



Palliative Care Clinical Academic Group

King's Health Partners

King's Health Partners brings together:

- three of the UK's leading NHS Foundation Trusts
- a world-leading university for health research and education
- nearly 4.8 million patient contacts each year
- 40,000 staff
- nearly 30,000 students
- a combined annual turnover of more than £3.7 billion
- services provided across central and south London and beyond, including nine mental health and physical healthcare hospitals and many community sites
- a comprehensive portfolio of high-quality clinical services with international recognition in cancer, diabetes, mental health, regenerative medicine, transplantation, cardiac and clinical neurosciences
- a major trauma centre and two hyper-acute stroke units

About King's Health Partners

King's Health Partners brings together a world-leading university for health research and education, King's College London and three NHS Foundation Trusts Guy's and St Thomas', King's College Hospital and South London and Maudsley.

We are an Academic Health Sciences Centre where world-class research, education and clinical practice are brought together for the benefit of patients.

To support our mission, we are delivering programmes of work to:

- Join up mental and physical healthcare so that we treat the whole person, through our Mind and Body Programme;
- Increase the value of the care we provide, and the outcomes we achieve for our patients and service users through a Value Based Healthcare approach;

- Bring together our partnership's collective strength in a range of specialist services to deliver world-class patient care and research through our institutes programme;
- Developing education, research and capacity building programmes in global health including partnerships with healthcare teams and organisations in Sierra Leone, Somaliland and Zambia.

We are uniquely structured to deliver our mission for excellence. Our 22 Clinical Academic Groups (CAGs) bring together all the clinical services and staff from the three trusts with the relevant academic departments of King's College London.

Foreword



At King's Health Partners we are committed to improving outcomes for our patients and service users and achieving maximum value for money in everything we do. We believe that being open and transparent about the care and outcomes we deliver results in a culture of improvement across our partnership.

This is why we are publishing a series of outcomes books that will help patients, service users, carers, referring clinicians and commissioners to make better-informed decisions. They will also help our staff to drive up the quality of the care we provide. The books report key outcomes for treatments provided by our 22 Clinical Academic Groups (CAGs). CAGs form the building blocks of our Academic Health Sciences Centre. By bringing together our clinical and academic staff across teaching, training and research, we can use their combined expertise to achieve better outcomes for our patients and service users.

Our books are designed for a clinical and lay audience and contain a summary of clinical outcomes, educational activities, research innovations and publications. They also focus on other important measures, such as staff satisfaction and wellbeing.

The primary purpose of King's Health Partners is to improve health and wellbeing locally and globally. We must deliver this goal in a challenging economic environment with rising demand for, and costs of, healthcare. We will only achieve sustainable health improvement if we strive to increase value. We define value in terms of outcomes that matter to patients, over the full cycle of care, divided by the cost of producing those outcomes. By publishing outcomes books, we have more information to support us measuring the value of the healthcare we provide.

Our goal is to use these books to allow us to reflect on and demonstrate where we are driving improvement and innovation.

Please send comments and suggestions to us at kingshealthpartners@kcl.ac.uk.

For more information please visit our website at www.kingshealthpartners.org.

A handwritten signature in black ink that reads "John Moxham".

Professor John Moxham

Director of Clinical Strategy, July 2018

Cicely Saunders International



Our mission is to support a centre of research to improve the care and treatment of all patients with progressive illness and make high quality palliative care available to everyone who needs it, in hospice, hospital or at home.

Cicely Saunders International was established in 2002 by Dame Cicely Saunders OM, DBE, FRCP (1918–2005), to fundraise for a purpose-built centre combining research, education, clinical care, and patient information support. The Cicely Saunders Institute opened in 2010. Today we fund research, education and capacity building programmes at the Institute.

Dame Cicely trained as a nurse, a medical social worker and as a physician. From 1948 onwards, she was involved with the care of patients with terminal illness, lectured widely on the subject, wrote many articles and contributed to a great number of books. She founded St Christopher's Hospice in 1967 as the first research and teaching hospice linked with clinical care, pioneering the field of palliative medicine.






















As Cicely said so eloquently learning is the key to improvement, and the more we can learn about the many complexities of palliative care the more we can do to improve care for patients and their families. Researchers supported by Cicely Saunders International are at the forefront of this work. Bringing in patients' voices can only make research better and more relevant and continuing to innovate is the way we can honour Cicely's legacy and take it forward into the future.

We recognise that an ageing population and increasing pressures on the health service cause everyone involved to think hard about the most effective way to deliver palliative care. Ensuring that the patient's voice is heard alongside the professional's is central to the Institute's purpose. We want to pioneer research to ensure that all people can live well, free of symptoms and with dignity.

John McGrath

Chairman, Cicely Saunders International,
July 2018

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The value of partnership at King's Health Partners

King's Health Partners aims to create a centre where world-class research, education and clinical practice (the 'tripartite mission') are brought together for the benefit of patients.

We want to make sure that the lessons from research are used swiftly, effectively and systematically to achieve better outcomes for patients and those close to them, improve public health and join up health and care services for people with physical and mental health problems.

By working together in this way, integrating care across different organisations and sectors, we can not only improve the health of the people we care for, but also achieve better value for money.

Integrating mental and physical health

The mind and body are inseparable, and mental and physical health conditions are often connected. Mental health illness can have a significant negative impact on physical health. Likewise, many people with long-term physical health conditions and progressive illnesses suffer from depression or other mental health conditions. Despite this, many health services separate care into physical and mental and often fail to share patient information. At King's Health Partners we are working to overcome these barriers by treating the whole person, through our Mind & Body Programme and across all of our CAGs. Focussing on the whole person and those close to them is a core principle of palliative care. We are committed to caring for vulnerable patients with

both physical and mental ill health in an integrated manner with better, faster diagnosis and treatment because we know that addressing mental distress improves physical health outcomes and vice versa. Across all Kings Health Partners we will treat the whole person by:

- screening all patients with chronic physical diseases for mental health conditions, and using the learning from this to improve the care we provide;
- improving our understanding of the physical health needs of people with severe mental ill health;
- addressing the traditional distinctions between the mind and body in research and education allowing us to train students and staff to deliver more integrated care;
- better organising and expanding current training provision for physical and psychiatric comorbidity;
- working with our local commissioners to find new ways of commissioning integrated services;
- linking IT systems across our partner trusts so that clinicians have access to a person's physical and mental healthcare records;
- investing in innovative programmes such as IMPARTS (Integrated Mental and Physical Healthcare: Research, Training and Services), 3DfD (3 Dimensions of care for Diabetes) and 3DLC (3 Dimensions of care for Long-term Conditions);
- recognising the importance of employee mental and physical health and wellbeing.

Public health

Public health is one of our biggest challenges. At the root of much of the ill health in south London is a high incidence of smoking, alcohol abuse and obesity. With our health and social care partners, we are developing strategies to tackle these public health priorities. We are also developing plans for an Institute for Urban Population Health and Care, a collaboration with local partners to bring about transformational change to health in local communities. We want to achieve a measurable improvement and impact on health gain and local management of physical and mental health problems through new evidence-based interventions, supported by our strategies relating to alcohol and tobacco. Palliative care, because illness, dying, and bereavement affect everyone, is regarded a public health challenge, especially ensuring the best access to care for all affected.

Informatics

Informatics is at the heart of our plans to join up care, research and education. Data is one of our most important assets at King's Health Partners and we have unique strengths in using informatics to improve care, public health, and the efficiency of our health system. Our aim is to use our strength to improve coordination of patient care, across physical and mental health, increase ownership by patients of their own health records, and to enhance clinical decision making through research and planning.

We work with our partners across south east London to develop and test new opportunities to use informatics to advance how we care for our local population.

Systems have been developed to enable electronic healthcare records to be shared across our partner organisations and with other healthcare organisations. Our work includes the award-winning 'HealthLocker' programmes, Cogstack, the Clinical Record Interactive Search (CRIS) and the Local Care Record. We are working with patients to make electronic patient information available in an anonymised format between partner trusts, primary care and social care. Together we have a powerful information resource for both practitioners and researchers.

Value Based Healthcare

King's Health Partners Value Based Healthcare programme is focused on supporting our partner organisations to deliver excellent and consistent health outcomes whilst protecting our NHS resources. We believe that in order to deliver transformational health improvements that are patient-centred, population-based and sustainable, we must make the best use of every pound available by continually focusing on value for patients and carers across the full cycle of care.

At King's Health Partners, our goal is to:

- develop meaningful and consistent patient-centred metrics, based on outcomes defined by patients, service users and carers;
- quantify the potential impact that investment decisions have on our patients, carers, the local health economy and wider society;
- ensure that the mental, physical and psychosocial needs of people are treated as one;
- evaluate and learn from the outcomes that we achieve through research and transparent use of data to reduce variation.

We are working with clinical teams across the partnership to redesign pathways of care based on the above principles.



Cicely Saunders Institute

Introduction to Palliative Care CAG

You matter because you are you. You matter in all the moments 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.

Dame Cicely Saunders

Introduction to Palliative Care CAG

In 2018 Palliative Care formed the twenty-second Clinical Academic Group within King's Health Partners.

This is a timely and important recognition of the tripartite vision for excellence in clinical care, research, and education and training that is the cornerstone of palliative care. We are proud of our history and the pioneering work of Dame Cicely Saunders, who recognised the need to bring together expert and compassionate care, teaching, and clinical research that has defined our understanding of effective palliative care. This mission is carried on through the work of the Palliative Care CAG, embedded within the clinical care provided across King's Health Partners, the wider community of hospices and other services we work with, championed by the charity Cicely Saunders International and other partners, and pioneered by the Cicely Saunders Institute: the world's first purpose-built institute of palliative care.

Palliative care is the type of care that puts the person and those close to them before their disease(s). It is the active total care of patients with life-limiting or life-threatening illnesses. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and those important to them. It is applicable at any point from diagnosis onwards, can occur together with treatment aimed to cure, and includes care for patients at the end of life as well as bereavement support.

The World Health Organisation defines palliative care as an approach that:

- affirms life and regards dying as a normal process;
- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement.

We have summarised some of the highlights from across our CAG below:



The infographic is a vertical purple rectangle with white text and icons. At the top right is a circular icon of two hands holding a heart. Below the title is a dotted line. The first section features a bar chart icon and text about outcome measures. The second section features a classical building icon and text about the Cicely Saunders Institute. The third section features a nurse icon and text about quality of life.

The Palliative Care Clinical Academic Group

.....

 Leads the advancement and implementation of **outcome measures** which matter most to patients and those most important to them, used across the globe

Hosts the **Cicely Saunders Institute**, the first purpose-built institute integrating research, education and clinical practice in palliative care 

 Pioneers and evaluates integrated models of palliative care that provide better symptom control and **quality of life**

King's Health Partners has a strong legacy of palliative care. Our new CAG is an ideal platform to achieve more for those affected by life limiting and threatening illness, wherever they are cared for. Dame Cicely Saunders, widely acknowledged as the founder of the modern hospice movement, trained as a nurse, a social worker and finally as a physician at St Thomas' Hospital. From 1948 she was involved with the care of patients with terminal illness, lectured widely on the subject, wrote many articles, and contributed to a great number of books. She founded St. Christopher's Hospice in 1967 as the first academic hospice linked with clinical care, pioneering the field of palliative medicine. In 1977, inspired by the work at St Christopher's Hospice, Consultant Oncologist Dr Thelma Bates set up the palliative care service at St Thomas' Hospital; the first hospital-based palliative care service in Europe, seeing the first patient on 5th December 1977. Since then clinical services have developed and expanded across all sites to include inpatient, outpatient and community palliative care services.

In 2002 Dame Cicely Saunders became the founder trustee of Cicely Saunders International and worked actively for the creation of an Institute, to, as she put it: "be a bridge between information, education, clinical care and science".

The Cicely Saunders Institute, the first palliative care institute in the world, was opened on the Denmark Hill site in 2010. The mission of the Institute established in Cicely's 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 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 changes in policy and in practice nationally and internationally, engage with patients and public, and inspire tomorrow's leaders in the field from around the world.

Figure 1 | Dame Cicely Saunders with a patient



Specialist multi-professional palliative care services operate in all our hospitals, provide a 24/7 service and receive referrals from any speciality. Our community palliative care services operate from a hub at Guy's Hospital, providing a valuable inpatient/community interface that ensures care for our local population is coordinated to take into account patient and family preferences regarding location of care and quality of life. Our teams work in close collaboration with other community services and local hospices including St Christopher's Hospice and Royal Trinity Hospice.

Resources for our patients and those important to them are available in the Macmillan Information and Support Centre at the Cicely Saunders Institute and at the Dimpleby Centre at Guy's Cancer Centre.

The Palliative Care CAG incorporates our close working with Rehabilitation Medicine services that provide consultant-led inpatient evaluations and reviews at King's College Hospital, Guy's and St Thomas', and Lewisham Hospital, and with the Regional Rehabilitation Unit at Northwick Park Hospital, an affiliated unit of King's College London and the Cicely Saunders Institute.

Our aims and ambitions

The King's Health Partners Palliative Care CAG has a unique international opportunity to combine our rich heritage of pioneering clinical services with our world-wide reputation as an academic centre of excellence. Palliative care exemplifies the tripartite agenda at King's Health Partners, and the nature of our speciality means that we have the ability to reach out and collaborate with colleagues across all other CAGs.

Our world-leading research profile, with a shared research agenda focused on improving patient outcomes, is becoming increasingly important as the population ages and more people end their lives with long-term conditions. Our Palliative Care CAG conducts research across all King's Health Partners sites and beyond into national and international settings, focused from the Cicely Saunders Institute, in four main multi-professional themes:

1. improving and evaluating care,
2. focussed symptom research,
3. development and measurement of outcomes and,
4. living and dying in society.

