life, with partners Hospice UK, Macmillan Cancer Support, Marie Curie, MND Association and Sue Ryder http://endoflifecampaign.org. The shared priorities are delivery of the national commitment on end of life care with: coordination of care between services, provision of a range of high quality community care options; and improvement in the quality of end of life care in hospital.

Centre for Global Health Palliative Care

The Centre for Global Health Palliative Care 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. We also support the King's College London strategy, specifically ensuring that world-class research is conducted while developing global leaders and delivering research-led education.

The Centre is directed by Professor Richard Harding. We currently have a large global health programme through partnerships with clinical and academic sites across the globe. Our approach is that we have the scientific expertise to work with our partners to assist in finding answers together. To support delivery on the King's 2029 Strategic Vision, our educational programmes and primary research inform partnerships that shape and transform palliative care provision around the world. We also support the King's Global Health Institute, ensuring that health services are "fit for purpose" through our palliative care research programme.

Our research within the Centre is funded by external, competitive research funding. Our programme of research is currently supported by the ESRC (in collaboration with the Centre for Conflict and Health at King's), NIHR (in collaboration with the Institute of Psychiatry, Psychology and Neuroscience), Medical Research Council, World Health Organization and the Open Society Foundation.

Key activities and impacts

- We are delighted to have been awarded the contract by WHO to conduct the WHO Global Evaluation of palliative care to inform the global response to Universal Health Coverage. Working with partners in Belarus, Jamaica, Oman, Thailand, Vietnam and Zimbabwe, we are establishing evidence for models, outcomes and costs of adult palliative care.

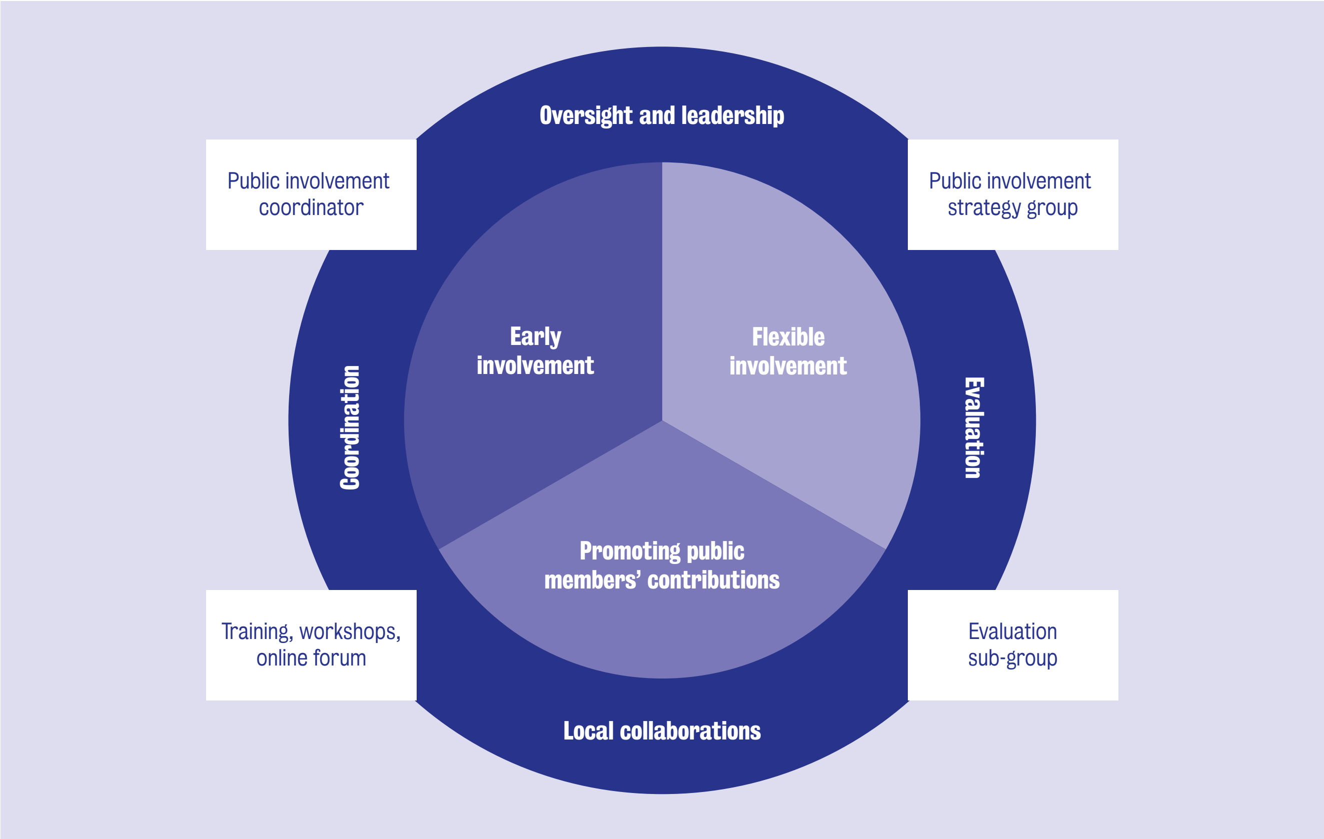
- We were awarded the contract by WHO Centre for Health Development to conduct a mapping of service delivery models that optimize quality of life and health services use among older people. This included a rapid review of systematic reviews on the effectiveness of service models, and a tertiary review of primary literature to map service delivery models to specific outcomes that optimize both quality of life and health services use.

- We strive to identify opportunities to translate scientific innovation and evidence from low and middle-income countries to the European context. In 2018, we were delighted to receive a European Research Council consolidator award for Professor Richard Harding to translate the paediatric outcomes research from Africa (led by the African Palliative Care Association) to the UK. This research brings together clinical and academic centres of excellence from across the UK to develop and validate a core child and family-centred outcome measure that reflects the symptoms and concerns of those affected by life-limiting and life-threatening illness.

- The development of paediatric palliative care measurement is also being conducted in Jordan and Turkey under our R4HC-MENA programme, where we are also identifying the specific concerns of refugee and migrant families affected by conflict. In 2020, we drew

WHO Evaluation Palliative Care in Six Countries Project, project launching and training visit to National Cancer Institute, Thailand, 2019.

Figure 30. Summary of our public involvement strategy (core principles and infrastructure)



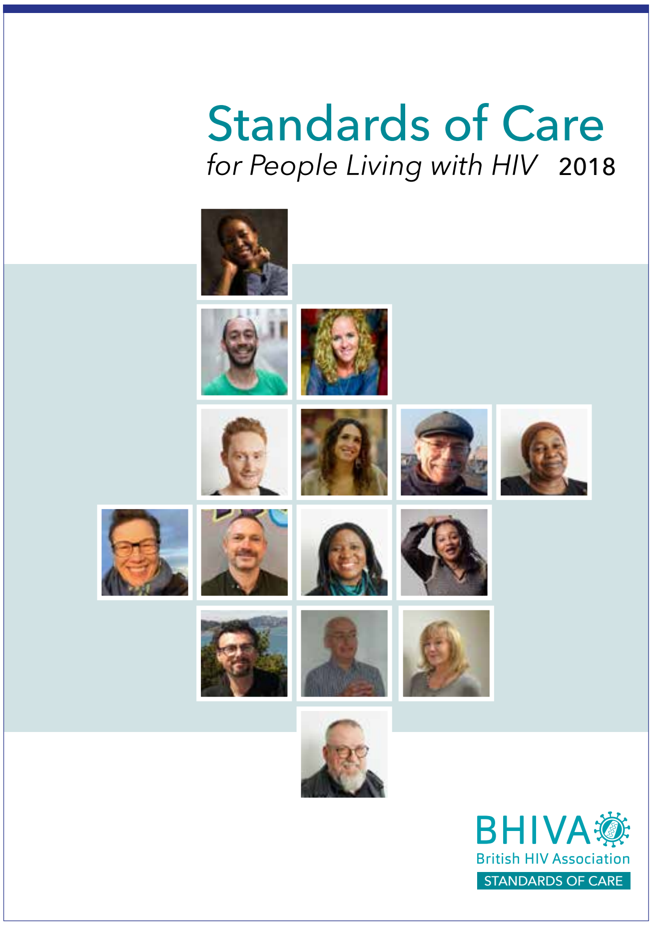
Source: Johnson, Ogden et al, 2020.

together our King's, Jordan and Turkey teams to share the learning from conducting research interviews with this complex population.

- Our 20-year programme of HIV palliative care research in sub-Saharan Africa is also offering relevance to the management of HIV in ageing high-income country populations. In 2018, the new British HIV Association (BHIVA) Standards of Care were launched. The standards are co-produced by health care professionals and communities of people living with HIV, and endorsed by Royal Colleges. In 2018 the first standards for palliative care were incorporated.

Public involvement and engagement

Public Involvement in research is when research is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. By 'public' we mean patients, families, carers, and people


Standards of Care
for People Living with HIV 2018

BHIVA
British HIV Association
STANDARDS OF CARE

British HIV Association Standards of Care.

Patient and public involvement workshop on the theme ‘Palliative Care and Ageing’, 2018.

who use health services. Alongside the moral imperative of including people in research that is relevant to them, public involvement intends to improve the quality, relevance, and impact of our work.

Our strategy

To guide and develop public involvement activities across the Institute, we implemented a public involvement strategy running from 2017–2020 (Figure 30). Our strategy follows principles agreed in an earlier expert consultation with local researchers and public involvement representatives (Daveson et al, 2015), including promoting early involvement, a high degree of flexibility in the methods used and promoting the contribution of public representatives to the research process. It also details core components of our public involvement infrastructure, including our public involvement coordinator, workshops, and online forum. Our strategy is overseen by our Institute’s public involvement strategy group, comprising CSI researchers, clinicians, and public representatives. Our strategy group meets quarterly, and since 2020, is co-chaired by a public representative.

Consultation to redesign our online forum for public involvement in palliative care, 2019.

Workshops

Active patient and public involvement is at the core of our research and is an essential and valued aspect of our work. We conduct public involvement workshops twice each year, during which public representatives offer their time to advise and collaborate with the Institute at all stages of our research. Our workshops include:

- **A themed section**, which includes teaching and sharing knowledge with public members in order to stimulate discussion and understanding on palliative care and the challenges surrounding research in this area.

- **A Dragon’s Den session**, where researchers and clinicians from the CSI present their work to public panels to gain feedback on, for example, how to engage patients in the work or their research plans. This is also an opportunity to recruit representatives to study advisory groups.

Workshops are typically attended by 10–12 public representatives and about 5 researchers. Across the past 3 years, themes have included 'Palliative care and ageing', 'does public involvement make a difference?', 'caregivers in palliative care research' and 'secondary and routine data analysis', and fifteen different research projects have been presented for feedback. More recently, in light of COVID-19 restrictions, we ran our first virtual Dragon's Den Session. The session was attended by 16 public members and 6 researchers, and included presentations from projects about bereavement, rehabilitation, and end of life care. Attendees provided positive feedback for the virtual event, and we are planning to continue with this format alongside our face-to-face workshops when they resume. Feedback from these workshops have been overwhelmingly positive.

Online forum

Since the launch of our online forum (www.csipublicinvolvement.co.uk) in 2016, we have conducted essential evaluation and improvement work to this platform. Our mixed-methods evaluation (Brighton, Pask et al, 2018) tested the functionality, feasibility, and acceptability of our online forum for public involvement in palliative care and rehabilitation research. Through focus groups with researchers and public members, we found that although the forum was functional, feasible and acceptable, it required further development to make it more engaging and empowering for public users. Our experience with the development and evaluation of the online forum have been shared with local research groups, and through dissemination at national and international conferences.