We pioneer and evaluate service improvements, discover and trial new treatments and therapies, generate the evidence on which much international health policy and guidance is based, and develop, refine and validate the measures and assessment tools to support improved assessment, clinical practice and care.

Given the nature of specialist services delivered across King's Health Partners and the diversity of the local population that the hospitals serve, there is a unique opportunity to develop innovative research programmes to discover interventions that improve palliative care and end of life care, both locally and globally. Our patients are from a wide range of ethnic, cultural and socially diverse backgrounds, often presenting with highly complex palliative care needs requiring intensive multidisciplinary input. Delivering palliative and end of life care within this setting is challenging and requires a flexible, innovative and nimble specialist service to ensure patient and carers' needs are met.

Our aims and ambitions as a CAG include:

- Putting patients and those close to them at the heart of all we do, advancing further our public, patient and societal engagement to improve the quality and impact of research, education and care and extending our virtual and face-to-face fora.
- Driving even higher our world-leading academic leadership in palliative care research and education to improve care wherever people are cared for and inspire current and future generations. This will be evidenced by how we conduct and disseminate high quality research to transform treatments, practice and services globally, build academic and clinical/academic capacity and collaboration to foster the leaders of tomorrow, win competitive grants and become well known as the top centre for clinical academic palliative care.
- Boosting specific links with other CAGs to develop further academic and clinical collaboration. This includes: Cancer, Cardiovascular, Respiratory, Neurology, Pharmacology, Diabetes and others. A major strength is that we have always focussed on multi-morbidities, and so can drive forward improvements for the populations of tomorrow, where multimorbidity will be a common experience.
- Strengthening our collaboration with the Mind & Body Programme. We are mapping our access to psychological support services across King's Health Partners, with a view to piloting additional services for our patients and those close to them. This work will link to our aim to upskill staff working in mental health services who care for patients with severe physical illnesses.
- Translating research into practice via our joint service innovations with colleagues in the Intensive Care Units, Emergency Departments, heart failure, respiratory, oncology, haematology, renal, neurology and elderly care services.
- Bolstering our close working relationships with colleagues in the London Evelina paediatric palliative care service at Guy's and St Thomas'. This includes improving pathways of care for patients transitioning between paediatric and adult services in inpatient and community settings.
- Extending our national and international profile as a leader in quality improvement and service innovation.
- Improving the quality and safety of transitions of care for patients moving between community and inpatient settings by maximising our opportunities as a provider of specialist palliative care across organisational boundaries.

- Advancing our emerging profile in the health economics of complex or advanced illness and care, developing and refining the tools for economic assessment based on patient perspectives, to provide and facilitate Value Based Healthcare.
- Continue our provision of specialist evidence-based clinical services based at all sites, with services evolving to meet the changing needs of our patients, carers and colleagues in each clinical setting. This includes developing our expertise in the delivery of supportive care in parallel with disease-modifying therapies.
- Expand our leadership of specialist palliative care pharmacy services, including support for hospice providers and leadership of the London Opioid Safety and Improvement Group (LOSIG).

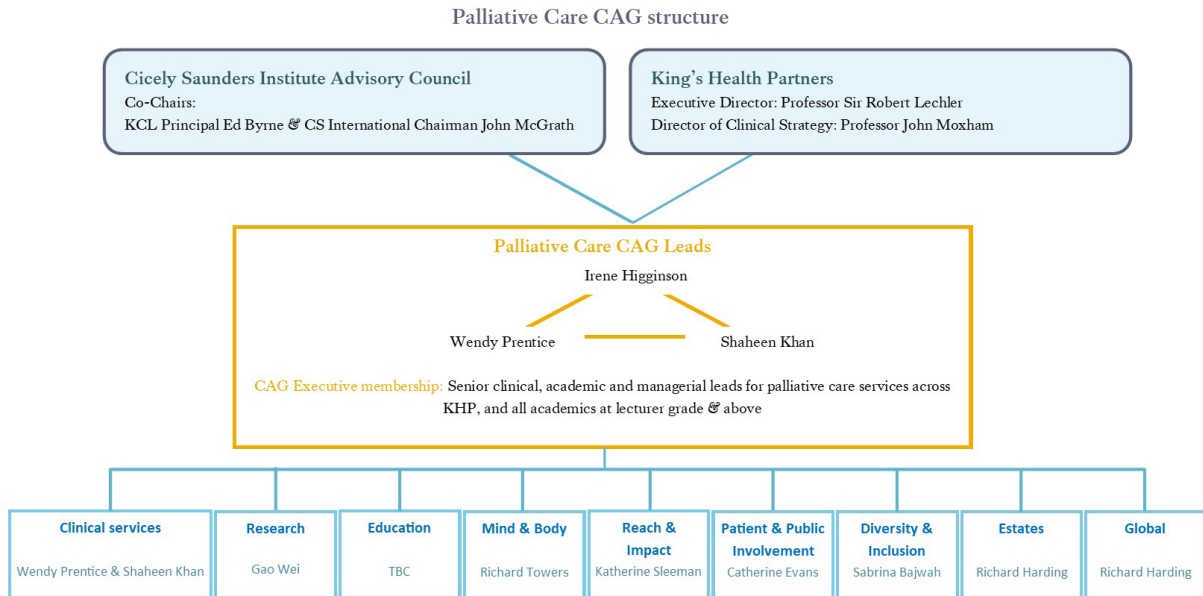
Specific objectives for us between now and July 2019 will include:

- Develop an action plan related to our mind and body work in integrating mental and physical healthcare. We have appointed a dedicated lead for this within our CAG Executive team. Collaboration with colleagues in South London and Maudsley NHS Foundation Trust is an exciting component of this work.
- Explore commissioning options to set up a sustainable breathlessness triggered support services, based on our published trials, meta-analyses and experience in this field.
- Map our data management processes across the CAG to harness the international expertise at Cicely Saunders Institute to facilitate improvements in the use of routine data to inform clinical practice and research across all sites.
- Establish a forum for discussing service innovations to assist staff dealing with clinical uncertainty. This will include our work at King's College Hospital within ITU (including development of the PACE tool¹) and our work at Guy's and St Thomas' in relation to cardiopulmonary resuscitation, advance care planning, and the AMBER² Care Bundle.
- Share our outcomes with patients and staff, building on the publication of this outcomes book, by developing and publishing an outcomes scorecard at regular intervals. We believe this will support our efforts to continually improve quality and experience for our patients and those important to them.
- Appoint a named lead within our CAG Executive team to drive our education and training strategy. This will bring together and advance our educational offerings, including the change and innovation in clinical practice at a local, national and international level, and our popular undergraduate, postgraduate and multi-professional training, and identify new opportunities such as blended and e-based learning.
- Explore opportunities to create an intercalated BSc in Palliative Care, and specific training for registrars in palliative medicine, hosted at CSI with teaching and research delivered across all of our clinical sites.

1 Psychosocial Assessment and Communication Evaluation (PACE).

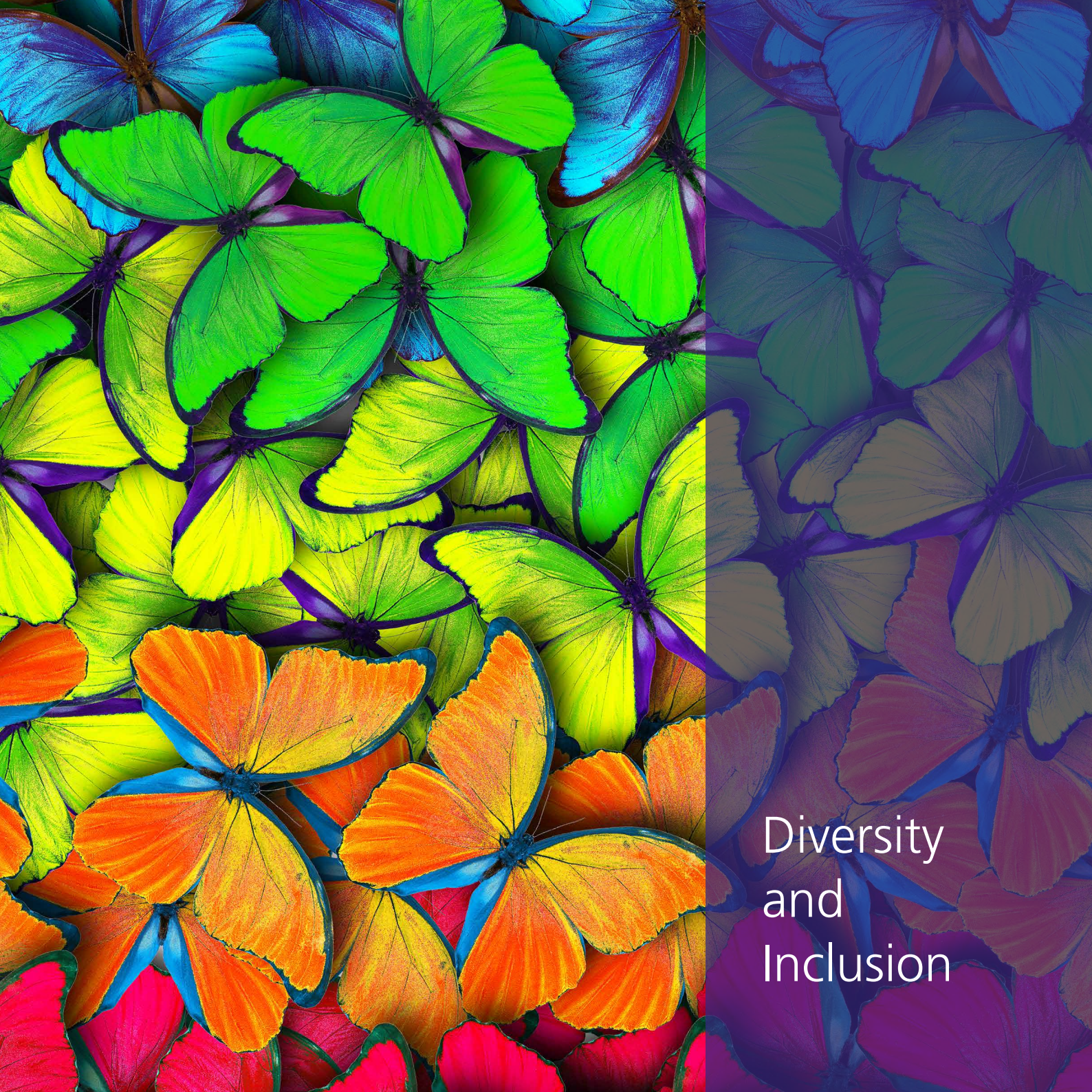
2 Assessment, Management, Best Practice, Engagement, and Recovery (AMBER).

CAG leadership structure



- Finance issues will be discussed at CAG Executive level and between relevant individuals
- All clinical, academic and administrative staff in the CAG are welcome to join a group if they have an interest, but it is not compulsory to do so.

KEY: Area of responsibility and Named lead CAG Leadership team Reporting lines



Diversity
and
Inclusion

Our vision for the future is to continue to identify gender inequality across the CAG and beyond – to shed light on and improve opportunities across all protected characteristics.

CAG Diversity and Inclusion Committee

Passionate about diversity and inclusion

We are passionate in our commitment to ensuring Diversity and Inclusion across the CAG. 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. Our Athena Swan Committee

was established in December 2013. This now forms part of the CAG Diversity and Inclusion Committee. We are incredibly proud of our Athena Swan Silver Award, Race Equality Charter Bronze Award (see Figure 2) and the Stonewall Diversity Award.

Figure 2 | Athena Swan, Race Equality and Stonewall Diversity Awards



To demonstrate our commitment, Diversity and Inclusion is now included as a compulsory regular agenda item for all CAG Executive Groups, our email signature reflects our commitment to Athena Swan, the Race Equality Charter and Stonewall Diversity and all staff are offered the King's College London rainbow

lanyard as a show of our commitment to the LGBT+ community. Starting in 2018 we are now conducting regular Diversity and Inclusion quantitative surveys with qualitative follow up of identified areas to ensure that we are focussed in our actions.

Figure 3 | Diversity and Inclusion survey results (2018) for the Cicely Saunders Institute

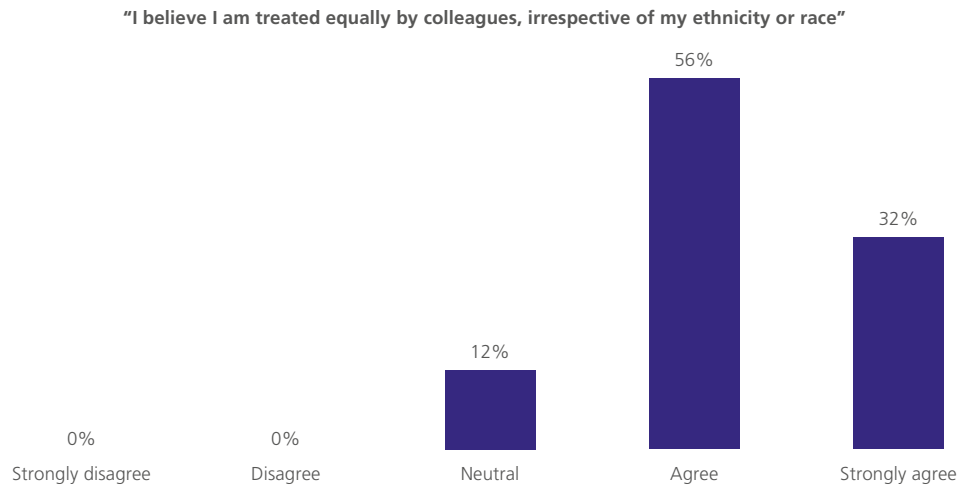


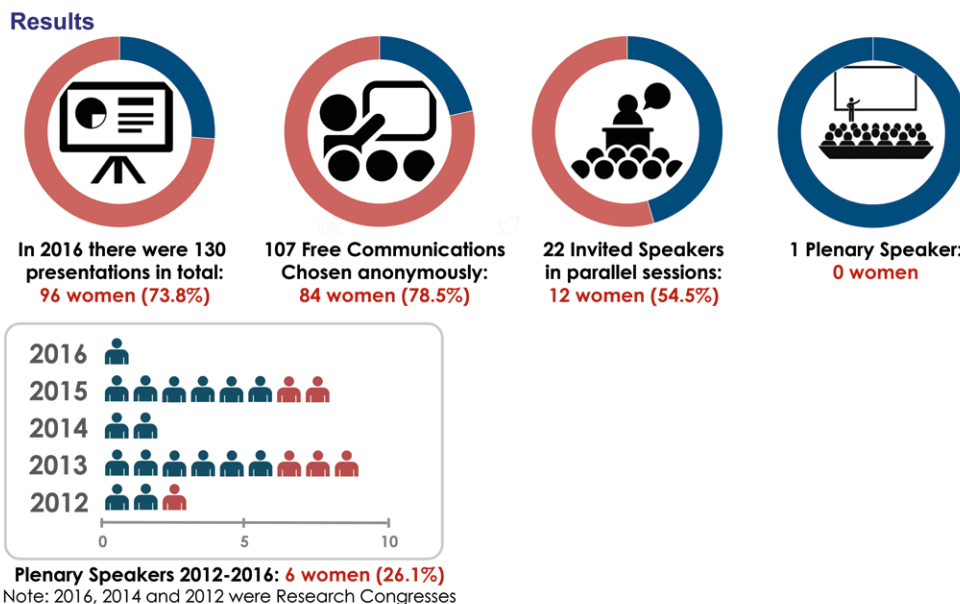
Figure 4 | CSI researchers wearing rainbow lanyards routinely offered to all Palliative Care CAG staff to demonstrate commitment and support to the LGBT+ community



Through our work in the Palliative Care CAG we have made a measurable positive difference for gender equality not just locally and nationally but internationally. Led by Dr Katherine Sleeman (NIHR Clinician Scientist and Honorary Consultant in Palliative Medicine), research was conducted to determine any “leaky pipeline” within palliative care. The programmes of the European Association of Palliative Care (EAPC) conferences were examined and the gender of each speaker

recorded with a three-tier hierarchy of free communication sessions, parallel sessions and plenaries used to indicate senior academic visibility (low to high). This data indicated there is an attrition of women along the academic pipeline in palliative care. As a direct result of this work, the EAPC now routinely collect and analyse gender information on abstract submission and reasons for women declining invitations to give plenaries is now explored (see Figure 5).

Figure 5 | Results demonstrating the ‘leaky pipeline’ within palliative care (Sleeman et al., 2017)



Recognising the Athena Swan post-May 2015 charter, we are committed to identifying gender inequality in all academic, clinical and professional services across the CAG and beyond to shed light and improve opportunities across all protected characteristics. Dr Sabrina Bajwah (Clinical Senior Lecturer and Honorary Consultant) was profiled for the online magazine “Womanthology” in 2017, where she discussed the need to empower women from ethnic minorities to smash not only the glass ceiling but also the bamboo ceiling in science, technology, engineering and mathematics. Dr Bajwah also recently took part in a King’s College London debate and was featured in the “Women’s Empowerment” issue of *In Touch* magazine (see Figure 6). She talked about the detrimental effect of positive action on gender equality. Dr Bajwah continues to act as a Black Asian and Minority Ethnic mentor for students and staff across the Palliative Care CAG and leads the CAG’s Diversity and Inclusion Committee.

Figure 6 | The effect of positive action on gender equality: *In Touch* magazine Women’s Empowerment issue featuring Dr Sabrina Bajwah





Outcome Measures

*How people die remains in the
memory of those who live on.*

Dame Cicely Saunders

Types of outcome measures

Clinical outcomes

Clinical outcomes are changes in the health or quality of life of patients and those close to them, which in part result from the care they have received. In specialities like palliative care, patient-centred outcomes are given high priority because these reflect the view of the patient without interpretation of a clinician. The Cicely Saunders Institute has pioneered outcome measurement in palliative care across the globe, with the measures which the team developed, led by Professor Higginson, used now in over 135 countries.

Research outcomes

Research outcomes demonstrate the value and impact of our research, to patients, the public and society. Research outcomes include sharing results at scientific conferences and papers, influencing policy, and producing new clinical tools. We want the lessons from research to be used swiftly, effectively and systematically, with the widest possible reach.

Quality of care outcomes

Quality of care is a guiding principle in assessing how well we perform in our mission to improve the health of patients and those important to them such as their carers and family. The outcomes we collect assess the quality of care including how safe, effective, patient-centred, timely, efficient and equitable the care we provide is. This includes patient experience, which reflects patients' interactions with health care systems and also the degree to which their needs are met.

Performance measures

Performance measurement involves regularly monitoring outcomes and results to generate reliable data on the effectiveness and efficiency of our care. Performance may relate to a group, organisation or the system as a whole. Performance outcomes can be used to clarify goals, document progress towards them, and establish standards against which we can continuously improve all aspects of care.

Patient centred outcome measures

Good healthcare is no longer a disease-centric process. Modern healthcare is patient-centric, where patients (and those close to them) are active participants in care, and their concerns drive assessments and care. This has always been a central pillar of palliative care, although measurement of the right outcomes initially proved difficult.

In response, for the last 20 years the team which formed the Cicely Saunders Institute has been leading the national and internationally development of outcome measures in palliative care and of symptom management for palliative care patients.

To better understand concerns and to demonstrate objectively the impact of the team and the difference we make for patients and families, we need to have appropriate tools that are able to capture changes in symptoms and quality of life experienced by patients. Our research has

developed, refined, adapted and improved the Palliative Care Outcome Scale (POS) family of measures. The POS is a brief tool that captures the most important concerns of patients, including symptoms, information needs, practical concerns, psychosocial concerns, mood and family anxieties. A key focus is to provide POS measures that can help day-to-day clinical practice and care, as well being valuable in research and training. We aim to measure palliative care problems and concerns at the first visit, and then subsequently whenever the phase of illness changes, and on discharge.

Table 1 | POS family measures

| POS family | |
|------------------|---|
| POS v1 | POS v1 is the original version. It has shown validity in home, hospital and hospice settings. |
| POS v2 | POS v2 was developed for use with individuals with palliative care needs, irrespective of diagnosis and clinical settings. Particularly valuable for people who are diagnosed with a chronic or progressive disorder. |
| POS-S – symptoms | An extension of POS including more assessment symptoms. |
| African APCA POS | A version of the POS adapted for African use. It has been piloted in eight eastern and southern African countries and validated across five African services. |
| IPOS | An integration of POS, POS-S and APCA POS based on feedback from clinicians, patients, families and testing of the measures’ properties. |
| IPOS-5 | A briefer version of the full IPOS with only five items. |
| IPOS-DEM | A proxy-completed measure for people with dementia living in care homes. It is developed for use by unqualified care staff. IPOS-DEM incorporates common symptoms and problems experienced by this population. |
| IPOS-Renal | Is a short measure combining the most common symptoms renal patients experience plus additional items from IPOS on concerns beyond symptoms, such as information needs and practical issues. |
| MyPOS | A version of the POS developed to use with individuals with Myeloma and including the specific symptoms of myeloma. |

Updates of the POS are regularly posted on the dedicated POS website (www.pos-pal.org) to help support clinicians and researchers. The website provides free downloadable versions of the POS and POS family of measures, guidance on their use, translations, and research publications. We refine and validate new versions of POS for use in different settings and to support the care of different groups of patients, building on a core Integrated Palliative Care Outcome Scale (IPOS) that can be used in all situations, with additional components for specific diseases or settings. Workshops, seminars, and e-learning courses are continuously being developed by the POS team, training professionals on the use of the tool.

IPOS Patient Version

For staff use
Patient number:

www.pos-pal.org

Name:

Date (dd/mm/yyyy): / /

Please write clearly, one letter or digit per box. Your answers will help us to keep improving your care and the care of others.
Thank you.

Q1. What have been your main problems or concerns over the past week?

1. _____

2. _____

3. _____

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick **one box** that best describes how it has affected you over the past week.

| | Not at all | Slightly | Moderately | Severely | Overwhelmingly |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Pain | 0 <input type="checkbox"/> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |
| Shortness of breath | 0 <input type="checkbox"/> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |
| Weakness or lack of energy | 0 <input type="checkbox"/> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |
| Nausea (feeling like you are going to be sick) | 0 <input type="checkbox"/> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |
| Vomiting (being sick) | 0 <input type="checkbox"/> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |
| Poor appetite | 0 <input type="checkbox"/> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |
| Constipation | 0 <input type="checkbox"/> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |
| Sore or dry mouth | 0 <input type="checkbox"/> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |
| Drowsiness | 0 <input type="checkbox"/> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |
| Poor mobility | 0 <input type="checkbox"/> | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |

Please list any **other** symptoms not mentioned above, and tick **one box** to show how they have affected you over the past week.

1. _____ 0 1 2 3 4

2. _____ 0 1 2 3 4

3. _____ 0 1 2 3 4

IPOS PATIENT
www.pos-pal.org
Page 1 of 2
IPOSv1-IPF-EN 26/02/2014

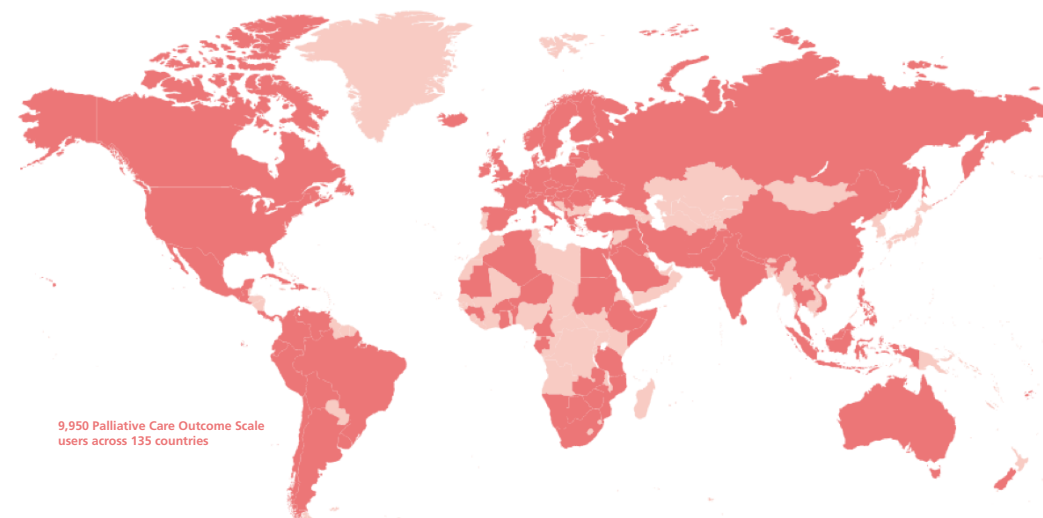
Local and global use of outcome measures

Since its launch, POS has been tested and improved by researchers around the world. The POS and IPOS are now available in many languages and with different translations, e.g. Dutch, German, Portuguese, Spanish, Punjabi, Italian, Chinese, Greek and Arabic and Urdu.

To help clinical teams to provide the best in care, we developed and tested a decision support tool to provide a guide on how to respond to the needs and concerns of patients with progressive illness and their families (van Vliet et al., 2015). The tool

addresses four areas of clinical uncertainty: information needs, family anxiety, depression and breathlessness. Systematic reviews and two international Delphi rounds, conducted as part of a European Project 'Euro Impact' found that good patient care, psychosocial support and empathy, and open communication were central to supporting patients and families affected by all POS concerns as a core requirement. Assessment was recommended for increasing problems (i.e. scores), followed by non-pharmacological interventions and for breathlessness and depression, pharmacological interventions. Accompanying guidance was built based on the eight-step International Society for Quality of Life Research framework (van Vliet et al., 2015).

Figure 7 | Where the Palliative Care Outcome Scale (www.pos-pal.org) is helping in clinical care and research (2018)



We make constant efforts to facilitate the use of outcome measures developed in a wide variety of settings. The POS is used across King's Health Partners' organisations in routine clinical practice and research. In research, we have used the IPOS and other measures to understand trajectories of illness of people with chronic kidney diseases (Murtagh et al., 2011c), Parkinson syndromes (Higginson et al., 2012b; Saleem et al., 2013) and heart failure (Malik et al., 2013).

Integrating outcome measures into clinical practice to improve care as it happens

To provide practical user-friendly support to care teams, we developed the Outcome Assessment and Complexity Collaborative (OACC) project, that draws on existing psychometric studies of outcome measures in palliative care and has an agreed standardised suite of measures to transform palliative care for patients and families. In response to results from a Europe wide study called the PRISMA³ project, including an online survey on the use and experiences of professionals with outcome measurement in palliative care, the team developed guidelines

³ PRISMA was a major three year coordinating action project funded by the European Union. Its aim was to inform best practice and harmonise research in end-of-life care for cancer patients across Europe.

and training materials for clinicians. Additionally, the project has integrated health information technology to establish workable ways of capturing and processing data, and provide regular feedback of results at an individual and organisational level, to improve the quality of the services provided.

Figure 8 | OACC Resource pack



Through collaboration with the national charity Hospice UK, the OACC team worked with hospices and hospital palliative care teams nationally to support the implementation and use of the measures more widely. More than 220 OACC resource packs have been distributed to services across the UK. A subset of the OACC measures was used in the national pilots led by NHS England and Public Health England to test a palliative care clinical dataset and develop palliative care currency.