Based on this evaluation, we received support from our local Clinical Research Network to further develop the online forum. Following co-production workshops with researchers, public members and a professional web designer, the forum was given a fresh new format and relaunched in November 2019. This has led to an increase in forum activity, supporting productive discussions about new and ongoing research studies.

Awards for innovation, contributions, and putting patients and carers first


'Innovation Award', NIHR Clinical Research Network South London awards, 2018

In 2018, our team were awarded both 'Most Innovative Patient and Public Involvement Activity', and 'Most active contribution from a member of professional services staff' for the evaluation of our Institute's public involvement strategy at the Collaboration for Leadership In Applied Health Research and Care South London 'Know your CLAHRC awards'. Our team were also awarded the 'Innovation Award' at the NIHR Clinical Research Network South London awards, acknowledging the development of the CSI online forum for public involvement in palliative care and rehabilitation research and its impact on improved research delivery.

In 2019, Margaret Ogden, a CSI Patient and Public Representative, and co-chair of the Institute's Strategy Group won the 'Putting Patients and Carers First Award' at the NIHR Clinical Research Network South London awards. She was recognised for her contribution to improving a number of NIHR studies in palliative care and rehabilitation, plus the substantial role she has played in a co-produced project to evaluate and improve patient and public involvement across the Institute.

Education and resources

As part of our ongoing work to promote good practice in public involvement in palliative care research, members of our strategy group are responsible for sharing good practice internally and externally. Public involvement is now co-taught with a public member as a core research methods session on our MSc Palliative care, and we run an annual methodological skills session on public involvement with our researchers. Our team has also developed multiple resources for researchers and public members within our Institute, including a co-produced induction booklet, public representative role description template, researcher 'how to' and payment guide, and grant application costing guidance. Beyond our Institute, we have shared our practices and examples with teams in the Health Research Authority, the NIHR Centre for Engagement and Dissemination, Dunhill early career researchers, and healthcare researchers at UCL.

Evaluation of our public involvement

A key component of our strategy is the evaluation of our public involvement activities. In 2018 we audited involvement across all research projects and conducted focus groups and interviews with 19 researchers and seven public representatives to understand the impact of our strategy. The audit identified high levels of early involvement across our research projects and identified areas for future development (e.g. co-productive working). Our qualitative study found that building and maintaining relationships, taking a flexible approach and finding the 'right' people were important for successful public involvement (Johnson, Ogden et al, 2020). Our infrastructure (e.g. workshops, the online forum, our public involvement coordinator) supported these principles, and had scope for further development in terms of increasing diversity of membership and supporting new creative ways of involving public members in our work. Our evaluation work has been presented at multiple international conferences, including the International Perspectives on Evaluation of Public Involvement Conference in 2018 and the European Association of Palliative Care Conference in 2019.

Public engagement

We continue to run engagement events to connect with our local communities. These events are excellent opportunities to hear public members thoughts on our current and future research, invite new members to our public involvement group and open conversations about palliative care and rehabilitation.


'The Sound of Anxiety', Live Research Project, Science Gallery, October 2019.

- **Open House Research Showcase:** In September 2017, the Institute opened its doors to the general public as part of the London Open House weekend. Over 60 members of the public attended this event. They were able to explore the CSI building in a guided tour, take part in games and quizzes, meet CSI researchers and the artists who contributed to the building.

- **#Cicely100 centenary celebrations:** We ran twitter campaigns #LightforCicely #VoiceofCicely and #CicelysLegacy using Dame Cicely's quotes that generated over 42,000 impressions, and had a featured

The Departure Lounge, Lewisham Shopping Centre, May 2019.

Google doodle to celebrate the anniversary of her birth (www.google.com/doodles/dame-cicely-saunders-100th-birthday). We tweeted a paper a day for 100 days, to highlight the breadth and impact of our research. Research papers were chosen because they have led to change: from impacting on clinical care, to policy and education, to the field itself through methodological development.

- **The Departure Lounge:** Throughout May 2019, in collaboration with the Academy of Medical Sciences and The Liminal Space, a free installation was opened for a month in Lewisham Shopping Centre. The Departure Lounge pop-up shop used the metaphor of travel, findings from medical science, and personal stories from the end of life to explore what it means to have a 'good death' with the over 2,500 people who visited the space. Free flat pack versions of The Departure Lounge have been sent to community groups across the UK to start a truly national conversation about death and dying. www.departure-lounge.org.

- **The Sound of Anxiety:** In October 2019, we conducted an experiment at the Science Gallery over three weekends, asking visitors to listen to recordings and see if they could guess why the recorded person was breathless. We also asked people to rate how they felt before and after listening, to see whether listening to other people being breathless might make participants feel the symptom themselves. Over 250 people took part over the course of the experiment and we found that most people correctly identified the recording of an anxious person breathing. We are hoping the findings will increase our understanding of the link between anxiety and breathlessness.

> 'Palliative care stems from the recognition of the potential at the end of life for discovering and for giving, a recognition that an important dimension of being human is the lasting dignity and growth that can continue through weakness and loss.'

Cicely Saunders (2006) Foreword In: Ferrell B and Coyle N (eds) Textbook of palliative nursing, 2nd edition New York: Oxford University Press.

Our early response to COVID-19

Context

Health care services became overwhelmed with the tsunami of COVID-19 cases in many countries. COVID-19 has an overall case fatality ratio estimated between 1 and 4%, with patients with multimorbidity and who are older at high risk of serious illness and death from COVID-19 infection.

The World Health Organization quickly issued guidance on how to maintain essential health services during the pandemic, highlighting prevention, maternal care, emergency care, and chronic diseases among others, but with no mention of palliative care. As of 22 October there are 41,104,946 confirmed cases of COVID-19, including 1,128,325 deaths, as reported to the World Health Organization.

Palliative care is commonly misunderstood as only being relevant for people who are dying. However, the relief of suffering, through provision of holistic and compassionate care, is an essential component of care for all patients with life threatening illness.

Our clinical services in South London were at the epicentre of the UK pandemic of COVID-19. The first cases of COVID-19 were confirmed in our hospitals in early March 2020, and the first deaths began around mid-March 2020. As cases increased, day by day wards in the hospitals were turned over to COVID-19, and the number of patients seen by community teams increased.

A united clinical academic response

We employed our Palliative Care Clinical Academic Group (CAG) to launch a combined response, and we believe the clinical academic integration helped this response:

- Orientation of our clinical services to COVID-19, with rapid reviews and evidence updates provided from the academic teams – and a search facility offered by the academics of any evidence questions.

- Used our leadership of the National NIHR Palliative and End of Life Care Applied Research Collaborative (ARC) to convert a planned meeting to bring NHS and Public Health England in to discuss clinical and research issues, leading to our engagement in guidance.

- Rapidly reached out to research funders to seek their agreement to re-focus our Institute research towards COVID-19, with an aim to produce guidance and learning that would help improve palliative care for people with COVID-19 worldwide. NIHR, Dunhill Medical Trust and Cicely Saunders International all gave rapid agreement for our research to change in this way, and consequently we launched a new COVID-19 research programme.

- Increased clinical activity by the clinical academics within the Institute. This enabled us to provide a 7 day service in the hospitals for patients and families.

- Engaged locally and nationally to share and exchange findings.

- Quickly transferred all our MSc teaching to online rather than face to face format.

As a consequence, we have worked locally and with NHS England, NICE and international organisations and governments to help improve the guidance on palliative and end of life care during

COVID-19. We produced guidance and support for people who do not have COVID-19, and needed to shield to protect themselves, and need symptom or other support. We have published timely editorials, rapid reviews, case series, and modeling studies.

Rapid reviews and early clinical data

Our first study (Costantini et al, 2020) examined the preparedness for, and impact of, the COVID-19 pandemic on hospices in Italy to inform the response in other countries. This survey of 14 hospice services showed hospices were able to respond rapidly and flexibly to COVID-19 but PPE was inadequate, and guidance was not setting specific. This was the first publication on palliative care in COVID-19 worldwide. Similar surveys have now been carried out in India and Africa.

We then conducted a rapid systematic review of the role and response of hospice and palliative care in epidemics/pandemics to inform response to COVID-19. Published in March 2020 (Etkind et al, 2020) the review was to understand whether and how palliative care had a role, as it was missing from all guidance. This unique paper included recommendations for hospice and palliative care services, including shifting resource to the community, redeploying volunteers, facilitating staff camaraderie, and using technology to communicate with patients/ carers (Table 3).

Table 3. Recommendations for the palliative care and hospice response to COVID-19

Systems	**Policies** • **Maintain flexibility** and the ability to **rapidly modify or implement new policies**, such as changes to admission criteria. • If visiting hours are limited, **consider** providing **daily telephone support to families.**
	Training and protocols • **Provide protocols for non-specialists** on symptom management and provide basic palliative care training including communication. • **Consider** separate guidelines for **specific populations** such as those in care homes.
	Communication and coordination • **Identify** a **key decision maker** to improve communication, particularly if multiple professionals are involved outside of their usual practice. • **Involvement** in **triage systems** to assess likelihood of response to treatment and risk of dying. • **Share** protocols and advice within organisations.
Systems (continued)	**Data** • **Standardise information collection & monitoring** to inform operational changes (for example number of patients seen, main symptoms and concerns, treatments, effectiveness of treatment, and outcomes).
Space	**Maintain ability to move resources between settings** • **Consider moving resources** from inpatient to community setting according to need. • **Ensure** palliative care services are integrated into new systems for care, including community care centres and temporary hospitals.
	Technology • **Use virtual technology** to **enable communication** when visiting is restricted.

Staff	**Deployment**	• **Deploy staff flexibly** between palliative care settings according to need. • **Prioritise** sufficient **staff numbers**. • If patient contact with volunteer services needs to be restricted, **consider alternative roles** (for example, psychological support, bereavement support).
	Skill mix	• **Involve chaplains and psychologists** with specialist palliative care expertise.
	Resilience	• **Facilitate** camaraderie, **promote connectedness**, develop systems for reducing stress, and **support non-specialist staff**. • **Provide training in communication** and bereavement.
Stuff	**Medicines and equipment**	• **Include** relevant **symptom medications in formularie**s (to treat breathlessness, cough, fever, delirium, anxiety, agitation and pain). • **Ensure** supplies of medications, **IV and subcutaneous** delivery systems and lines.
	Personal protective equipment	• **Ensure** sufficient **supplies of PPE**.

Source: Etkind et al, 2020.

In April 2020 we published a case series of 101 patients referred to hospital palliative care services (Lovell, Maddocks et al, 2020). We found palliative care input was brief, most common symptoms were breathlessness and agitation, and symptoms usually responded to regular doses of opioid and benzodiazepine.

International guidance and research

With international collaborators, we published in the European Respiratory Journal (Bajwah et al, 2020) rapid guidance on palliative care in COVID. This included development of information sheets for people admitted to hospital with COVID-19 and their family/friends. These have been translated into 25 languages and are freely available (Figure 31).

Our ‘Practice Pointer’ in the BMJ (Ting et al, 2020) further outlined clinical management of people with severe COVID, including how symptoms should be managed, and how patients and their families should be kept informed. Further, we contributed to consensus recommendations for palliative care for patients with COVID-19 using the Convergence of Opinion on Recommendations and Evidence (CORE) process. 68 international experts in palliative care, respiratory medicine or critical care medicine provided recommendations concerning: advance care planning; (pharmacological) palliative treatment of breathlessness; clinician-patient communication; remote clinician-family communication; palliative care involvement in patients with serious COVID-19; spiritual care; psychosocial care; and bereavement care.