Several successful training workshops have been facilitated by CSI and Hospice UK nationally to build local capacity in various organisations: St Luke's Hospice, Sheffield, St John's Hospice, Lancaster, St. Barnabas House, Worthing, St. Catherine's Hospice, Preston, and St. Gemma's Hospice, Leeds, as well as the annual workshops we host at the Cicely Saunders Institute.

We performed a multi-method qualitative study to explore the use of Patient Centred Outcomes Measures (PCOMs) in palliative care and identify key considerations for successful implementation. 38 interviews with patients, family carers and staff from nine specialist palliative care services were performed between December 2014 and November 2015. From this work benefits, challenges and lessons for implementation were identified (Figure 9) (Pinto et al., 2018).

Figure 9 | Results from OACCs evaluation on PCOMs

Benefits of using PCOMs

- Greater confidence to raise important concerns
- Ability to recognise improvement in the face of deteriorating health
- Improving the structure and efficiency of clinical assessments
- Ability to demonstrate the impact and quality of care provided

Challenges of using PCOMs

- Potential added burden to patients and families
- Potential increase on staff workload

Lessons for implementation

- Selecting appropriate and valid measures
- Staff training and education
- Provide regular feedback to increase motivation amongst staff
- Having peer and senior management support
- Investment in infrastructure

From Pinto C., Bristowe K., Witt J., Shipman C., Davies J., de Wolf-Linder S., Dawkins M., Higginson I., Daveson B., Murtagh F. *Making Outcome Measures Work in the Context of Deteriorating Health – Lessons for Implementation: A Multi-method Qualitative study.* Pall Med 2018; 32(15):204.

Research to explore ways of implementing the Integrated Palliative care Outcome Scale for Dementia (IPOS-Dem) into long-term residential practice was undertaken across three residential long-term care settings in London with staff and clients. IPOS-Dem was found to be acceptable and suitable for caregiver staff without professional training. This measure

is now in high demand across Europe. The requirements of palliative care measures used by staff without a professional qualification were identified, including the importance of lay terms, and a video presentation on the purpose of the measurements and instructions of how to use them was developed in response (Ellis-Smith et al., 2017).

Figure 10 | OACC study day





Clinical
Services

We have to listen to the details of symptoms, giving constant attention to changing needs. We are concerned both to relieve suffering and that our patients should maintain their own character and style to the end.

Dame Cicely Saunders

Our clinical services

Our clinical services include:

- Inpatient advisory services based at Guy's, St Thomas' and King's College Hospital (Denmark Hill, and Princess Royal University Hospital) sites;
- Community palliative care services working in Lambeth and Southwark;
- Consultant-led outpatient clinic services (five days a week);
- A 24/7 specialist palliative care on-call service covering our hospitals and related community services in Lambeth, Southwark and Lewisham;
- Close collaboration and joint working with our local hospice partners;
- Bereavement support which includes an annual memorial service at Southwark Cathedral, memorial services at all hospital sites, and access to specialist psychological support when required for bereaved carers.

All teams are highly responsive, standards for time from referral to assessment are:

- Routine referrals – seen within two working days (inpatient) and five working days (community);
- Urgent referrals – seen within 24 hours;
- Emergency referral – seen as soon as possible after referral (often less than one hour).

Our clinical teams working across King's Health Partners are multi-professional providing:

- Evidence-based symptom control;
- Complex psychosocial care;
- Advance care planning;
- Liaison with other specialist palliative care services (hospital and community);
- Support for provision of individualised end of life care (EoLC) in the last days of life.

The teams aim to provide a service that:

- Improves quality of life;
- Facilitates patient choice;
- Treats patients and carers with respect and dignity at all times.

The teams are also committed to research, audit and education to continually improve the service, increase the evidence which underpins care, and extend palliative care skills and knowledge to a wide range of other health and social care professionals.

Figure 11 | Members of our community palliative care team



In 2017 we celebrated the 40th anniversary of the St Thomas' Palliative Care service, highlighting this development as the first hospital-based palliative care service in Europe. In 2013 King's College Hospital celebrated its centenary with the team contributing to the lecture series reflecting on the past, present and future of palliative care.

Figure 12 | Members of the original palliative care service at St Thomas' Hospital, 1977



Team performance measures

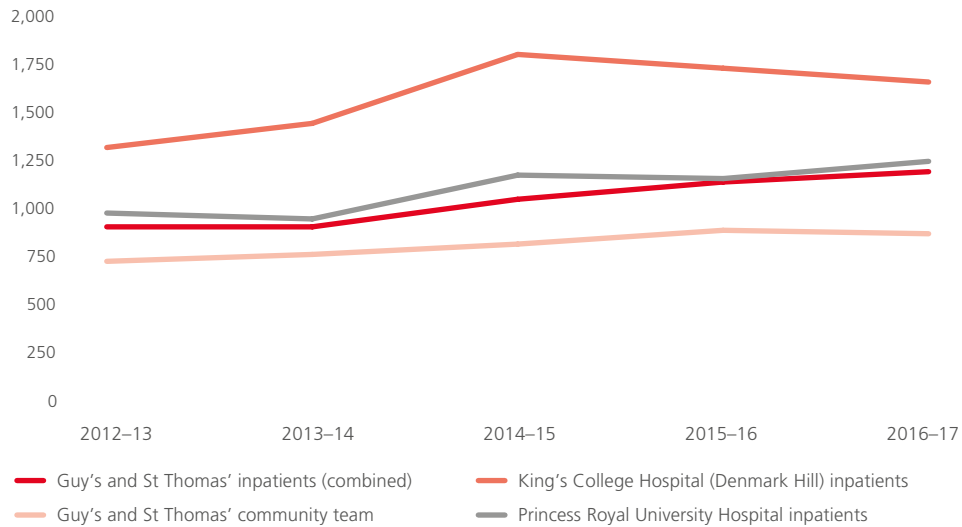
Performance is monitored via a number of different processes including departmental scorecards, trust-wide metrics applied to the hospitals of King's Health Partners (e.g. proportion of adult inpatient deaths supported by individualised end of life care), standards of care via trust End of Life Care committees, bereavement surveys, proactive incident surveillance, response to complaints, compliments, and departmental clinical governance meetings. Quality improvement projects allow us to focus on topical issues and address specific concerns. Integration into each hospital's mortality surveillance groups and other committees facilitate this.

Our teams are leading national and international discussions in relation to routine use of data within palliative care services. Learning from outcomes measurement at King's College Hospital (Denmark Hill) and Princess Royal University Hospital, through the CAG we will develop similar capability at Guy's and St Thomas'. For the purposes of this report, data from King's College Hospital and Princess Royal University Hospital is showcased, with data from Guy's and St Thomas' provided where possible.

Referrals

The total number of referrals to clinical services remains high; approximately 5,000 patients are seen per year across the CAGs hospitals, outpatient clinics, and community services. Roughly an equal number of family members and friends are seen. Referrals across all sites are increasing year on year.

Figure 13 | Number of new referrals per year for our clinical teams



Time from referral to assessment

It is essential that our clinical service can respond rapidly when required, in order to support patients, carers and fellow healthcare professionals across King's Health Partners, in often rapidly changing and challenging clinical circumstances. We are piloting interventions such as our 'front of house' model at King's College Hospital (Denmark Hill), providing proactive specialist palliative care input to the acute medical unit to improve patient experience from the point of admission to hospital. We anticipate that for some patients this will streamline their management within the hospital and facilitate improvements to their inpatient experience.

At King's College Hospital (Denmark Hill), 1,391 (87%) of referrals are seen within one day of referral and 96% within three days. At Princess Royal University Hospital, 1,160 (94.5%) of referrals are seen within one day of referral.

Across all clinical sites, small numbers of patients are seen beyond two days from referral, these are usually team requests for later assessment or family and/or bereavement referrals. Through our CAG we plan to develop agreed team performance metrics, visible via a common scorecard, to include our clinical services at Guy's and St Thomas' hospitals and our community services.

Source of referrals: clinical case-mix

Of the 1,225 new referrals received at King's College Hospital (Denmark Hill), in 2016–17, 391 (31.9%) were for patients with a main diagnosis of cancer, and 753 (61.5%) were for patients with non-cancer diagnoses including heart failure, stroke, neurodegenerative conditions, and respiratory illness. This is one of the highest proportions of non-cancer referrals for any palliative care team nationally.

At Princess Royal University Hospital, of the 937 new referrals received in 2016–17, 295 (31.5%) were for patients with a main diagnosis of cancer, and 631 (67.3%) were for patients with non-cancer diagnoses. This represents a very rapid increase in the proportion of non-cancer patients at Princess Royal University Hospital, (from 56% in 2015–16 and 33% in 2014–15). The high proportion of multiple non-cancer conditions reflects the complexity of this patient population and the increasing proportion of patients with multiple comorbidities

At Guy's and St Thomas', our teams see a significantly higher proportion of patients with cancer (approximately 70% of all cases), linked to our specialist provision to the Guy's Cancer Centre and the associated regional cancer network.

Phase of illness

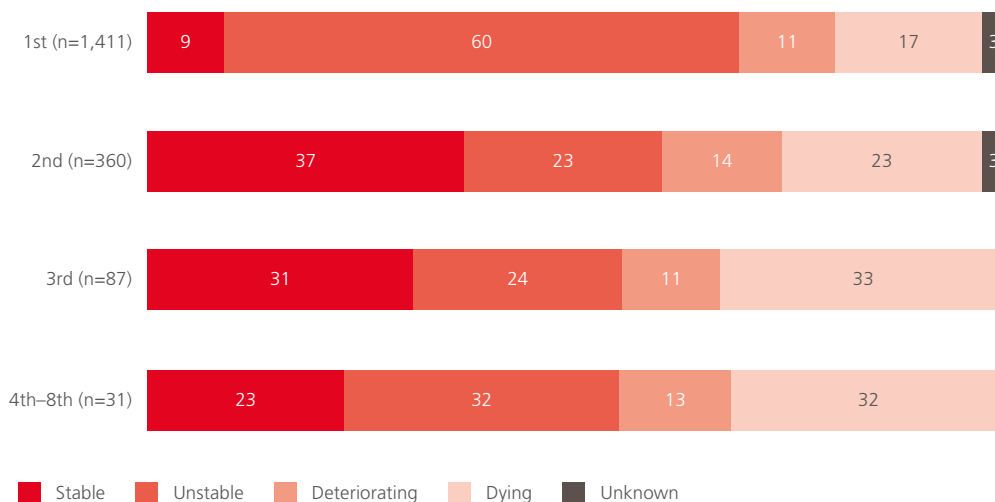
Phase of illness for our patients is recorded at first assessment and again whenever there is a change in phase, or on discharge. Phase of illness is recorded as 'stable', 'unstable', 'deteriorating', 'dying' or 'bereavement'. The phase of illness reflects the palliative care plan required to address patient and family needs. For example, a person whose care plan is meeting their needs is described as being in 'stable' phase, whereas 'unstable' phase indicates new, acute, and unexpected problems to be addressed, and 'deteriorating' phase indicates more gradual and expected concerns. 'Dying' phase indicates last few days of life.

Capturing this information allows us to embed the routine use of data when managing staffing and planning our input into the care of individual patients. It also allows us to demonstrate our impact by quantifying our ability to alleviate distress, reduce symptom burden, and stabilise complex situations.

Data is currently being captured across Guy's, King's and St Thomas' sites, but is not yet routinely embedded into daily practice at Guy's and St Thomas'. This is something we envisage being able to standardise across our CAG during 2018/2019.

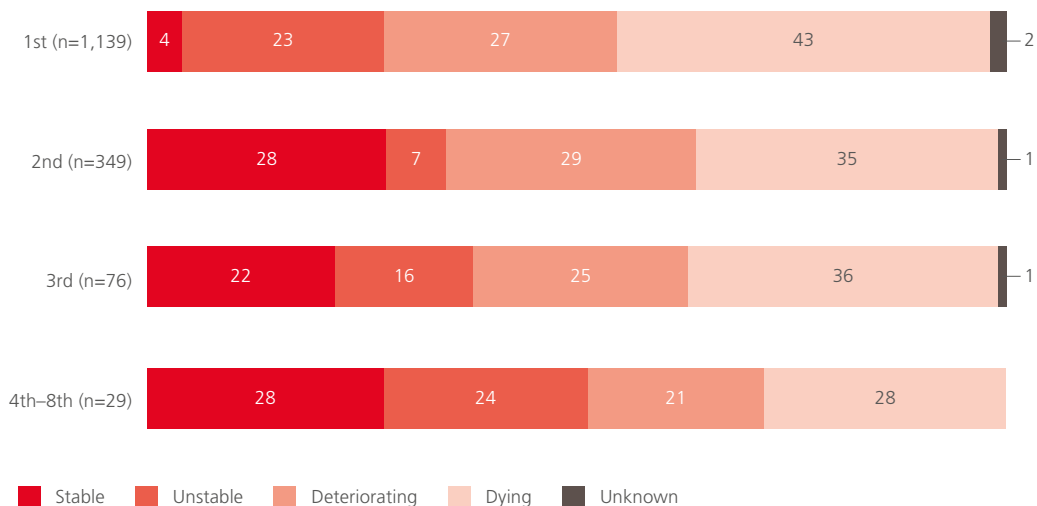
At King's College Hospital (Denmark Hill), the most common phase recorded is 'unstable' (60%).

Figure 14 | Distribution of phase of illness at King's College Hospital (Denmark Hill), 2016–17



At Princess Royal University Hospital there is a greater proportion of people in 'deteriorating' and 'dying' phases.

Figure 15 | Distribution of phase of illness at Princess Royal University Hospital, 2016–17



When a patient's phase of illness changes, we aim to record an IPOS score so that we can assess their symptom burden and palliative care requirements. By comparing the first with subsequent scores we are able to measure improvements or deterioration in the severity of problems, and therefore indicate the impact of the palliative care team.

Our CAG is leading on the use of outcomes of this type in palliative care nationally, and working towards comparable data between teams (and eventually benchmarking) to improve quality of care. In 2015 the palliative care team at King's College Hospital was shortlisted for 'Palliative

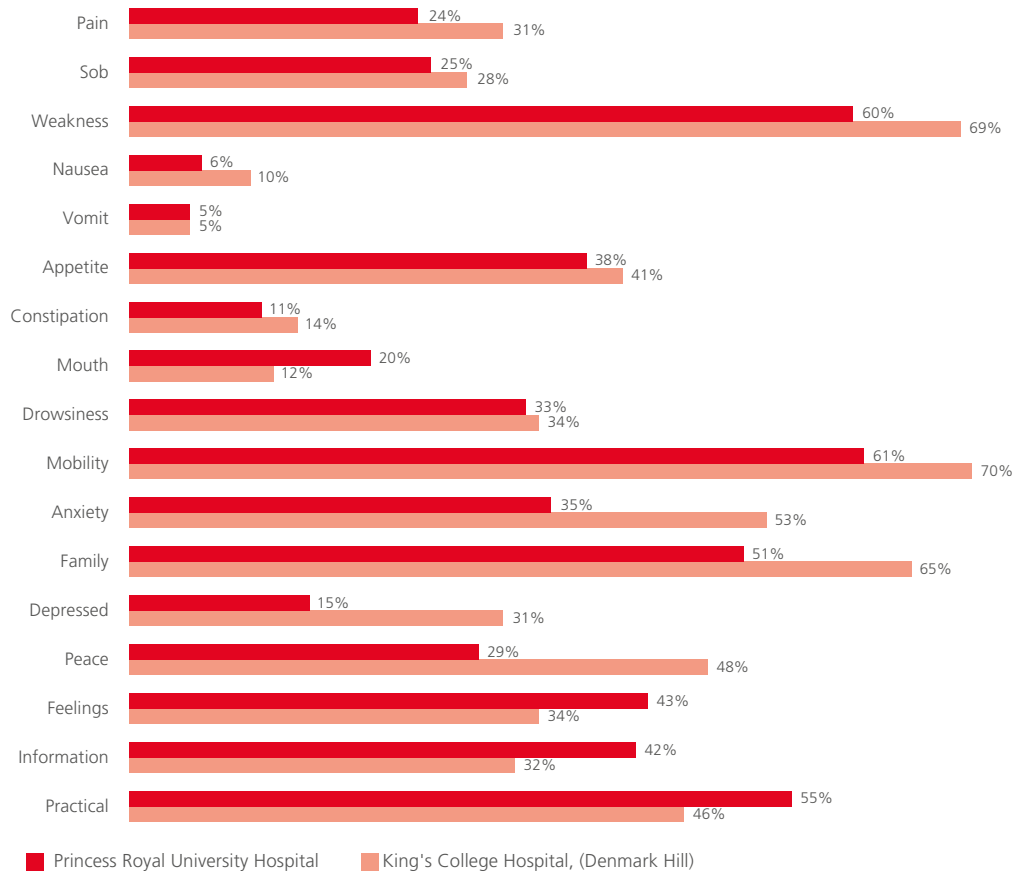
Care Team of the Year' at the British Medical Journal awards, for their work on outcomes.

When we first assess people referred to our palliative care services we often find that they have complex needs. Patients usually have multiple symptoms, on average as many as 13–14 different symptoms and problems, very commonly not only pain, but weakness, shortness of breath. Many also often have practical care, information, emotional, social and spiritual needs. We have been able to clearly document these, which helps us to prioritise what is important for patients and those close to them (see Figure 16).

After a period in our care (phase) we measure the changes, to determine how we are doing. As Figure 16 shows, we are able to see considerable improvement in many areas, although some problems, such as weakness, mobility and

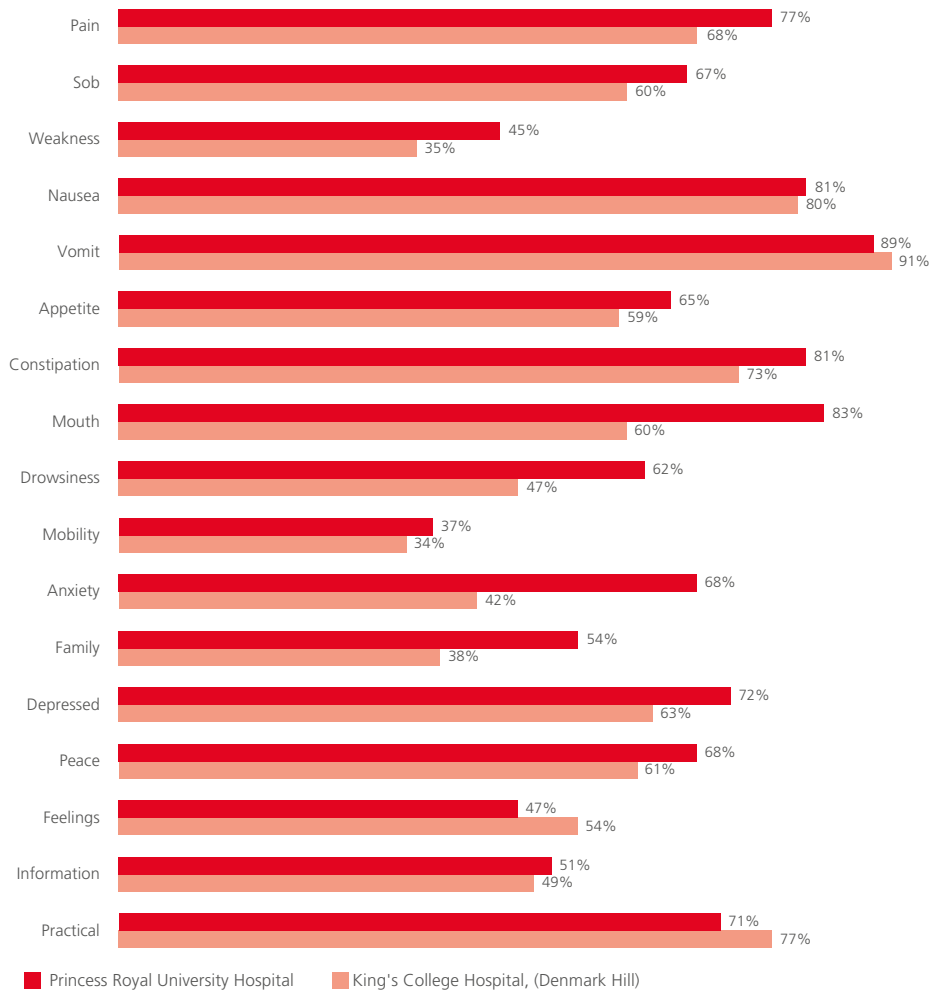
breathlessness are more difficult to alleviate. The gaps identified in this monitoring has led us to new research in the Cicely Saunders Institute to pioneer better treatments into all the symptoms that people face.

Figure 16 | Prevalence of palliative care symptoms and concerns at first assessment, King's College Hospital (Denmark Hill), and Princess Royal University Hospital; 2016–17



This figure shows the proportion of patients with a moderate, severe or overwhelming level of that symptom at the start of phase in whom there was an improvement by the end of the phase of illness.

Figure 17 | Improvement in palliative care symptoms and concerns (IPOS items), King's College Hospital (Denmark Hill), Princess Royal University Hospital, 2015–16



End of life care in the last days and hours of life

We aim to upskill and empower clinical teams to deliver high quality, consistent and compassionate care for all people that are approaching the end of their lives. Services are designed to complement and support the care delivered by other hospital and community services. We also aim to ensure that those patients and families who need input from specialist palliative care professionals receive this when needed.

Strategic approach for improving end of life care

We have established End of Life Care Strategy Groups covering all sites to oversee, monitor and review implementation of CAG, trust, and national initiatives to improve the quality of care for dying patients and their families. The group includes members from palliative care but extends beyond this to key individuals from other specialties and trust executives.

Shared key priorities common to all clinical teams within the CAG include:

- Upskilling colleagues to deliver compassionate high-quality care to dying people and their families, ensuring that people are consistently treated with dignity and respect;

- Improving the identification of people that are dying, including electronic notifications to palliative care teams and out of hours practitioners;
- Upskilling inpatient and community teams to have the confidence and skill to develop and implement individualised end of life care plans for patients that are dying, including proactive management of physical symptoms, psychological distress, spiritual care needs, identification of preferred place of care and managing family/carer distress;
- Electronic prescribing order sets, supported by readily available clinical guidelines, to ensure symptom control needs are met;
- Developing an education strategy to underpin sustainable improvements in the quality of end of life care including a network of End of Life Care champions and link nurses;
- Robustly monitoring quality of care. This includes participation in national audit work, and a proactive approach to seeking feedback from patients, staff, and bereaved carers;
- Research and development to ensure new initiatives are evaluated (e.g. acute medicine interface/palliative care) in Intensive Care Unit, continuing to participate in research, and ensuring research and patient outcomes are embedded into clinical practice;
- Processes to support rapid discharge of patients to their preferred place of care at the end of life. This includes sharing of treatment escalation plans via Coordinate My Care, the London-wide electronic palliative care coordination system. This enables us to share information with colleagues across multiple organisational boundaries in order to improve outcomes for our patients.

Highlights from across the CAG

Leading on quality improvement nationally

In March 2016 Guy's and St Thomas' was selected from 40 hospitals to be one of 10 members of the 'Building on the Best' national programme for improving End of life Care in acute trusts. A programme of quality improvement work has been undertaken, with a sustainable community of practice continuing. Our end of life care leads now represent acute trusts on the Hospice UK quality improvement advisory group.

Practical support for those facing death of a loved one includes concessionary car parking, meal vouchers, fold out beds and packs with toiletries for those staying in hospital. A range of written information is available to support communication with families.

Bringing people together

All our clinical teams regularly run Dying Matters events bringing together local charitable and NHS organisations with members of the public to encourage open discussion of end of life issues and signpost resources.

Proactive support offered to patients and families by spiritual care teams at Guy's and St Thomas', enabled by electronic EoL notifications routinely copied to spiritual care.

Supporting children

Our palliative care social worker teams have developed a range of resources for children whose relative has a life-limiting illness, or who are bereaved.

Priorities for the care of the dying

At Kings College Hospital the 5 Priorities for Care of the Dying have been adapted into the ICARE framework to give generalist hospital teams a memorable prompt to consider the holistic needs of dying patients. ICARE is used both in formal staff education and in real time clinical practice.

Developing resources for patients, carers, and staff

Our clinical team at Guy's and St Thomas' is working with the Royal College of Physicians and other key stakeholders to develop a suite of resources for patients, carers and staff in relation to advance care planning conversations and discussions about cardiopulmonary resuscitation.

Priorities for the Care of the Dying Person

- Wherever possible the decision to commence an end of life care plan should be made by the responsible Consultant following a face to face assessment of the patient and in consultation with a senior nurse who is familiar with the patient.
- Where the Consultant who knows the patient best is not available, the decision may be taken by an experienced Registrar in discussion with an available Consultant and a senior nurse. This decision should be agreed with the relevant Consultant as soon as possible.

| | |
|-------------------------|---|
| i Identify | <ul style="list-style-type: none"> • Identify that a person is dying • Deterioration in patient's condition suggest the patient is actively dying i.e., has the potential to die in hours or short days • Exclude reversible causes e.g., renal failure, infection, hypercalcaemia, opioid toxicity, over sedation • Is specialist opinion needed from the consultant with experience in the patient's condition? |
| C Communicate | <ul style="list-style-type: none"> • Communicate sensitively with the dying person and those identified as important to them • Explain the recognition of dying or the potential for dying and rationale for this • Discuss and agree an individualised plan of care with the patient and those identified as important to them • Communicate with the rest of the MDT and others involved in delivering patient care • Clearly document this plan of care and all conversation in the medical notes |
| A Assess | <ul style="list-style-type: none"> • Assess the wishes and needs of the dying person (including symptom control, psychological, social and spiritual) • Consider preferred place of death |
| R Respect | <ul style="list-style-type: none"> • Respect the needs of those identified as important to the patient • Engage them in care as much as they wish • If contact genuinely impossible then document reason (e.g., no family) |
| E Establish | <ul style="list-style-type: none"> • Establish an individualised plan of care which should include decisions around nutrition, hydration, symptom control, psychological, social and spiritual support • Minimum 4 hourly review and delivery of care by nursing staff • Minimum daily review by responsible medical team • MDT review (to include the responsible Consultant or Registrar and a senior ward nurse) maximum of every 3 days and/or the patient improves or the patient and/or family or healthcare professional express any concern over the plan of care • Is plan of care still appropriate? (e.g., has patient condition improved?) • Is referral to palliative care team required? (e.g., uncontrolled symptoms, support for patient, family, and/or MDT) |

A strategic approach to education and training

including specialist end of life care practitioners and Practice Development Nurses, eModules, mandatory training. We deliver a monthly two day multiprofessional "Transforming End of life Care" course for all health care professionals at Guy's and St Thomas' and have developed an advanced communications skills training course for staff. Our team run an end of life care simulation session on the Trust induction programme and have launched a matrix outlining training considered essential to different professional roles alongside a prospectus of courses available. Innovative education has also been a focus of the End of Life Care Darzi fellowship throughout 2017/18.

Learning from feedback

iPads in King's College Hospital bereavement offices to support improved response rates in bereaved carer surveys (sought as a matter of course after every hospital death).

Enabling and spreading innovation

Innovative ways of utilising the volunteer workforce to support dying patients are being explored, an example of this is a hand massage therapy service developed by the social work team at Kings College Hospital.