We explored patterns of mortality during the COVID-19 pandemic and implications for palliative care, service planning and research using national registry data (Bone et al, 2020). We identified a 220% increase in deaths in care homes in England and Wales. We estimated that around one in five of all COVID-19 deaths occurred among people who might have been in their last year of life in the absence of the pandemic, indicating a group for whom palliative care may be particularly relevant.

We synthesised evidence of uncertainty associated with COVID-19 and provided recommendations to address disease, health system, health professional, patient and family uncertainty (Koffman et al, 2020) and made recommendations to help hospital clinicians prevent poor bereavement outcomes and support staff (Selman et al, 2020). The latter included: ‘proactive, sensitive and regular communication; accurate information provision; enabling family members to say goodbye in person and supporting virtual communication; symptom management and emotional and spiritual support; signposting to bereavement services; supporting relatives to adapt funerals; consistent leadership and support from health professionals’. With collaborators in Jordan, we described how a cancer centre in Jordan introduced changes to DNRCPR policy during COVID-19 (to allow for unilateral decision making) in anticipation of ventilator shortages (Shamieh et al, 2020) and made recommendations for countries with limited resources.

With our partners at the African Palliative Care Association, we rapidly surveyed hospice and palliative care services across Africa and discovered challenges with infection control and staff anxiety (Boufkhed et al, 2020). An analysis of African case management guidelines found a general absence of palliative care (Afolabi et al, 2020).

Figure 31. Information for patients admitted to hospital 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 people you wish to be kept informed.

This information leaflet was compiled by Dr Sabrina Bajwah (Cicely Saunders Institute, King's College London) with extensive input from co-authors and patient/carer groups to accompany the ERJ editorial "Managing the supportive care needs of those affected with COVID-19". Please cite this editorial as follows:

Bajwah S, Wilcock A, Towers R, Costantini M, Bausewein C, Simon ST, Bendstrup E, Prentice W, Johnson MJ, Currow DC, Kreuter M, Wells AU, Birring SS, Edmonds P, Higginson IJ (2020). Managing the supportive care needs of those affected by COVID-19. ERJ: doi (10.1183/13993003.00815-2020)

Produced in April 2020

www.europeanlung.org 1

Source: Bajwah et al, (2020).

Figure 32. Including the patient voice in COVID-19 research: concerns expressed by patients and families

Reduced professional support

- Anxieties around delay and disruptions
- A need for clear and accessible information
- Identifying inequalities and the most at-risk

Risk of reduced quality of care

- Fears around rationing of care
- Concerns about communication of care preferences
- Maintaining a holistic approach with diminished resources

Strains on informal care networks

- Increased responsibilities for informal carers
- Fears around caring and risk of infection
- Loss of informal care due to isolation measures

Risk of reduced quality of care

- Heightened risk of complicated grief
- Providing sufficient bereavement support
- Impact of societal grief on mental health

Source: Johnson, Ogden et al, 2020.

Including the patient voice during COVID-19

The patient voice was largely missing during COVID-19. Therefore, to support the national palliative care response to COVID-19 and ensure inclusion of the voices of people with serious illness, we led a rapid virtual consultation with public involvement networks to hear their experiences, concerns, and priorities for palliative care research during the COVID-19 pandemic (Johnson, Ogden et al, 2020). Responses from 44 people called for work to address timely professional support with increasing service demand; sustaining informal care networks under increasing strain; ways of monitoring and detecting compromised outcomes of care; and bereavement support responsive to increasing loss and grief (see Figure 32). These were shared widely across national palliative care clinical and research networks, and fed into our own palliative care research in response to the COVID-19 pandemic.

Improving palliative care for people affected by the COVID-19 pandemic by sharing learning (CovPall)

With colleagues at Hull York Medical School, The University of York and Lancaster University, we are undertaking a large international study of the palliative care response to COVID-19. 'CovPall' aims to understand how palliative care services and hospices have responded to the COVID-19 pandemic. This study has won new funding from the MRC. This international survey comprises two work packages. The first asks clinical leads of hospices and palliative care services to complete an online survey which asks about their practice, challenges and innovations. To date we have received 458 responses from services across the UK, Europe and the Rest of the World. Analysis of this data will allow services to learn from each other to support planning and response to potential future waves of the pandemic. The second work package comprises a collection of pseudonymised information from the clinical records of patients with COVID-19 to understand the symptoms patients have experienced, how they have changed over time, and what treatments/therapies are used. 19 sites are currently collecting data.

Sharing our Clinical Learning

We quickly turned our guidance on the management of breathlessness into a quick guide for people who needed to self-manage at home and had severe illness, such as COPD or lung disease. This was taken up nationally and internationally, being widely disseminated via the King's website and Twitter channels. Following the same framework as our rapid review, to share our clinical learning, the King's College Hospital team prepared a *Case Report: The impact of and response to the COVID-19 pandemic on a hospital palliative care team*, which charts the growth in cases and reflects on the response and the learning (Table 4).

Palliative care was seriously at risk of being overlooked during the pandemic, but due to the unfortunate high mortality from COVID-19 in certain groups, it was essential. While efforts to preserve life and cure people from COVID-19 are vital, we should also recognise that all people with life threatening illness should have access to palliative care, and for those at risk of deteriorating or dying, a parallel or urgent care plan may need to be in place. Multiple actions were taken by the Cicely Saunders Institute team to respond to COVID-19, across clinical and academic interfaces. There are now new clinical imperatives, including offering a comprehensive 7-day service, and continuing the teaching and research interfaces.

> 'The search for meaning is not only a challenge of patients and families. As individuals and as a caring team, many workers feel compelled to seek answers or, more often, to develop a readiness to live with questions.'
>
> **Cicely Saunders and Robert Kastenbaum (eds)(1997) 'Hospice care on the international scene' New York:Springer Publishing Company p7.**

Table 4. Palliative care service response to COVID-19 pandemic

Systems	**Hospital level changes** • Contribution to development of clinical decision aid for hospital-wide triage, and participation in hospital triage board to support complex decision-making. • Participation in daily Medicine meetings, enabling timely involvement in decision-making; input to hospital end of life group to support policy and process changes to manage the pandemic.
	Palliative care team organisation • Move from key worker model for palliative care caseload, to a 'zoned' caseload, split into COVID/non-COVID wards, with team members allocated to each. • Introduction of full 7-day working within three weeks (2 specialist nurses and one consultant on site at weekends, in addition to the existing training grade doctor on call, to support the COVID-19 workload). • Introduction of buddy system for region-wide consultant telephone on call service. • Weekly Multi-Disciplinary Meeting and bereavement meetings continued; discharge meeting and other non-essential meetings stopped.
	Clinical guidelines and teaching • Development of guidance within Electronic Patient Record system, to help teams' parallel plan for deteriorating patients at risk of dying. • COVID-19 symptom control guideline developed; available on Trust intranet and hard copies displayed on each COVID ward and handed to junior doctors. Updated as knowledge evolved. This formed the basis for an editorial published in the European Respiratory Journal which provided guidance on symptom management in COVID-19, including patient and carer information leaflets which have been translated into 25 languages. • Development and delivery of "bite-sized teaching" on palliative care for people with COVID-19; teaching delivered to over 500 people on 12 medical wards & the Emergency Department over 8-week period from March to May.
	Research • Strengthened clinical/academic integration through weekly remote meeting with clinical academic colleagues, to flag important clinical questions for rapid review by researchers and to identify and plan potential clinical research studies. This led to publication of the first case series of palliative care needs of patients with COVID-19, and a rapid review on the role and response of palliative care during pandemics. • Participation in national and international clinical studies, including the RAPID study (Symptom burden and trajectory of moderate to severe COVID-19) and COVPALL study (Rapid evaluation of the COVID-19 pandemic response by palliative and end of life care).
Space	• **Maintenance of social distancing** through use of larger spaces within the Institute, made vacant by academic and research team working from home. • **Move to remote meetings using videoconferencing platforms** to enable participation in palliative care senior team, hospital and sector palliative care meetings. • **Move to virtual outpatient clinics.** Regular Interstitial Lung Disease and Motor Neurone Disease clinics delivered by telephone. Remote IT access for hospital Electronic Patient Record set up.

Staff	**Flexible deployment of staff** • Capacity within the clinical academic team provided flexibility to support service delivery and ability for rapid deployment, for example to cover sickness. • Palliative care social workers partly redeployed to Trust family liaison team, supporting the families of COVID-19 inpatients across the Trust, through proactive daily phone updates and bereavement support.
	Promotion of resilience and camaraderie • Promotion of mind and body wellbeing, including setting up twice weekly team distanced exercise sessions. • Team "Happy board" set up, following initial thank you email from a local GP. • Thank you hampers made up by palliative care administrators and distributed to COVID-19 wards to support ward staff. • Use of charity funds to purchase essential items for patients.
	Recognition of concerns/anxieties • Regular check-ins with team at MDM and daily handover, to recognise anxieties and manage concerns, e.g. certain staff chose not to work on COVID-19 wards.
	Flexibility to ensure team adequately staffed • Time off in lieu put in place to ensure all team members had regular breaks, whilst ensuing a minimum number of team members were present daily, taking account of potential for sickness.
	Clinical supervision continued virtually to support psychological well-being
Stuff	**Syringe pump availability** • Guidelines on use of syringe pumps updated for staff unfamiliar with use. • Additional syringe pumps procured as initially pumps were prioritised for use in ICU, and demand on wards was also high. • Plan for management of symptoms with regular subcutaneous medication in the event of critical syringe pump shortage put in place.
	Pharmacy • Agreed ward stocklist for palliative care drugs, ring-fenced from ICU-stocks. • Ward stocks of midazolam standardised, including different vial strengths to minimise wastage. • Backup version of clinical guideline agreed with an alternative drugs to use in the event of critical shortage of midazolam.
	Supply of essential PPE for team secured, with visors supplied by local school.
	Charitable donation of phone and tablets to facilitate telephone and video calls between patients and families.

Source: Edmonds et al, 2020.

Education and capacity building

PhDs in Palliative Care

The Institute has a vibrant and enthusiastic group of PhD students, who are an integral part of our research and who gain from our internal programme of researcher and academic development. Our PhD student body, typically around 15–20 registered either part- or full-time, spans a wide range of professional backgrounds – currently medicine, allied health, social science and psychology graduates are represented. Each student is allocated 2–3 supervisors with whom they have regular, usually monthly, meetings to receive feedback that directs their research activities, and help them identify training and development needs. Our shared supervision model provides breadth of expertise, both clinical and methodological, and helps us develop new supervisors, who benefit from working closely with more experienced staff.

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, which they access and use according to their training and development needs. Each student develops a bespoke programme in agreement with their supervisors. 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 2017 and 2019 national Postgraduate Research Experience Surveys is highest in the sector. Every one of our students (100%) 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. Positive experiences around supervision and research skills training were particularly apparent.

PhDs completed in during this report period include:

- **Dr Mary Abboah-Offei** – Development and testing of a novel community-based intervention of integrated palliative care to improve person-centred outcomes for people living with HIV/AIDS.
- **Dr Jo Bayly** – Developing a short term integrated rehabilitation service for people with thoracic cancer.
- **Dr Anna Bone** – Mixed methods study that examines the influences of older people's emergency hospital attendance towards the end of life.
- **Dr Simon Etkind** – Describe and explore the influences on care preferences, and the stability of care preferences, in frail older people with experience of acute healthcare.
- **Dr Clare Ellis-Smith** – Development and evaluation of an IPOS-Dem to improve assessment and management of symptoms and concerns experienced by people with dementia living in care homes.
- **Dr Lesley Henson** – Exploring and understanding factors associated with emergency department attendance by patients with advanced cancer towards the end of life: A mixed methods study.
- **Dr Pauline Kane** – Feasibility and acceptability of a palliative-specific patient-reported outcome measure (PROM) based intervention to assess the symptoms and concerns of advanced heart failure patients.
- **Dr Natasha Lovell** – Improving the management of refractory breathlessness: a feasibility randomised controlled trial of mirtazapine.