Development of a symptom control observation chart

at Guy's and St Thomas' to enable ward staff to anticipate, monitor and treat physical symptoms effectively.

Feedback to improve our services

The QUALYCARE survey is a postal survey of bereaved carers aiming to examine the quality of care provided to people in their last three months of life. This survey has been used in four studies over the past seven years, and two further surveys are underway.

The survey takes about 60 minutes to complete. It includes questions in the following areas:

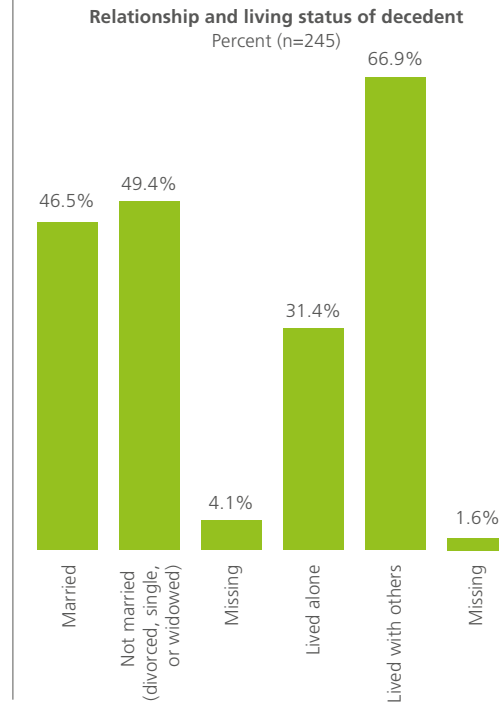
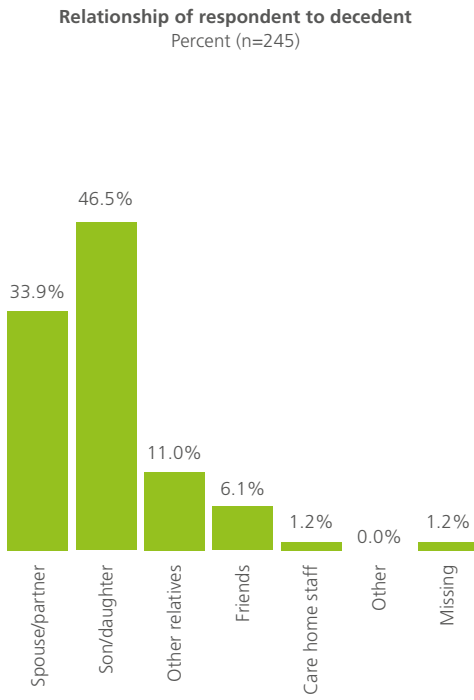
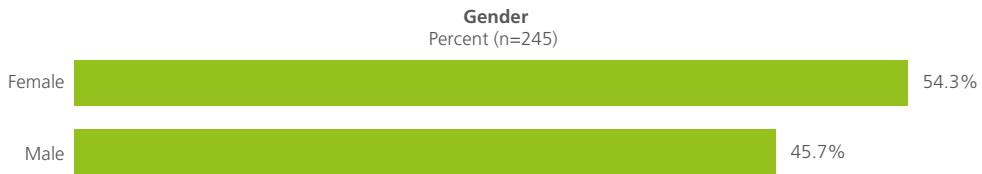
- Experiences and quality of care in each setting that the decedent stayed in the last three months of their life;
- Problems and concerns in the last week of life;
- Preferences for place of care and place of death;

- Caregiver burden in the last three months of life (Zarit Carer Burden Index);
- Caregiver grief inventory (Texas Revised Inventory of Grief);
- Demographic details of decedent and respondent.

As part of the International Access Rights and Empowerment (IARE) study, this survey was distributed to patients aged 65 years or older who had received specialist palliative care at King's College Hospital or Guy's and St Thomas' and died in 2012. Summary data is presented in Figures 18 and 19.

Figure 18 | Summary of deceased patients' demographic and clinical characteristics

| Characteristic | | Number (n=245) | Column % |
|----------------------|----------------------------|----------------|----------|
| Decedent age (years) | Mean (Standard Deviation) | 79.7 | (8.3) |
| | Median (Range) | 79 | (65–101) |



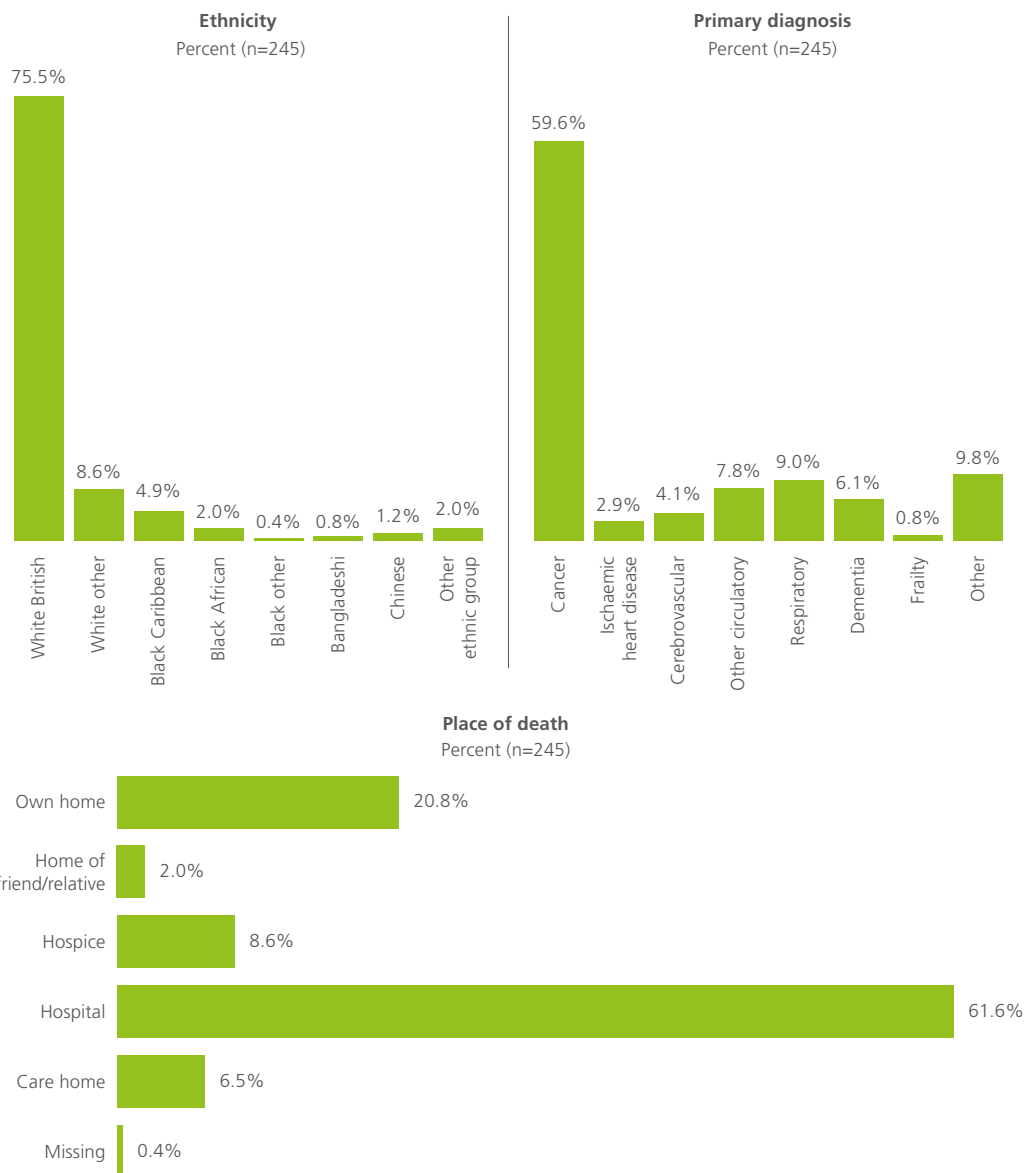
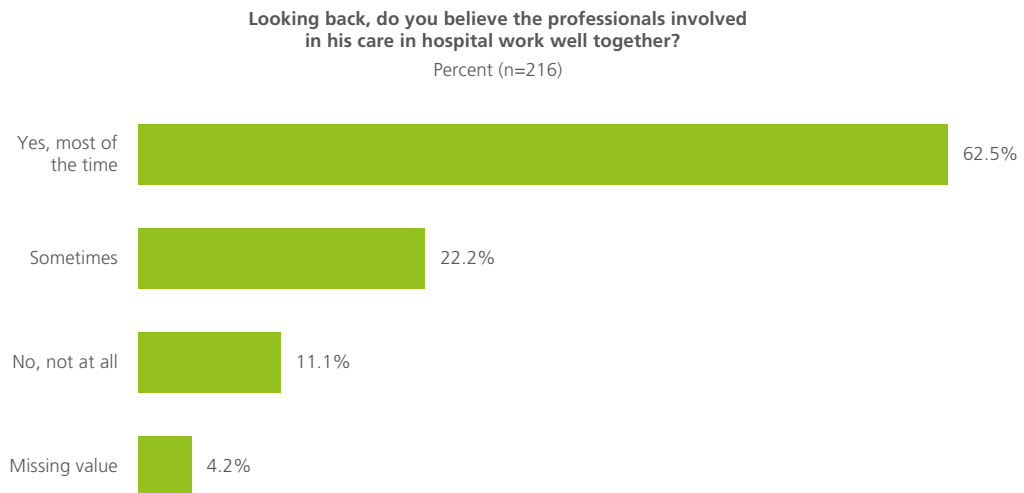
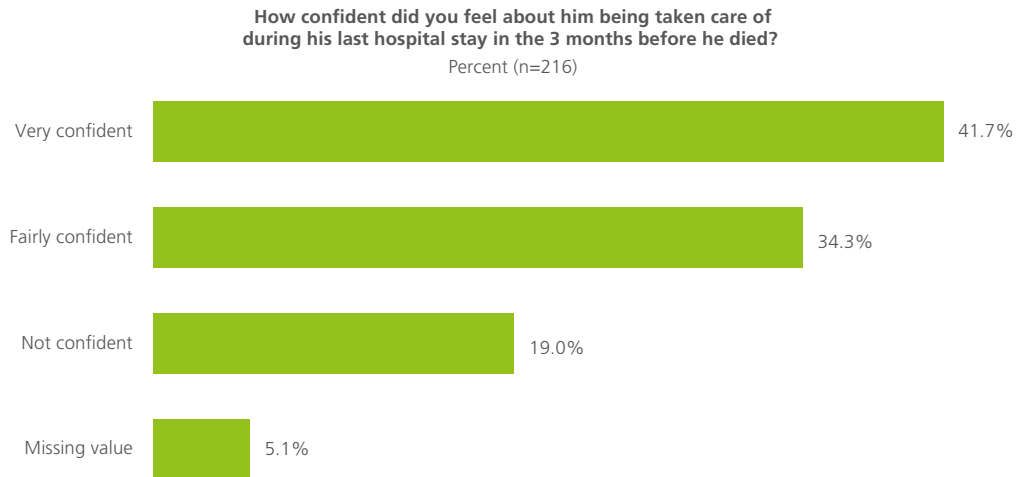
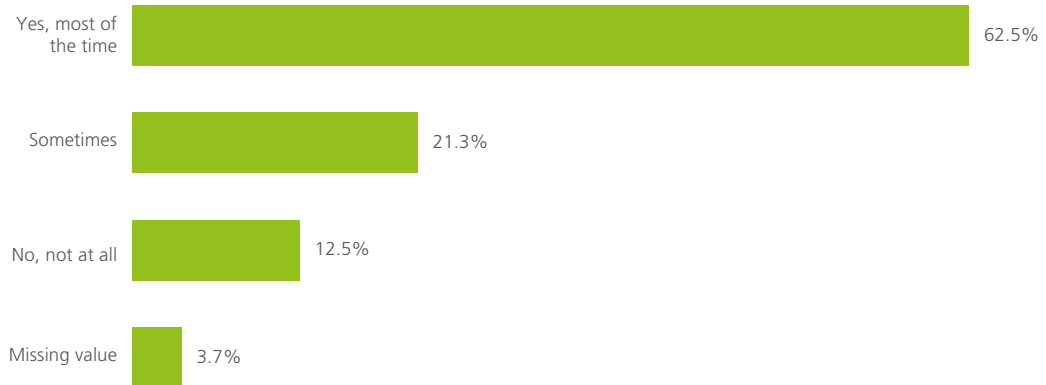


Figure 19 | Relative or friend's experience of or satisfaction with care received by the decedent in hospital (n=216)



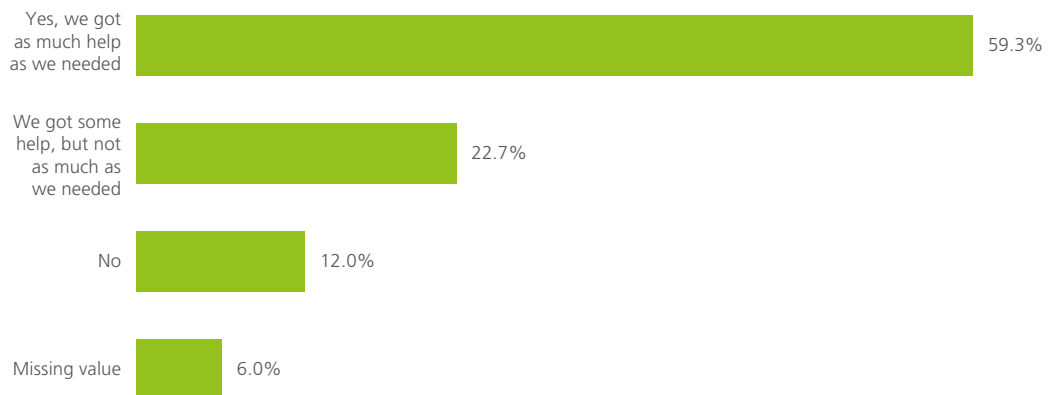
Looking back, did you receive information about his condition that was clear and easy to understand?

Percent (n=216)



Altogether, do you feel that he, and you and your family got as much help and support during his last hospital stay as you needed?

Percent (n=216)



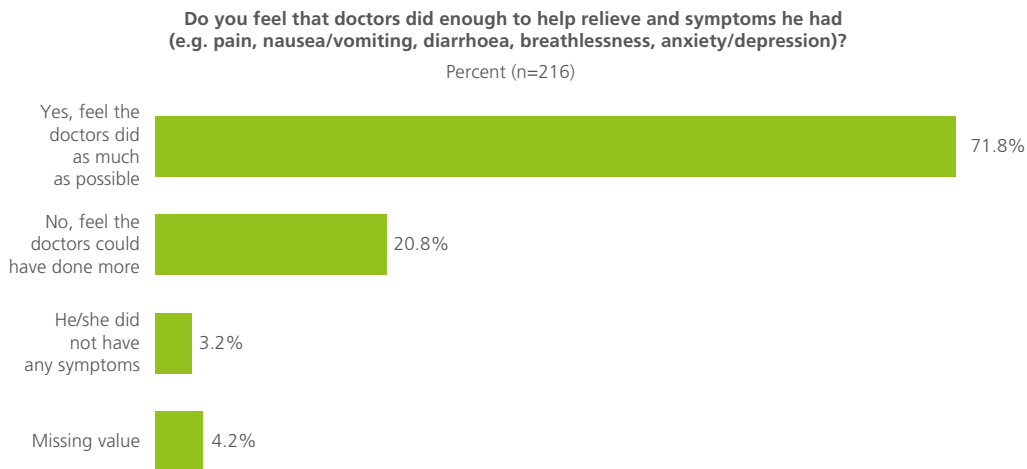
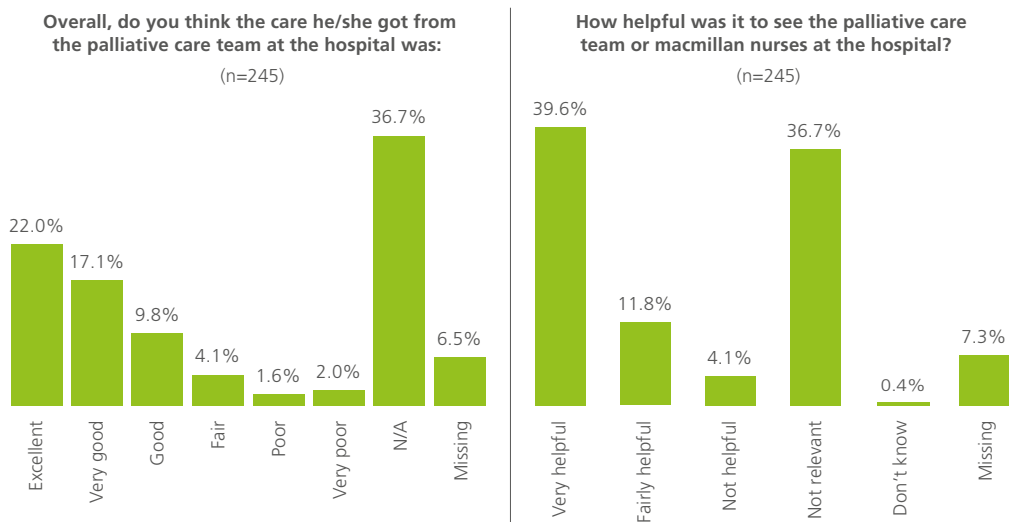


Figure 20 | Questions about palliative care in hospital setting.



Future plans for bereaved carer surveys

We are currently in the process of surveying bereaved relatives for the IARE II study, using an updated version of the QUALYcare survey. This study focuses on older people who died in hospital, hence we will be surveying bereaved relatives of decedents at King's College Hospital and Princess Royal University Hospital. A twin survey is being conducted in Dublin, Ireland, to allow for international comparison.

Staff surveys

Providing support for colleagues in other teams is an essential element of the service we provide. We conduct staff surveys periodically to ensure that our service is aligned with the needs of our referring colleagues. We envisage building on this approach as part of our CAG development, ensuring that colleagues from across King's Health Partners are aware of how we can help and support them and our patients.

King's College Hospital (Denmark Hill) and Princess Royal University Hospital sites staff survey of palliative care 2017

Hospital staff gave predominantly positive feedback about palliative care service operation and were mostly aware how to refer to palliative

care services (89%), however staff were less sure about how to refer out of hours (56%). How the current model of palliative care met patients' end of life care needs was rated 'sufficient' to 'excellent' by 88% of respondents. Satisfaction with the service provided by the palliative care team was rated at 79%.

From the feedback collected it can be concluded that in general the needs of hospital staff are being met but there remains a need to increase awareness of out of hour's referral and develop an educational strategy to reach out and further develop knowledge and skills in a range of areas including from symptom management and patient/family support.

Guy's and St Thomas' staff survey of palliative care 2014

We surveyed all Guy's and St Thomas's Foundation Trust hospital Consultants, as well as GPs in Lambeth, Southwark and Lewisham who are served by our community palliative care team, to ascertain their views on our service. Key themes identified: Positive feedback provided on many aspects of the service, including positive comments about individual team members. There was a lack of awareness amongst some colleagues regarding our 24 hour on-call service, regarding referral pathways and outpatient clinic service. Importantly there is support from other disciplines for the development of inpatient specialist palliative care beds and a demand for specialist palliative care team to provide more input into the Emergency Department.

We strive to embed feedback from our patients, carers and fellow healthcare professionals into our daily practice, and use this information to inform service developments across the CAG.



Supporting
Patients,
Families
and Staff

The palliative care nurses always treated Dad with dignity, respect and kindness even when he wasn't aware of what was happening. The care was far beyond our expectations.

Bereaved carer – King's College Hospital end of life care survey, November 2017

Supporting patients, families and staff across the CAG

The following provide examples of additional activities, facilities and support offered by the Palliative Care CAG including:

- Open access drop in information and support centres, for anyone, staff, patient, family – at Cicely Saunders Institute, and Guy's Hospital campus – see Figure 22;
- Schwartz rounds to discuss difficult cases, see Figure 23;
- Dedicated resources for children (see Figure 21), talk back and debriefing sessions and Dying Matters events (Figure 24).

Figure 21 | Resources developed by the Kings College Hospital palliative care social work team to support children whose relative has a life limiting illness or who are bereaved



Figure 22 | The Macmillan Support Centre (Cicely Saunders unit King's College Hospital) and the Dimbleby Cancer Centre at Guy's Hospital provide a welcoming and relaxing environment for patients, carers or family and friends of people with cancer or other long-term and life threatening conditions. Services offered include: psychological support, benefits advice, support groups and complementary therapy.



Schwartz Rounds are open to all members of staff across the CAG giving an opportunity to discuss the social and emotional challenges and ethical dilemmas associated with our jobs. Feedback is very positive, as set out in the chart below.

Figure 23 | Summary of feedback on Schwartz Rounds



Topics for Schwartz Rounds in 2017–18 have included paediatric organ donation, the Grenfell Tower fire, parent fabricating illness and “my best day at work”. Some examples of feedback are provided below.

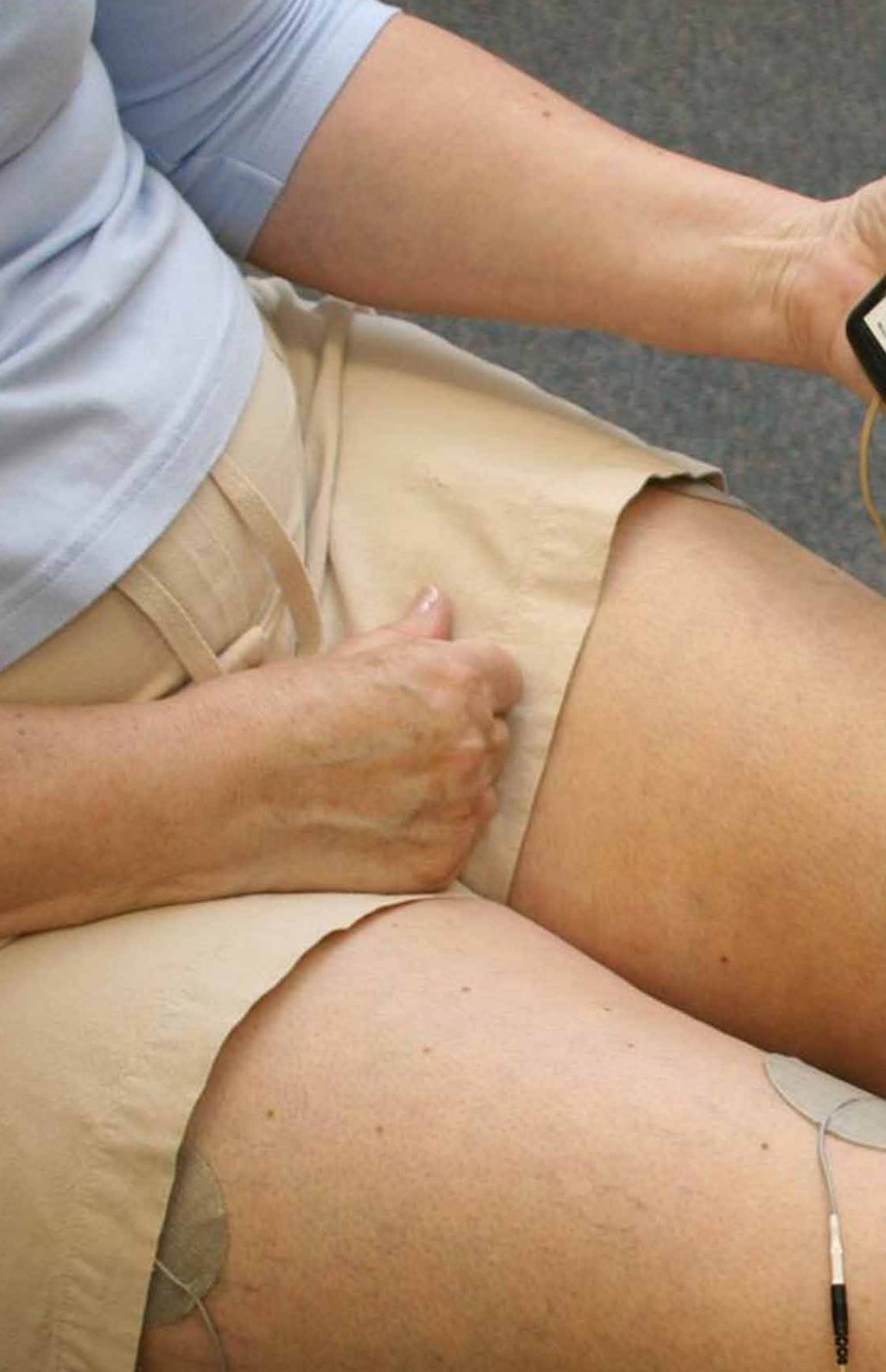
“The openness and vulnerability demonstrated by today’s panel surpasses anything I have ever seen. I have unfounded respect for them all and commend them all for their honesty.”

“The story was exceptionally well told and very relevant – showed importance of working in a team.”

“Lovely to hear a positive story from beginning to end. Thank you.”

Figure 24 | Clinical teams across all sites hold annual Dying Matters events to raise awareness of death and dying. These events are an opportunity for organisations, charities, local community and outreach groups to come together to inform attendees about the variety of help, support and resources available relating to end of life care, planning and bereavement support. Clinical staff, patients, carers and the general public are able to talk about dying and a range of issues relating to palliative care and advance care planning.





Service
Innovations

We need to go on learning so that in 10 years' time we are doing things better than we are now.

Pioneering and evaluating new models of care and interventions

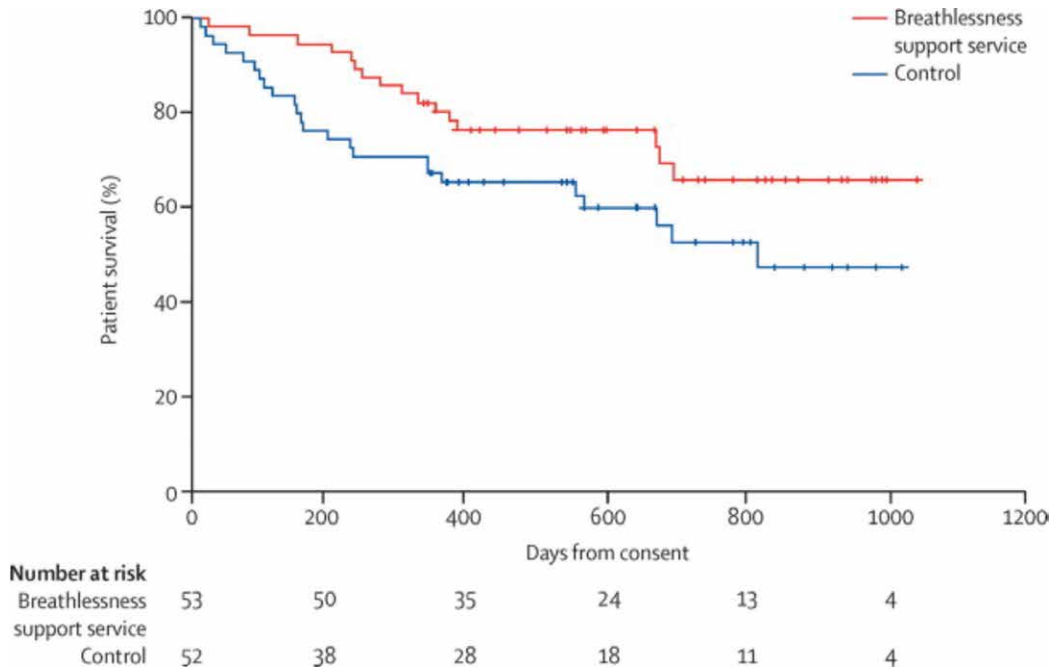
If we are to respond to the urgent challenges of improving care in the future, better services are needed to support people, whatever their condition and wherever they are cared for. We have developed a series of innovative world leading programmes and projects to explore this, and to discover, develop and evaluate new models of care that are more integrated with existing services and consider the needs of people with multi-morbidity.