- **Dr Eve Namisango** – Outcome Measurement in children and Young people with Life Limiting and Life threatening conditions.
- **Dr Cheng-Pei Lin** – Development of a culturally-appropriate advance care planning intervention for people living with advanced cancer in Taiwan and preliminary exploration of its feasibility and acceptability.
- **Dr Jen-Kuei Peng** – Utilisation of acute care and palliative care in patients with end-stage liver disease: a nationwide population-based cohort study.
- **Dr Mendy Dzingina** – Development of a health-economic version of the POS (POS-E) to derive palliative care-specific QALYs.

MSc, Postgraduate Diploma and Postgraduate Certificate in Palliative Care

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 United Kingdom and the world with over 600 graduates to date. The underpinning philosophy of the MSc and the integrated Postgraduate Diploma and Postgraduate Certificate is to enable students to develop 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 a deep knowledge and understanding of clinical, social, psychological, spiritual and ethical issues in palliative and end of life care, and their assessment and effective management. 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 then 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, and Jordan amongst many others. The diverse student body provides a unique opportunity to share experiences on how end of life care has developed across the world and also to reflect on social and cultural approaches to death, dying, caring and bereavement. The MSc has been designed to closely complement the requirements of the UK specialist training registrars in palliative medicine. Many students who attend our modules fulfil their training needs as consultants in palliative medicine in the making. We frequently refer to the training curriculum to ensure we continue to develop and modify the course to ensure it matches the needs of the specialty. Over the last three years, the results

2019 intake for MSc, PG Diploma and PG Certificate in Palliative Care.

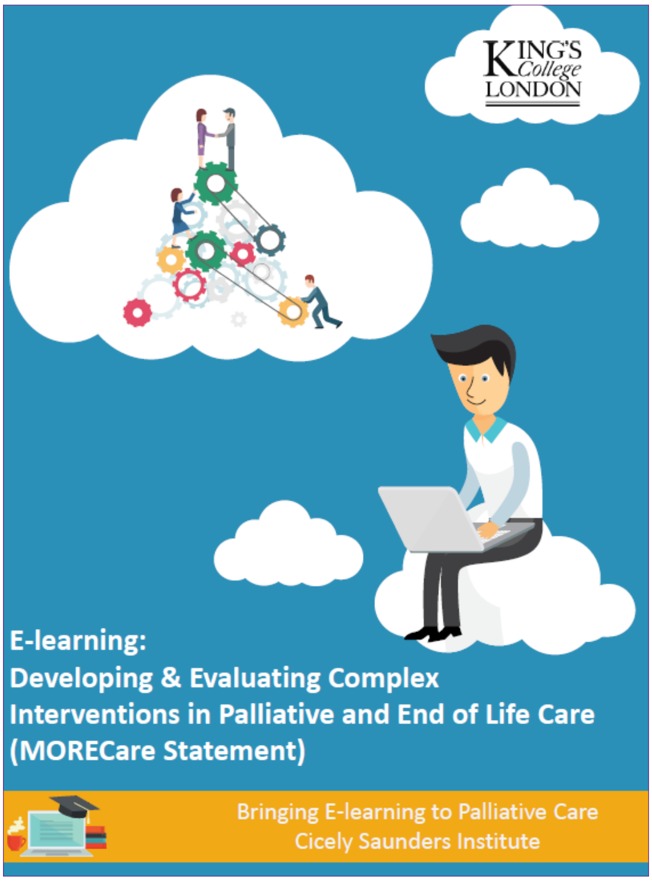
2019 intake for MSc, PG Diploma and PG Certificate in Palliative Care.

from the Postgraduate Taught Experience Survey have been 100% for student satisfaction. During the COVID-19 global pandemic, we successfully migrated all our MSc teaching to e-learning, matching, where possible, many of the benefits of face-to-face teaching through virtual break-out rooms and group work.

MORECare and E-learning to disseminate research guidance into practice

Despite being a core business of medicine, end of life care is neglected. It is hampered by research that is difficult to conduct with no common standards of mixed methods, complex outcomes, and economic evaluation. We have refined our innovative e-learning platform to enable researchers, clinicians, members of ethical committees, and funders globally to understand how to conduct high quality, rigorous, and ethical research in end-of-life care (https://tinyurl.com/y8kc5dr6).

The course explains the best methods of designing and conducting research, which evaluates palliative and end-of-life care services and treatments using the MORECare Statement. The learning platform consists of six modules. These are framed around the MORECare statement key areas with specific objectives for each module. The time required to complete the six modules is estimated at 7–10 hours and includes readings, presentations, and assessment. So far, several hundred participants have completed their programme of learning on this platform.



Poster for E-learning; Developing & Evaluating Complex Interventions in Palliative and End of Life Care.

EUPCA participants 2019–2021.

The Institute's YouTube channel (www.youtube.com/user/CSIKCL) hosts approximately 100 videos and features recordings of seminars and lectures and workshops, providing an inexpensive 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 in 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.

Palliative Care Research Course for Specialist Training Registrars

In Summer 2019, we ran for the first time a two-day, intensive research methods course focused on the curriculum training requirements of UK Specialist Training Registrars in Palliative Medicine. During the highly interactive course, participants were introduced to developing research questions, critical appraisal of scientific literature, considering the ethical requirement of palliative care research, clinical trial design, and developing an understanding and appreciation of the role of medical statistics.

The European Palliative Care Academy

The European Palliative Care Academy (EUPCA) (http://www.eupca.eu) is an exciting joint project of the Robert Bosch Stiftung, Germany and four academic centres across Europe. Together with partner institutions in Germany, Poland and Romania, Dr Jonathan Koffman and Dr Catherine Evans developed a challenging curriculum to capacity build emerging palliative care leaders from all professional backgrounds. The programme comprises six modules – Project Management, Personal Development, Research as Applied to Palliative Care, Team Work, and Advocacy – and includes a personal project and an observation week at a European institution of the participant's choice. The third EUPCA intake successfully graduated from the programme in Brasov, Romania. The students originated from over 15 European countries including Albania, Lithuania, Spain, Greece, Turkey and Denmark among others, and included a wide variety of professional backgrounds. The fourth EUPCA cohort commenced their studies, attending the Research as Applied to Palliative Care module at the Cicely Saunders Institute in 2020.

The Medicine MBBS programme

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, led by Dr Rachel Burman, is designed to spread throughout the five-year MBBS.

Each MBBS year group 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. Students in the King's College Hospital and Guy's and St. Thomas' hospital clusters benefit from small group tutorials on ageing, loss, advance care planning, diagnosis of dying, anticipatory prescribing, how to talk to patients about dying, and bereavement care. In the final year, students attend a half-day hospice visit as part of their General Practice attachment. In addition, all the palliative care teams within each cluster site contribute regularly to personal tutoring, educational supervision, delivering revision lectures and webinars, communication skills courses, supervise quality improvement projects and participate as examiners.

Since 2018, the Institute has hosted and supervised over 40 students during their 'Scholarly Project Module'. This module is intended to develop students' research, critical appraisal and clinical reasoning skills and constitutes an integral part of their lifelong professional development that leads them to become doctors as well as scholars and scientists. The students supervised specifically elected to undertake their project on palliative and end of life care topics and then deliver a presentation based on their work.

Electives and placements

Elective placements are regularly undertaken at Guy's, King's and St Thomas' by overseas medical, nursing and allied health students. Programmes of study are individually tailored with time shared across the clinical and academic departments as well as Trinity Hospice and St Christopher's Hospice.

Specialty training in palliative medicine

Dr Shaheen Khan is Chair for the London Specialist Training Committee. Dr Polly Edmonds is deputy chair of the Specialist Assessment Committee for Palliative Medicine. Professor Higginson is on the exam board for the Royal College of Physicians examination in Palliative Medicine. These posts have contributed to substantial improvements across several domains of the General Medical Council trainee survey, including clinical supervision, handover and workload.

Visitor programme

The Institute has welcomed individuals or groups, be they academics or health professionals from a range of backgrounds and all 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, Europe, Denmark, Germany, France and Italy, and beyond (Canada, China, Jordan, Singapore, South Korea, Taiwan, Turkey and the USA). The clinical team at King's College Hospital similarly host visitors that have included four MSc students from Parma University, Italy.

Widening Participation Summer School

In late July 2019, we ran for the first time a 'Widening Participation' event as part of the Medical School's Summer School for local state school children who are considering a career in medicine and health-related professions. Over 25 students attended the fun and highly interactive afternoon. In addition to having a gentle and general introduction to palliative and end of life care, health and social care professionals explained their motivations for working in palliative care and what their training involved.

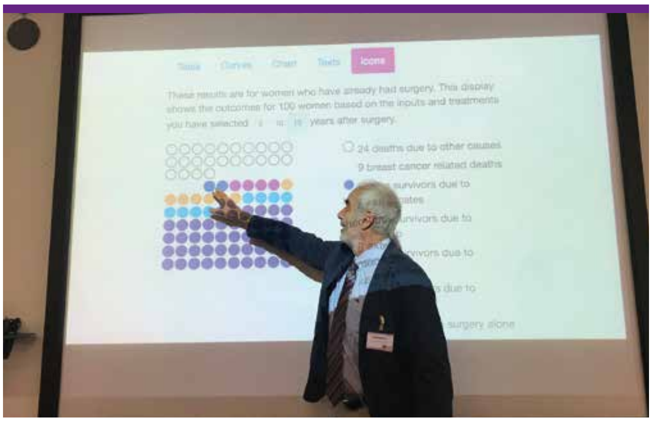
The Cicely Saunders Institute Seminars, workshops and Annual Lectures

Many people have attended our events either physically at the Institute or increasingly remotely through video-links. We facilitate and optimise opportunities for local, national and international networking to improve practice, education and policy. This is exemplified in our knowledge exchange seminars previously supported by the South London NIHR CLARHC and now South London NIHR Applied Research Collaboration (ARC) that works closely with the ARC East of England. Speakers are invited as individuals leading in their respective fields, undertaking cutting-edge research with clinical practice and/or methodological advancements.

During the past three years, the Open Seminar Series has 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. In 2018, to mark the centenary of Cicely's birth and her remarkable contributions to the field of palliative care, we curated a series of events, lectures and workshops to celebrate her life and showcase the on-going development of palliative care, both in the UK and internationally.

2018

- "Nothing about us without us: Including people with learning disabilities" by Irene Tuffrey-Wijne, Associate Professor, Kingston & St George's University and Amanda Cresswell, Co-Researcher.
- "New Palliative care outcome scale (POS) two-day clinical and research workshop". Various speakers, including Professor Irene Higginson, King's College London.
- "Hospice and Palliative Care in the USA: Policy Update and Future Challenge" by Dr Pedro L Gozalo, Health Economist at Center for Gerontology and Health Care Research, and Associate Professor of Health Services, Policy and Practice (Research), Brown School of Public Health, USA.
- "Examining Differences in US Hospice Care Experiences by Profit Status Using the CAHPS Hospice Survey" by Marc Elliot, Senior Principal Researcher and Distinguished Chair in Statistics at RAND.
- "Reciprocal Relationships and the Importance of Patient and Public Feedback in Health Research" by Dr Elspeth Mathie, Senior Research Fellow at CRIPACC (Centre for Research in Public Health and Community Care), University of Hertfordshire.
- "Integrating Palliative and Critical Care: Lessons from Recent Trials" by Professor J. Randall Curtis, Harborview Medical Canter, University of Washington, Seattle, USA.
- Michal Galazka International Study One-day International Study Day entitled "New Frontiers, New Technologies" with international speakers on use of technology in health care including remote monitoring in the community, wearables, the global aspects of technology in different locations, and the opportunities for big data and outreach presented by technology.
- "Why missing data matter" by Dr Jamilla Hussain, NIHR Doctoral Research Fellow, Hull York Medical School.
- "Assisted Ventilation to Prolong Life: A Matter of Choice" by Professor Louise



Professor David Spiegelhalter presenting at Michal Galazka International Study Day The transformative power of big data in health care, 2019.

Rose, Sunnybrook Health Sciences Centre, Canada and King's College London.

- "Episodic Disability, Rehabilitation and Chronic Disease: Lessons Learned from the Field of HIV and Ageing" by Professor Dr Kelly O'Brien, University of Toronto.

- "Health, till death do us part? Impact of spousal bereavement on health and mortality among older adults in Sweden" by Lucas Morin, Aging Research Center of Karolinska Institute, Stockholm.

2019

- Palliative care outcome scale (POS) two-day clinical and research workshop. Various speakers, including Professor Irene Higginson, Dr Mev Hocaoglu, King's College London.

- "Rehabilitation and palliative care – companions, competitors or collaborators?" Professor Derick Wade, Consultant in Neurological Rehabilitation, Oxford Brookes University.

- "Uncovering the contributions and costs of family caregiving towards the end of life" by Professor Gunn Grande, Division of Nursing, Midwifery and Social Care, University of Manchester.

- "Doctors need to believe in miracles too: truth-telling about therapeutic aims of cancer treatments" by Professor Dame Lesley Fallowfield, SHORE-C, Brighton & Sussex Medical School Care, University of Sussex.

- "Global Health Palliative Care: partnerships, evidence and mutual benefit" by Professor Richard Harding, Herbert Dunhill Chair in Palliative Care and Rehabilitation, Cicely Saunders Institute, King's College London.

- "The Namaste Care intervention for people with advanced dementia living in care homes: findings from a feasibility cluster RCT" by Professor Katherine Froggatt, International Observatory on End of Life Care, Lancaster University.

- "Using connected datasets to deliver system-wide insights: a matched analysis of health and social care costs at the end of life" by Dr Jenny Shand, University College London.

- "The role of effective self-management in person centred care" by Professor Barby Singer, Edith Cowan University, Perth, Australia.

- "Volunteers and Palliative Care Provision: What is the evidence of their effect?" by Professor Catherine Walshe, International Observatory on End of Life Care, Lancaster University.

- "Measuring Outcomes in children with serious illnesses and their families: What matters" by Eve Namasango, Cicely Saunders Institute, King's College London.

- "Guidance on how to develop complex interventions to improve health and healthcare" by Professor Alicia O'Cathain School of Health and Related Research, University of Sheffield.

2020

- "Using human-centred design to mitigate the impact of neoliberalism on burdensome end of life care" Dr Liz Dzeng, University of California, San Francisco, USA.

- "Interdisciplinary research, my journey and insights", by Professor Dame Jessica Corner, University of Nottingham.

- "How opening a shop helped us learn to talk about death" Nick Hillier and Holly Rogers, Academy of Medical Sciences.

- "The ImproveCare study: Six lessons from a feasibility cluster RCT of the AMBER care bundle for patients in hospital setting" Dr Jonathan Koffman, Cicely Saunders Institute, King's College London.

The Expert Panel discussion on grief and loss at the Greenwood Theatre.

The Cicely Saunders Annual Lecture

This is a highlight of our annual educational calendar and is presented by an international leader in the field. In July 2018, Rabbi Baroness Julia Neuberger DBE, Senior Rabbi, West London Synagogue gave a lecture entitled 'Improving End of Life Care: lessons learned, what now, what next?' where she spoke of the lessons learned from the Independent inquiry into the Liverpool Care Pathway for the Dying Patient.

In October 2019 Joan Teno, Professor of Medicine at Oregon Health & Science University gave a lecture titled 'Got quality? The urgent need to focus on quality and not solely costs'. At both events, we welcomed over 100 guests physically at the Institute including representatives from the media, policymakers, patients and carers. We also provide outside video links to partners sites across the United Kingdom, Europe, USA and Africa.

Cicely Saunders International Annual Lecture 2019

'Got quality? The urgent need to focus on quality and not solely costs'

Mon 7th Oct 2019

17.00 - 18.30 BST

Cicely Saunders Institute
King's College London
Bessemer Road
London, SE5 9PJ

by Dr Joan Teno

Professor of Medicine at Oregon Health & Science University, Adjunct Professor of Health Systems, Policy, and Practice, Brown School of Public Health.

Cicely Saunders International Annual Lecture 2019 Poster.

In November 2020, the Annual Lecture will be held virtually for the first time and will focus on the impact of the COVID-19 pandemic on palliative care. Dr Eve Namisango, Professor Steven Pantilat and Professor Irene Higginson will present 'Palliative Care in an era of COVID-19: Perspectives from three continents'.

A conversation starter around loss, grief & bereavement

The Cicely Saunders Institute held an exciting new *'Conversation Starter'* event around the often-taboo subject of grief and loss, as part of Dying Matters Week in May 2018. Over 100 people, including members of the public, patients, carers and healthcare professionals, came together for a theatrical performance entitled *'Sisters, Seagulls and Send Offs'* at the Greenwood Theatre, London performed by the Haylo Theatre Company. The evening was introduced by Baroness Ilora Finlay of Llandaff (Professor of Palliative Medicine and cross-bench member of the House of Lords). The evening then continued with an expert panel discussion, chaired by Baroness Ilora Finlay with experts with professional and personal experience relevant to our theme of loss, grief, and bereavement, and the arts, including a clinical academic in palliative care, representatives from bereavement organisations, and a cultural expert. Audience members reflected on their personal experiences of the deaths of loved ones and the complex emotions associated with loss.

Clinical services

> ‘Clinical Academic Groups join up experts in their field to offer patients the very best care and treatment. Palliative Care is the perfect example of these groups successfully turning evidence into practice. They really get the importance of bringing together research, education and clinical excellence to achieve the best possible quality of care for patients and their families during the most challenging of times.’

Professor John Moxham, Director of Value Based Healthcare at King’s Health Partners

Palliative care services

The clinical palliative care services affiliated to 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, and in the communities of Lambeth and Southwark. Our clinical teams operate 24/7 and receive over 4,000 referrals each 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 a number of ways. Our patients have outcome measures routinely collected and all are screened for recruitment into ongoing palliative care and research studies. We are one of the top weighted recruiters within King's into the national Clinical Research Network studies. Further details of our annual activity can be found in our annual reports.

We continue to have close working relationships with all of 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 and innovation, translational research and leading 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 (see Education and capacity building).

Clinical and academic integration has strengthened through the formal recognition of Palliative care as a Clinical Academic Group (CAG) within King's Health Partners in 2017. Prof Irene Higginson, Dr Shaheen Khan and Dr Wendy Prentice are 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). Our programme of joint journal clubs, clinical academic division and forum meetings and clinical evidence updates / team meetings allows regular exchange of information and ideas. The bi-annual Knowledge Exchange Seminars were relaunched under the CAG in 2018 and to date have delivered three excellent interactive

King's College Hospital Staff at the Cicely Saunders Institute.

events allowing for discussion and dissemination of latest evidence underpinning clinical practice.

We pioneered a Breathlessness Support Service joint with respiratory medicine, which the Health Innovation Network are picking up for wider roll out across London. This influenced other services locally to be more informed and better equipped to manage breathlessness.

Bereavement follow-up is provided to friends and relatives of all patients known to the service, and 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.

The excellent foundations in place across all areas of our tripartite agenda (clinical care, research and education) facilitated a rapid response to the COVID-19 global pandemic in spring 2020 (see Partnerships and engagement). This was a hugely challenging time for palliative care services in our area with a 400% increase in referrals and rapid adaptions required. The strengths of our well-established teams and clinical academic links allowed an excellent response to the situation ensuring high quality palliative care support was available to all those patients and families who required it alongside support for staff both in hospital and in the community.

Guys and St Thomas' Staff.

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. The environment is welcoming and accessible to all, respectful of privacy and dignity, supportive to users' comfort and well-being, and listens to the voice of users.

Rehabilitation services

Specialised neurorehabilitation following trauma and complex neurological illness/injury is provided across London by a network of eight provider units, two of which are integrated with the Institute. The Regional Rehabilitation Unit (RRU) at Northwick Park Hospital, directed by Professor Lynne Turner-Stokes, is an affiliated unit of King's College London. It provides inpatient and outreach neurorehabilitation for a catchment population of over 15 million, spanning London and the Home Counties. The consultant-led rehabilitation teams in both services provide fully coordinated inter-disciplinary rehabilitation in a range of different service models including inpatient and outreach rehabilitation. They support a range of district specialist rehabilitation services and community-based teams, as well as linking with a number of specialist nursing homes to provide life-long residential care for patients with long term conditions resulting in complex neurological disability. The Frank Cooksey Rehabilitation Unit (FCRU) based at Lewisham Hospital, is the King's Health Partners specialist neurorehabilitation service.

Service innovations include:

- Our Specialist Community Outreach Team, who provide advice, support and spasticity intervention for people with complex neurodisability and their carers.

Above and below: Attendees at our international rehabilitation study day, Sept 2018.

- 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 care when required.

- Systems to review and re-evaluate patients with prolonged disorders of consciousness. The team helped develop the recent guidelines produced by the Royal College of Physicians.

- Spasticity management by the consultant physiotherapist supported by the rehabilitation medicine consultants, with a systematic method of recording the process and outcome of intervention, informing National guidelines.

- A clinic and integrated care pathway for hemiplegic shoulder pain which has developed a model of pain management for patients post stroke and acquired brain injury.

Through our links with Integrated Care at Guy's and St Thomas', our community services also work closely with colleagues in all rehabilitation and reablement services in Lambeth and Southwark for the benefit of our patients.

Staff and contributions to the disciplines

Staff lists 2017–20

Academic

- **Dr Sabrina Bajwah** Senior Clinical Lecturer
- **Dr Katherine Bristowe** Herbert Dunhill Lecturer
- **Dr Mendy Dzingina** Lecturer
- **Dr Clare Ellis-Smith** Lecturer
- **Dr Catherine Evans** NIHR Senior Clinical Fellow and Reader in Palliative Care
- **Prof Gao Wei** Professor of Statistics and Epidemiology
- **Prof Richard Harding-Swale** Herbert Dunhill Professor
- **Dr Lesley Henson** NIHR Clinical Lecturer
- **Prof Irene Higginson** Professor of Palliative Care & Policy
- **Dr Jonathan Koffman** Reader in Palliative Care
- **Dr Matthew Maddocks** Senior Lecturer in Health Services Research
- **Prof Charles Normand** Professor of Economics of Palliative Care and Rehabilitation
- **Prof Toby Prevost** Nightingale-Saunders Chair in Complex Clinical Trials and Statistics
- **Dr Lucy Selman** Cicely Saunders International Faculty Scholar
- **Dr Katherine Sleeman** NIHR Clinician Scientist and Clinical Reader in Palliative Medicine
- **Prof Lynne Turner-Stokes** Northwick Park Professor of Rehabilitation Medicine

Researchers

- **Tofunmi Aworinde** PhD Training Fellow
- **Venetia Baker** Research Assistant
- **Dr Joanne Bayly** Research Associate
- **Abdelhamid Benalia** Research Assistant
- **Dr Anna Bone** Research Associate
- **Dr Sabah Boufkhed** Research Associate
- **Dr Debbie Braybrook** Research Associate
- **Lisa Jane Brighton** PhD Fellow
- **Dr Dot Brown** Research Associate
- **Dr Emeka Chukwusa** Research Associate
- **Dr Laura Cottrell** Research Associate
- **Rachel Cripps** Research Project and Coordination Assistant
- **Joanna Davies** Dunhill Medical Trust PhD training fellow
- **Marsha Dawkins** NIHR Predoctoral Clinical Academic Fellow
- **Bethany Edwards** Research Assistant
- **Alice Firth** PhD Fellow
- **Dr Simon Etkind** PhD Fellow
- **Lucy Fettes** PhD Fellow
- **Maja Furlan de Brito** Research Assistant
- **Dr Barbara Gomes Da Silva** Research Fellow
- **Dr Ping Guo** Research Associate
- **Dr Nilay Hepgul** Research Fellow
- **Dr Mevhibe Hocaoglu** Research Associate
- **Halle Johnson** Research Project and Coordination Assistant
- **Anna Johnston** Research Project and Coordination Assistant
- **Javiera Leniz Martelli** PhD Fellow
- **Dr Cheng-Pei Lin** Research Associate
- **Dr Natasha Lovell** PhD Fellow
- **Dr Stephen Marshall** Research Associate
- **Silvia Miele** Research Project and Coordination Assistant
- **Dr Rohan Mongru** Clinical Research Training Fellow

- **Dr Kennedy Nkhoma** Research Associate
- **Dr Adejoke Oluyase** Research Associate
- **Sophie Pask** Research Assistant
- **Clarissa Penfold** Research Assistant
- **Cathryn Pinto** Research Assistant
- **Anna Roach** Research Project and Coordination Assistant
- **Dr Liadh Timmins** Research Associate
- **Dr Dominique Wakefield** NIHR Academic Clinical Fellow
- **Dr Lesley Thoms** PhD Fellow
- **India Tunnard** Research Project and Coordination Assistant
- **Richard Turner** Research Assistant
- **Dr Anna Weil** Clinical Research Training Fellow
- **Dr Rebecca Wilson** Research Associate
- **Dr Deok Hee Yi** Health Economist
- **Ka Man Yip** Research Assistant
- **Emel Yorganci** PhD Fellow
- **Peihan Yu** Research Assistant

Clinical

KCH Staff

- **Paula Alves de Oliveira** Practice Development Nurse
- **Cathy Woollard** Specialist Palliative Care Service Delivery Manager
- **Professor Rob George** Consultant
- **Dr Sabrina Bajwah** Senior Clinical Lecturer
- **Leanne Boyle** Clinical Nurse Specialist
- **Debbie Brown** Clinical Nurse Specialist
- **Chris Bridges** Clinical Nurse Specialist
- **Dr Rebecca Bright** Registrar
- **Dr Rachel Burman** Consultant and Honorary Senior Lecturer
- **Dr Matthew Carey** Consultant
- **Dr Rosemary Chester** Consultant
- **Kay Casson** Clinical Nurse Specialist
- **Lyn Chandler** Clinical Nurse Specialist Palliative Care
- **Dr Martin Davidson** Consultant
- **Dr Polly Edmonds** Consultant and Honorary Senior Lecturer
- **Dr Simon Etkind** Consultant
- **Dr Louise Exton** Consultant
- **Dr Stephanie Hicks** Consultant
- **Amanda Holland** Practice Development Nurse
- **Laura Harris** Matron
- **Dr Lesley Henson** Consultant
- **Prof Irene Higginson** Honorary Consultant in Palliative Medicine
- **Connie Jackson** Clinical Nurse Specialist
- **Jennifer Karno** Matron
- **Elizabeth Lammie** Social worker
- **Dr Jasmine Lee** Consultant
- **Dr Natasha Lovell** Consultant
- **Dr Beth Mackay** Consultant
- **Dr Lynne Marsh** Consultant
- **Dr Steve Marshall** Social Worker

CSI Staff at Gardening Club, 2019.

PhD celebratory meal, 2019.

- **Jennifer Morris** Social Worker
- **Prof Fliss Murtagh** Honorary Consultant in Palliative Medicine
- **Nicola Oldcroft** Social Worker
- **Dr Georgina Osbourne** Consultant
- **Dr Rishma Pau** Consultant
- **Dr Wendy Prentice** Consultant and Honorary Senior Lecturer
- **Dr Amy Proffitt** Honorary Consultant
- **Dr Fiona Ring** Consultant
- **Cristi Sheridan** Clinical Nurse Specialist
- **Dr Katherine Sleeman** Honorary Consultant
- **Ann Southwell** Team Administrator
- **Sarah Spencer-Adams** Clinical Nurse Specialist
- **Regina Steer** Clinical Nurse Specialist
- **Helen Stephens** Clinical Nurse Specialist
- **Dr Ruth Ting** Consultant in Palliative Care
- **Dr Richard Towers** Matron
- **Esther Willson** Palliative Care Practice Development Nurse

GSTT Staff

- **Dr Shaheen Khan** Consultant and Clinical Director
- **Dr Teresa Beynon** Consultant
- **Dr Irene Carey** Consultant
- **Dr Nick Gough** Consultant
- **Dr Samantha Jayasekera-Heffer** Consultant
- **Helen Thurkettle** Consultant Nurse
- **Dr Vandana Vora** Consultant
- **Steven Wanklyn** Consultant Pharmacist
- **Alexandra Adesanmi** Service Manager
- **Louise Farrow** Deputy Head of Nursing
- **Parveen Akhtar** Matron
- **Jo Beighton** Matron
- **Marsha Dawkins** Matron

Professional services

- **Gilda Andreani** EA to Professor Higginson
- **Sian Best** Administrative Director
- **Fern Brookes** Research Administrator
- **Louise Coulson** Administrator to C-CHANGE
- **Charlotte Faint** Research PA to Professor of Neurorehabilitation
- **Victoria Grey-Edwards** EA to Professor Higginson
- **Daniel Gulliford** PA to Dr Wei Gao/ Project Administrator
- **Malgorzata Kaminska** Data Entry Coordinator
- **Ashwiny Oulagambal Kistnareddy** EA to Professor Higginson/Department Manager
- **Lara Klass** Project Administrator
- **Virginie Lambertucci** Research Projects Administrator

Macmillan Centre Bake Sale, September 2019.

- **Taysha Morgan** PA to Professor Harding
- **Karen Murphy** EA to Professor Higginson
- **Veronica Murrey** PA to Professor Harding
- **Lelia Oniri** Projects Administrator
- **Deborah Tonkin** Institute Business Manager
- **Sophie Watson** PA to Professor Higginson/ Department Administrator
- **Alanah Wilkinson** Research Administrator
- **Mark Willis** MSc Administrator
- **Katie Witcombe** Outreach Administrator
- **Charlotte Wood** Executive Assistant/ Administrator

Macmillan Centre Staff

- **Michelle Goode** Macmillan Information & Support Centre Manager
- **Nicola Murphy** Macmillan Support Worker
- **Lindsay Farthing** Macmillan Support Worker
- **Kathryn Hair** Macmillan Support Worker

PhD students

- Dr Mary Abboah-Offei*
- Oladayo Afolabi
- Tofunmi Aworinde
- Dr Jo Bayly*
- Dr Anna Bone*
- Lisa Brighton
- Lucy Coombes
- Joanna Davies
- Dr Mendy Dzingina*
- Dr Clare Ellis-Smith*
- Dr Simon Etkind*
- Fei Fei
- Lucy Fettes
- Juliet Gillam
- Alessandra Giusti
- Dr Lesley Henson*
- Sameera Helal
- Dr Pauline Kane*
- Megumi Kishino
- Dr Cheng-Pei Lin*
- Houshen Li
- Dr Natasha Lovell*
- Javiera Martelli
- Dr Eve Namisango*
- Dr Jen-Kuei Peng*
- Dr Christina Ramsenthaler*
- Dr Lesley Thoms
- Emel Yorganci

Honorary appointments

- Dr Bárbara Antunes
- Dr Stephen Ashford
- Prof Claudia Bausewein
- Dr James M Beattie (joint with CSI and King's School of Cardiovascular Medicine & Sciences)
- Dr Sara Booth
- Dr Teresa Beynon
- Prof Massimo Costantini
- Prof Julia Downing
- Dr Marjolein Gysels
- Dr Sue Hall
- Dr Farida Malik
- Prof Miyashita Mitsunori
- Dr Emma Murphy
- Dr Fliss Murtagh
- Prof Richard Siegert
- Dr Steffen Simon
- Reverend Dr Peter Speck
- Dr Vicky Simms
- Dr Liesbeth van Vliet

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* Denotes completed

Contributions to the discipline

- We **collaborate** across six of the seven continents of the globe. Our staff have active collaborations with >100 universities and research institutes internationally and all UK universities with palliative care programmes. Examples include: UK: Lancaster University, University College London, University of Nottingham, The University of Edinburgh, University of Oxford, University of Manchester, University of Hull, University of York; Europe: University of Copenhagen, The European Palliative Care Research Centre (PRC) Norway, University College Dublin, Trinity College Dublin, Azienda Unità Sanitaria Locale di Reggio Emilia, University Hospital of Cologne, Ludwig-Maximilians-Universität München, Minsk State Hospice, Belarus; Africa: African Palliative Care Association, University of Cape Town; University of Zimbabwe, Hospice Africa Uganda, Island Hospice & Healthcare, Zimbabwe, College of Medicine, Malawi, Greater Accra Regional Hospital, Ghana; Americas: Harvard University, University California San Francisco, Memorial Sloan-Kettering Cancer Centre, Weill Medical College of Cornell University, The University of Texas MD Anderson Cancer Centre, University of Manitoba, Brown School of Public Health; Asia-Pacific: Mahidol University National Cancer Hospital, Marmara University, Thailand, Auckland University of Technology, University of Otago, University of Technology Sydney, Ho Chi Minh City Oncology Hospital Vietnam, Huazhong University of Science & Technology.

- Members of the Institute staff serve on **editorial and advisory boards** and regularly review for top international journals within and beyond palliative care and rehabilitation. These include: Journal of Palliative Medicine, Palliative Medicine, Journal of Palliative Care, Journal of the Royal Society of Medicine (Higginson); AIDS Care, Journal of Pain & Symptom Management (Harding); BMC Palliative Care, Frontiers in Human Neuroscience, Health and Quality of Life Outcomes (Gao); PLOS One (Evans); Journal of Palliative Medicine, Palliative Medicine Reports, Frontiers in Rehabilitation (Maddocks).

- Staff serve on **grant panels** for national, regional and international governmental bodies, statutory organisations and charities, to aid their assessment and support for palliative care and rehabilitation, and to improve research quality. These include: Irish Health Research Board, Research Council of Norway, Wellcome Trust, NIHR (Normand); NIHR COVID Recovery and Learning, NIHR Public Health Research Funding, NICE Public Health (Prevost), NIHR programme grants for applied research; European Commission, Horizon 2020 (Wei); NIHR Joint DHSC/UKRI Global Effort of COVID-19 Health Research (Evans), Marie Curie Research Grants (Koffman, Evans); Royal Marsden Partners Pan-London Fellowships (Sleeman).

- We undertake **advisory and consultancy roles** for discipline specific, professional and health and social care organisations, across government, charities and industry in the UK and internationally. Examples include: European Region of WHO, Steering Committee of the European Observatory on Health Systems and Policies, Centre of Ageing Better (Normand), European

Palliative Care Leadership Academy or EUPCA (Koffman, Evans), Danish Ministry on ageing (Ellis-Smith), National Institute for Clinical Excellence (Prevost), Fresenius Kabi, Helsinn, Council for Allied Health Professions Research (Maddocks), Docobo (Evans), MS Trust (Koffman), WHO, UK government on LGBT Health (Harding).

- Several **prizes and honours** have been awarded including: European Association of Palliative Care award for “Women in Palliative Care”, Winston Churchill Memorial Trust fellowship 2020 (Sleeman), 2018 BMJ Awards Research Paper of the Year finalist (Prevost), 2019 Highly Cited Researchers List from the Web of Science Group (Higginson), CLARHC 2018 Most Original Research Paper (Ellis-Smith), “Most active contribution from a member of professional services staff” (Johnson), Fellowship of Chartered Society of Physiotherapy (Ashford).

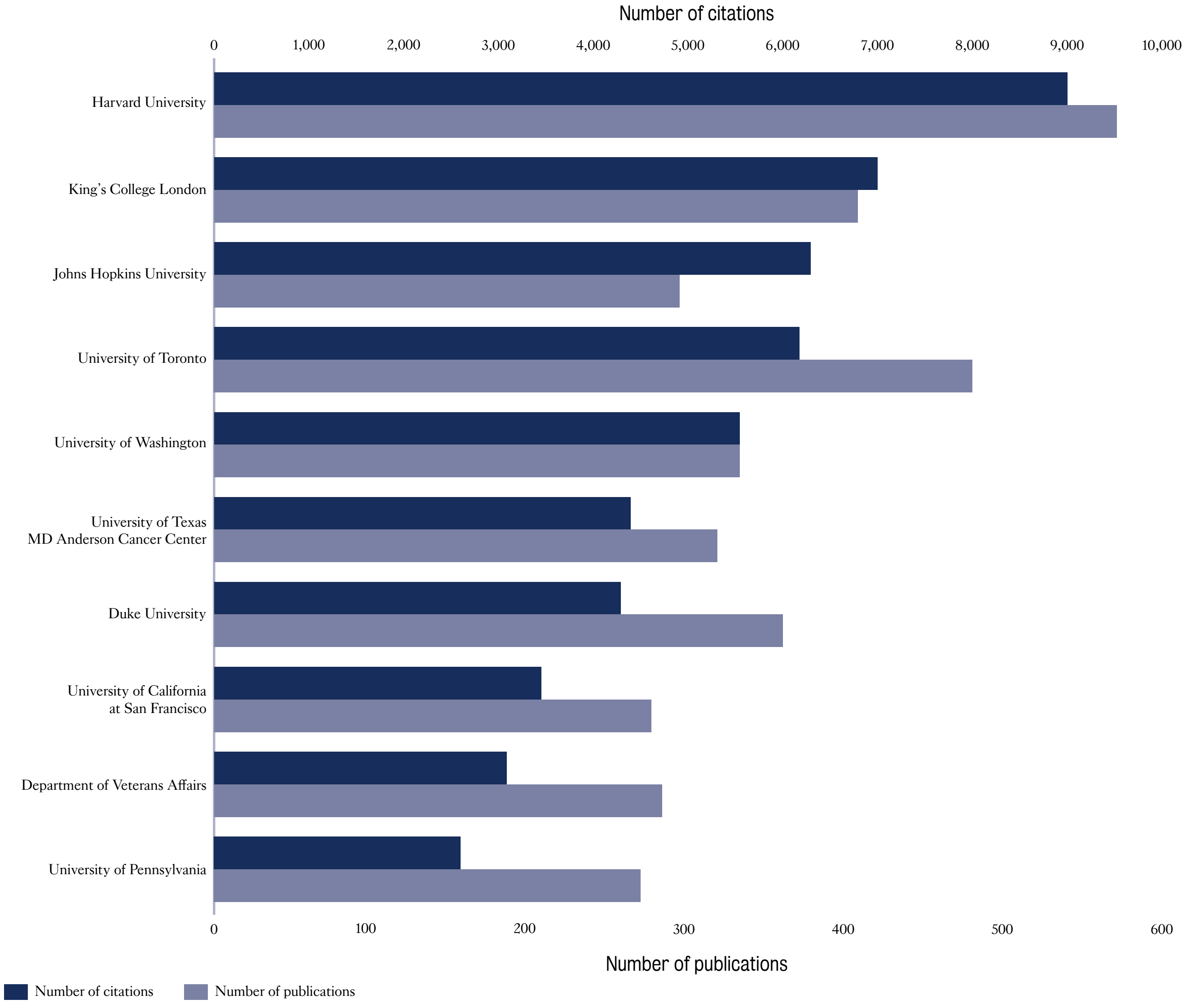
Birches in the Cicely Saunders Institute, created by artist Tania Kovats.

Education stand with brochures and materials for our programmes.

Publications

Independent analysis finds that our publications are first in Europe and second in the world (to Harvard) for citations of research in palliative care (Figure 33). Our top research and education outputs, by journal impact factor and percent in field, are shown in the following tables.

Figure 33. Research output (publications and citations) for the top ten institutions globally based on the research filter 'palliative care' searched in the SciVal Database (Elsevier) for 2014 to 2020 (as at 1 September 2020)



Source: SciVal, 2020.

Table 5. Top Research Publications (2017–2020) by Journal Citation Report Impact Factor

Title	Authors	Year	Journal	Impact Factor
Population-Based Quality Indicators for End-of-Life Cancer Care: A Systematic Review	Henson L.A, Edmonds P, Johnston A, Johnson H.E, Ng Yin Ling C, Sklavounos A, Ellis-Smith C, Gao W	2020	JAMA Oncology	24.799
The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions	Sleeman K.E, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson I.J, Gomes B, Harding R.	2019	The Lancet Global Health	21.597
Economics of palliative care for hospitalized adults with serious illness: A meta-analysis	May P, Normand C, Cassel JB, Del Fabbro E, Fine RL, Menz R, Morrison CA, Penrod JD, Robinson C, Morrison RS	2018	JAMA Internal Medicine	18.652
Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data	Sleeman K.E, Perera G, Stewart R, Higginson I.J	2018	Alzheimer's and Dementia	17.127
Place of death and factors associated with hospital death in patients who have died from liver disease in England: A national population-based study	Peng J.-K, Higginson I.J, Gao W	2019	The Lancet Gastroenterology and Hepatology	14.789
Safety of benzodiazepines and opioids in interstitial lung disease: A national prospective study	Bajwah S, Davies J.M, Tanash H, Currow D.C, Oluyase A.O, Ekström M	2018	European Respiratory Journal	12.339
Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis	Davies J.M, Sleeman K.E, Leniz J, Wilson R, Higginson I.J, Verne J, Maddocks M, Murtagh F.E.M	2019	PLoS Medicine	10.5
Holistic services for people with advanced disease and chronic breathlessness: A systematic review and meta-analysis	Brighton L.J, Miller S, Farquhar M, Booth S, Yi D, Gao W, Bajwah S, Man W.D, Higginson I.J, Maddocks M	2018	Thorax	8.834
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 I.J, Wilcock A, Johnson M.J, Bajwah S, Lovell N, Yi D, Hart S.P, Crosby V, Poad H, Currow D, Best E, Brown S	2020	Thorax	8.834
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	2020	Cochrane Database Syst Rev.	7.89

Title	Authors	Year	Journal	Impact Factor
Processes of consent in research for adults with impaired mental capacity nearing the end of life: Systematic review and transparent expert consultation (MORECare_ Capacity statement)	Evans C.J, Yorganci E, Lewis P, Koffman J, Stone K, Tunnard I, Wee B, Bernal W, Hotopf M, Higginson, I.J, Tanner D, Henry C, Grande, G, Dewar S, Owen G, Burman R, Adamis D, Dunn M, Kim S, Woods S, Vohora R	2020	BMC Medicine	6.782

Source: The Journal Citation Reports, 2020.

Table 6. Research Publications (2017–2020) in Top Citation Percentile by Field-Weighted Citations

Title	Authors	Year	Journal	Percentile
What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death	Bone A.E, Gomes B, Etkind S.N, Verne J, Murtagh F.E.M, Evans C.J, Higginson I.J	2018	Palliative Medicine	1
Economics of palliative care for hospitalized adults with serious illness: A meta-analysis	May P, Normand C, Cassel JB, Del Fabbro E, Fine RL, Menz R, Morrison CA, Penrod JD, Robinson C, Morrison RS	2018	JAMA Internal Medicine	1
The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions	Sleeman K.E, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson I.J, Gomes B, Harding R	2019	The Lancet Global Health	1
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	Etkind S.N, Bone A.E, Lovell N, Cripps R.L, Harding R, Higginson I.J, Sleeman K.E	2020	Journal of Pain and Symptom Management	1
Characteristics, Symptom Management, and Outcomes of 101 Patients With COVID-19 Referred for Hospital Palliative Care	Lovell N, Maddocks M, Etkind S.N, Taylor K, Carey I, Vora V, Marsh L, Higginson I.J, Prentice W, Edmonds P, Sleeman K.E	2020	Journal of Pain and Symptom Management	1
Symptom prevalence and quality of life of patients with end-stage liver disease: A systematic review and meta-analysis	Peng J.-K, Hepgul N, Higginson I.J, Gao W	2019	Palliative Medicine	2
Electronic palliative care coordination systems (EPaCCS): A systematic review	Leniz J, Weil A, Higginson, I.J, Sleeman K.E.	2020	BMJ Supportive and Palliative Care	3
Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data	Sleeman K.E, Perera G, Stewart R, Higginson I.J	2018	Alzheimer's and Dementia	4

Title	Authors	Year	Journal	Percentile
Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta analysis	Davies J.M, Sleeman K.E, Leniz J, Wilson R, Higginson I.J, Verne J, Maddocks M, Murtagh F.E.M	2019	PLoS Medicine	4
The conceptual models and mechanisms of action that underpin advance care planning for cancer patients: A systematic review of randomised controlled trials	Lin C.-P, Evans C.J, Koffman J, Armes, J, Murtagh F.E.M, Harding R	2019	Palliative Medicine	4
Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study	Bristowe K, Hodson M, Wee B, Almack K, Johnson K, Daveson B.A, Koffman J, McEnhill L, Harding R	2018	Palliative Medicine	5
Holistic services for people with advanced disease and chronic breathlessness: A systematic review and meta-analysis	Brighton L.J, Miller S, Farquhar M, Booth S, Yi D Gao W, Bajwah S, Man W.D, Higginson I.J, Maddocks M.	2018	Thorax	5
Influences on Care Preferences of Older People with Advanced Illness: A Systematic Review and Thematic Synthesis	Etkind S.N, Bone A.E, Lovell N, Higginson I.J, Murtagh F.E.M.	2018	Journal of the American Geriatrics Society	5
Service Delivery Models to Maximize Quality of Life for Older People at the End of Life: A Rapid Review	Evans C.J, Ison L, Ellis-Smith C, Nicholson C, Costa A, Oluyase A.O, Namisango E, Bone A.E, Brighton L.J, Yi D, Combes S, Bajwah S, Gao W, Harding R, Ong P, Higginson I.J, Maddocks M.	2019	Milbank Quarterly	5
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 N.A, Ansa G, Oppong-Agyei Y.D, Abas M, Higginson I.J, Harding R	2020	AIDS Care – Psychological and Socio-Medical Aspects of AIDS/HIV	5
Population-Based Quality Indicators for End-of-Life Cancer Care: A Systematic Review	Henson L.A, Edmonds P, Johnston A, Johnson H.E, Ng Yin Ling C, Sklavounos A, Ellis-Smith C, Gao W	2020	JAMA Oncology	5

Source: Scopus, 2020.

Table 7. Educational Publications (2017–2020) by Journal Citation Report Impact Factor

Title	Authors	Year	Journal	Impact Factor
Palliative care and management of troublesome symptoms for people with chronic obstructive pulmonary disease	Maddocks M, Lovell N, Booth S, Man W.D, Higginson I.J.	2017	The Lancet	60.392

Title	Authors	Year	Journal	Impact Factor
Knaul FM, Farmer PE, Krakauer EL, De Lima L, Bhadelia A, Kwete XJ, Arreola-Ornelas H, Gómez-Dantés O, Rodriguez NM, Alleyne GAO, Connor SR, Hunter DJ, Lohman D, Radbruch L, María Del Madrigal MDRS, Atun R, Foley KM, Frenk J, Jamison DT, Rajagopal MR, Lancet Commission on Palliative Care and Pain Relief Study Group (including Higginson IJ)	Alleviating the access abyss in palliative care and pain relief – an imperative of universal health coverage: the Lancet Commission report.	2018	Lancet	60,392
Kaasa S, Loge JH, Aapro M, Albreht T, Anderson R, Bruera E, Brunelli C, Caraceni A, Cervantes A, Currow CD, Deliens L, Fallon M, Gómez-Batiste X, Grotmol KS, Hannon B, Haugen DF, Higginson IJ, Hjermstad MJ, Hui D, Jordan K, Kurita GP, Larkin PJ, Miccinesi G, Nauck F, Pribakovic R, Rodin G, Sjøgren P, Stone P, Zimmermann C, Lundeby T.	Integration of oncology and palliative care: a Lancet Oncology Commission.	2018	Lancet Oncology	33,752
Palliative care and the management of common distressing symptoms in advanced cancer: Pain, breathlessness, nausea and vomiting, and fatigue	Henson L.A, Maddocks M, Evans, C, Davidson, M, Hicks S, Higginson I.J	2020	Journal of Clinical Oncology	32.956
Assisted dying: Restricting access to people with fewer than six months to live is discriminatory	Sleeman K, Chalmers I	2019	The BMJ	30.223
Palliative care for patients with severe COVID-19	Ting R, Edmonds P, Higginson I.J, Sleeman K.E	2020	The BMJ	30.223
Universal coverage for palliative care in respiratory disease and critical care	Maddocks M, Higginson I.J	2017	The Lancet Respiratory Medicine	25.094
Palliative care in interstitial lung disease: living well	Kreuter M, Bendstrup E, Russell AM, Bajwah S, Lindell K, Adir Y, Brown CE, Calligaro G, Cassidy N, Corte TJ, Geissler K, Hassan AA, Johannson KA, Kairalla R, Kolb M, Kondoh Y, Quadrelli S, Swigris J, Udwadia Z, Wells A.	2017	The Lancet Respiratory Medicine	25.094
Task-shifting must recognise the professional role of nurses	Afolabi O, Abboah-Offei M, Nkhoma K, Evans C	2019	The Lancet Global Health	21.597
Do we have adequate tools and skills to manage uncertainty among patients and families in ICU?	Harding R, Hopkins P, Metaxa V, Higginson I.J	2017	Intensive Care Medicine	17.679

Title	Authors	Year	Journal	Impact Factor
Palliative care as an essential component of the HIV care continuum	Harding R	2018	The Lancet HIV	14.813
Simple functional tests in COPD: Stand up and be counted!	Maddocks M, Nolan C.M, Man W.D	2017	European Respiratory Journal	12.339
Managing the supportive care needs of those affected by COVID-19	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	European Respiratory Journal	12.339

Source: The Journal Citation Reports, 2020.

Publications in peer reviewed journals 2017 (November–December)

Bhardwaj T, Koffman J. (2017) Non-pharmacological interventions for management of fatigue among children with cancer: systematic review of existing practices and their effectiveness. BMJ Support Palliat Care. 7(4):404–414. doi: 10.1136/bmjspcare-2016–001132.

Bone AE, Gomes B, Etkind SN, Verne J, Murtagh FEM, Evans CJ, Higginson IJ. (2017) What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. Palliat Med. 32(2):329–336. doi: 10.1177/0269216317734435.

Brighton LJ, Koffman J, Hawkins A, McDonald C, O'Brien S, Robinson V, Khan SA, George R, Higginson IJ, Selman LE.J. (2017) A Systematic Review of End-of-Life Care Communication Skills Training for Generalist Palliative Care Providers: Research Quality and Reporting Guidance. J Pain Symptom Manage. 54(3):417–425. doi: 10.1016/j.jpainsymman.2017.04.008.

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MSc alumni 2018 and their research dissertations

Luke Skelton The pharmacological and non-pharmacological management of delirium in palliative care patients: Systematic review.

Richard Cervin How much palliative care does Lithuania need – using an epidemiological, population-based approach?

Natasha Wiggins Understanding the factors associated with patients with dementia achieving their preferred place of death: A retrospective cohort study.

Emma Nicholas A case note review to examine the impact of health and social factors on the place of death in multiple sclerosis patients within the UKMSTB.

Sarah Hanrott Patient experience surveys in palliative care: Attitudes of nursing staff. A qualitative study.

Aine Ni Laoire Financial toxicity in advanced cancer patients in Ireland.

Aoibheann Ni Chonfhaola A qualitative study exploring the experience of staff in homeless accommodation working with homeless people with life limiting illnesses in Dublin, Ireland.

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Usha Ramanthan Effectiveness and cost-effectiveness of advance care planning for adults, with multiple sclerosis, amyotrophic lateral sclerosis or Parkinson's disease, and their caregivers: A systematic review.

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Laura Tupper Satt Palliative care needs assessment and interventions for patients with advanced diseases in the acute medical setting: A systematic review.

Shoko Yamada A systematic review of outcome measures used in home palliative care for older people with non-malignant diseases at the last one to two years of life.

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Nurul Ahmad Sudirman A scoping review of assistive technologies to support independence in palliative care.

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Karina Cately Paramedics' Experience and Perception of the Integration of 'Coordinate My Care' into Prehospital Healthcare Practice: Qualitative Interviews.

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Huei Chung Palliative Care in the Greater China region: A Systematic review using narrative synthesis.

Parisa David Secondary analysis of in-depth qualitative interviews with people who identify as lesbian, gay, bisexual and/or trans to explore communicative strategies in disclosing, and exploring sexual orientation and gender identity in consultation with health care professionals.

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.

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

Rosanna Ellis A systematic literature review to assess the effectiveness and acceptability of psychedelic drugs for the treatment of anxiety and depression in adults with advanced disease.

Melissa Fong Shi Yun Service use, needs, and preferences of frail older people with limited access to palliative care services: secondary analysis of survey data from the IARE II study – question to be developed in conjunction with supervisor.

PeiQi Goh A Systematic Review on Barriers and Facilitators to Rehabilitation in Advanced Disease.

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

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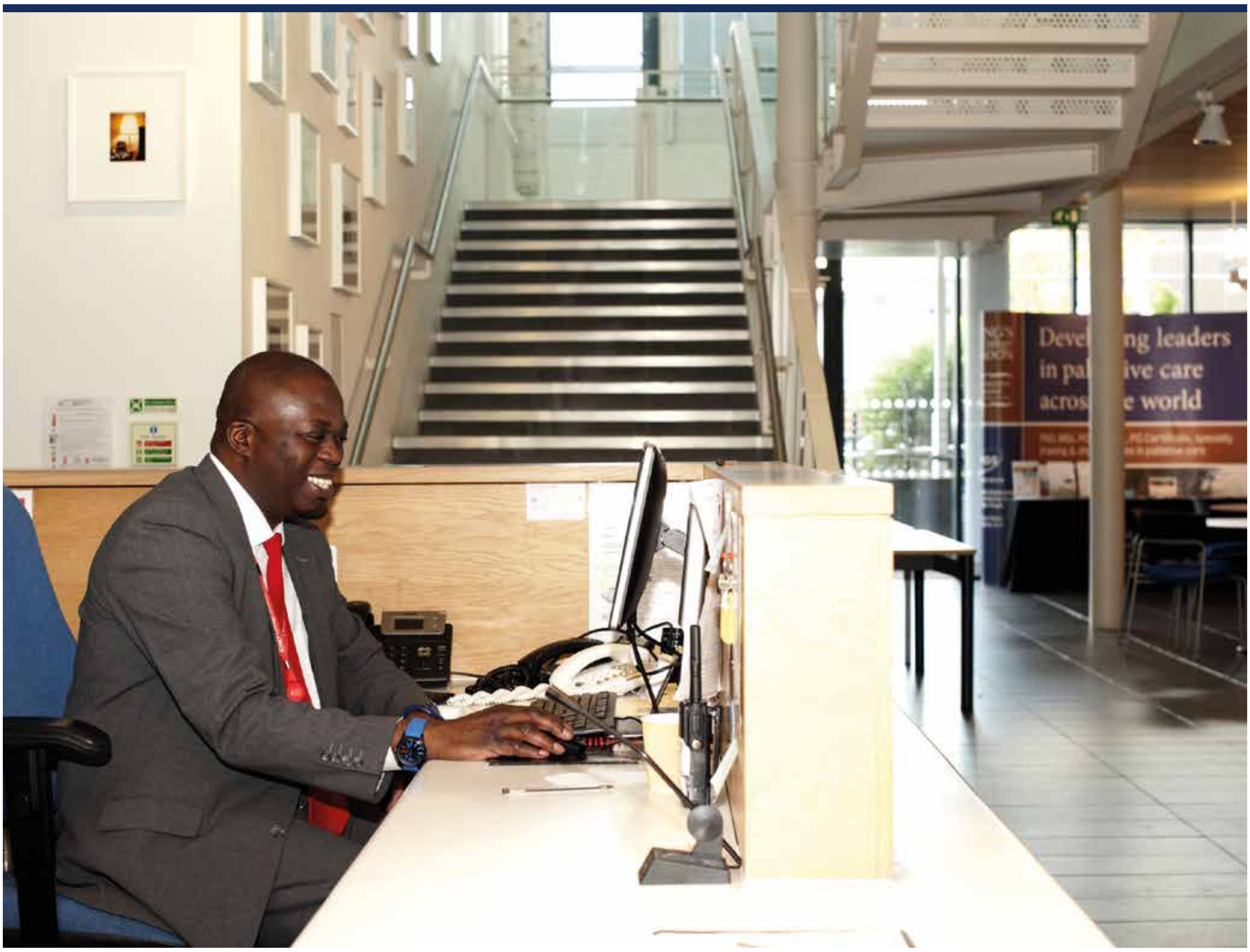
- The Wolfson Foundation
- Thomas Deane Trust
- United States Cancer Pain Relief Committee
- World Health Organization
- Yorkshire Cancer Research

Light for Cicely installation, created by artist Caroline McCarthy.



Reception and foyer in the Cicely Saunders Institute.

> ‘We have to learn how to feel “with” patients without feeling “like” them if we are to give them a kind of listening and steady support that they need to find their own way through.’

Cicely Saunders (2003) ‘Watch with me’ Sheffield:Mortal Press, p3.

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