Breathlessness Support Service

Breathlessness is a common and distressing symptom that causes considerable disability and social isolation. Two million people in the UK, and more than 75 million worldwide, are affected by breathlessness every year. They have high use of emergency services and breathlessness is also a trigger of deterioration. People with

advanced disease and breathlessness have shorter life expectancy and, on average 14 other symptoms, such as pain, fatigue and depression. In a randomised controlled trial led by Professor Irene Higginson, we investigated the effectiveness of the Breathlessness Support Service, a short-term, single point of access service integrating palliative care, respiratory medicine, physiotherapy and occupational therapy. The service improved patients' view of how their breathlessness was reducing their quality of life, compared with the control group (mean difference 0.58, 95% CI 0.01–1.15, $p=0.048$; effect size 0.44). Overall, survival over six months (94% vs. 75%) was also improved (Figure 25). The findings support the early integration of palliative care for patients with advanced disease and breathlessness, and have been widely shared, including in the American Society for Clinical Oncology (ASCO) guidelines for integration of oncology and palliative care and published in *Lancet Respiratory Medicine*.

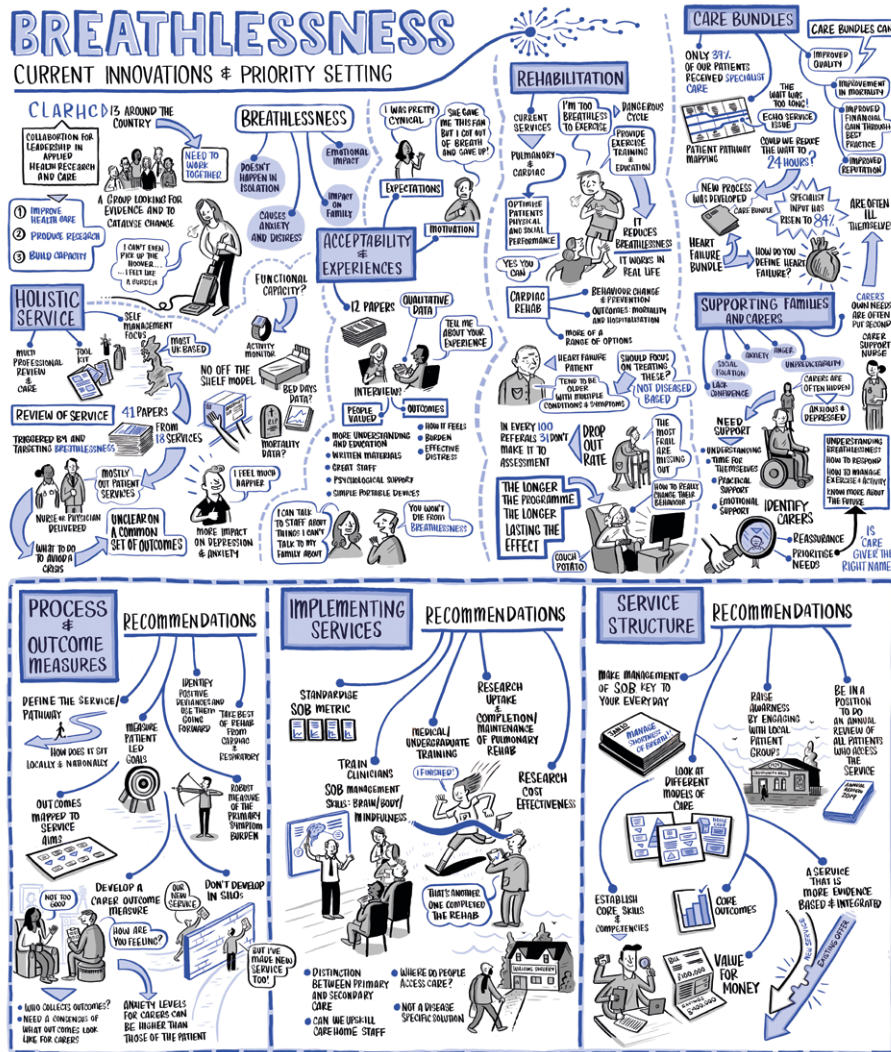
Figure 25 | Kaplan-Meier estimates of survival according to study group (Higginson et al., 2014)



Based on this we have completed a meta-analysis of the effects of breathlessness triggered services in advanced disease. This National Institute of Health Research project led by Dr Matthew Maddocks reports how acceptable, effective, and cost-effective breathlessness triggered services are. We also assess which people are most likely to benefit from these services and if certain types of service are more effective. Our meta-analysis shows overall benefits of the services on psychological health and is

currently in press. Our responder analysis showed greatest benefit was gained by those with the worse breathlessness and least control. A group of stakeholders subsequently met to make recommendations on policy and future services, which centred on improved access to multi-professional care for patients and carers. Figure 26 shows sections from the graphical record of the consensus day which included clinicians, academics and potential service users.

Figure 26 | Graphical record of the consensus day



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Cicely Saunders International
Returns care on the road of life

Collaboration for Leadership in Applied Health Research and Care South London (CLARHC South London)

NHRI CLARHC
Northwest London

NHS
National Institute for Health Research

Word leading Intensive Care Unit model of care

King's College Hospital currently has one of the largest critical care services in the UK, known worldwide for excellent treatment and care and providing specialist emergency cover for 5.5 million people across south east London and England. The service sees patients from the widest range of ethnic backgrounds and socioeconomic groups in the developed world, and treats every kind of critical illness and injury. In 2007 a collaborative project between intensive care and palliative care was successfully funded through NIHR to develop an innovative model of care to support patients and carer's in Intensive Care Units in whom the prognosis is uncertain. Research findings have now been fully implemented and embedded across all the critical care units at the King's College Hospital, Denmark Hill site. In practice, this means there is a full time palliative care social work service attached to the four critical care units providing psychosocial support to patients and families as well as educational and emotional support to nursing staff through reflective groups and debriefs. In addition to this, bereavement support is provided and follow-up on all deaths that happen on these wards. There has also been a psychosocial assessment tool completed for all patient admitted to the units. Findings of this project have been published and the development and enhancement of the service continues as the number of critical care beds increases.

In the past year we have also partnered with the wards to create memory boxes for children, received a considerable grant for resources to create a children's library of books and had rollout of teaching sessions for staff on supporting children visiting the wards. We have also trialled a weekly supportive group for nursing staff and presented this audit at the British Association of Critical Care Nurses annual conference. As a result of the major incidents in London this year, the social work team along with the palliative care matron have been involved with initial discussions in improving staff support for critical care nurses in these instances in the future. There is a regular social work and Clinical Nurse Specialist presence at team meetings and educational sessions for doctors, nurses and therapists across critical care. We are hoping to expand the social work service in response to increased demand on what is a unique and important service and look forward improvement in psycho-social care and palliative care partnership in the year ahead.

Over the next one to two years we plan to review our provision of specialist palliative care to intensive care units across all King's Health Partners sites, developing our provision at Guy's and St Thomas' further based on our experiences at King's College Hospital. In addition, in July 2018, the largest critical care centre in Europe will open at King's College Hospital. Plans include an increase in bed size as well as ground breaking innovations in patient care including technological advancement and an outdoor critical care space. Our clinical service will support this exciting development.

Recently, one of our social workers was a part of an event at the House of Lords, along with critical care staff and previous patients, to promote the new building.

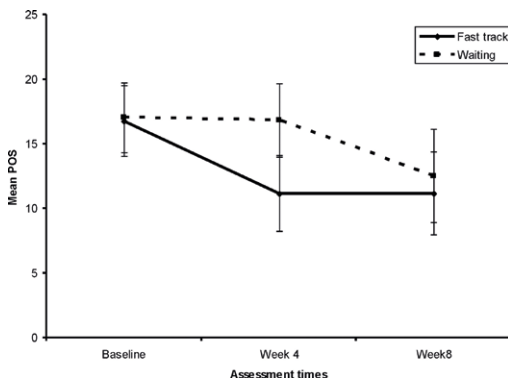
Adapting and evaluating a short-term palliative care intervention for patients with long-term neurological conditions – OPTCARE Neuro

Long-term neurological disorders (e.g. Parkinson's disorders, Multiple Sclerosis, motor neurone disease) affect approximately 10 million people in the UK, and around one billion globally. For many, the disease becomes progressive. In these instances, and in late-stage disease, people often experience profound symptoms, deterioration in their quality of life and emotional, social and spiritual concerns. We have developed a joint programme of work, bringing together neurology, rehabilitation and palliative care, to tackle the many problems experienced by people with long-term neurological conditions. Professor Irene Higginson and Dr Wei Gao developed and lead a world first multi-centre national trial (OPTCARE Neuro), to investigate the effectiveness of a new service, modelled using evidence from our research and others', offering early short-term integrated palliative care for people with long-term neurological conditions.

Adapting and evaluating a Hospital2Home case conference model for patients with Progressive Idiopathic Fibrotic Interstitial Lung Disease (H2H-ILD)

In partnership with the Royal Brompton Hospital, we trialed an individualised multi-professional case conference intervention (H2H), delivered in the patient's home using a fast-track randomised controlled trial with qualitative interviews. Those who received H2H immediately showed a significant improvement in their palliative care needs (as measured by the Palliative Care Outcome Scale), and this was sustained eight weeks after (Figure 27). Patients in the 'Waiting List' group received H2H after four weeks and improved only after they had received the new service. Improved patient and carer quality of life and reduced anxiety and depression were also found. This body of work formed the basis for development of a palliative care needs assessment tool to be used in respiratory clinics in a joint project between the Cicely Saunders Institute and Hull York Medical School), which has been endorsed by the National Institute of Clinical Excellence (NICE).

Figure 27 | Line diagram showing change in mean (with 95% CIs) Palliative Care Outcome Scale (POS) over time, Hospital2Home palliative care trial (Bajwah et al., 2015)



Neuromuscular electrical stimulation to improve exercise capacity in COPD

People with chronic respiratory disease often report a reduced ability to exercise, which affects their everyday independence. In a multicentre trial by Dr Matthew Maddocks, we determined the effectiveness of a novel exercise treatment called Neuromuscular Electrical Stimulation (NMES), which produces a comfortable contraction of the thigh muscles. NMES can be completed at home and does not provoke breathlessness like other forms

of exercise can. Fifty-two people were randomly allocated to receive either active or placebo NMES, daily, over 6 weeks. Compared to placebo, active NMES led to improvements in leg muscle strength and size, which translated into an improved ability to exercise. People who had received NMES also reported greater ease in undertaking activities of daily living, such as climbing the stairs.

Improving how clinical uncertainty is managed and improving decision making

ImproveCare, a collaboration between the Cicely Saunders Institute and the University of Cambridge, is an NIHR feasibility cluster randomised controlled trial comparing the AMBER care bundle to usual care. The AMBER care bundle (which stands for **A**ssessment, **M**anagement, **B**est Practice, **E**ngagement, and **R**ecovery uncertain), is a complex intervention developed to better care for hospital patients whose situations are clinically uncertain and who are at risk of dying during their hospital stay despite treatment. For these patients, staff will develop a plan with patients (where possible) and their family, documenting what is important to them. The patient's status and their wishes will be revisited daily.

Comparing palliative care service delivery models across England, resource utilisation and cost-effectiveness – C-CHANGE

Models of palliative care vary across the country, even within care settings (eg community, hospice or hospital advisory), and care is also delivered diversely. The C-CHANGE project compares different models of palliative care and considers how different models of service delivery affect resource use and cost-effectiveness. To ensure we can comprehensively characterise different models of palliative care provision, C-CHANGE has developed criteria to define models of palliative care delivery for people with advanced disease across England. The methodology includes semi-structured interviews with team leads, and piloting criteria with study sites.

SPACEtoolkit for community services

This five-year study, led by Dr Catherine Evans, will develop and test the feasibility of a new toolkit to improve care in the community. It builds on earlier studies testing single components of services

and care. The Symptom and Psychosocial Assessment and Communication Evaluation toolkit (SPACEtoolkit), aims to improve communication with and assessment of older people admitted to community hospitals, to reduce anxiety and distress for them, and those close to them. The study will be an important step forward in transforming care in community hospitals by providing staff with evidence-based tools to improve care. It will also enhance our understanding of care for people in this neglected situation, and provide a solid foundation for a future study to test how the tools we develop may work nationally.

Effectiveness and cost-effectiveness of inpatient palliative care

Most adults die in hospitals and most die from advanced chronic illness. With an ageing population, the demand for specialist palliative care is likely to continue. Through NIHR funding, we are conducting a Cochrane systematic review led by Dr Sabrina Bajwah of the evidence of the effectiveness and cost-effectiveness of specialist palliative care. This review has the potential to aid the future development, funding, and implementation of, evidenced based inpatient specialist palliative care locally, nationally and internationally.



Education
and
Training

It's wonderful how the MSc in Palliative Care combines being extremely professional, yet deeply personal. Whilst the academic focus is very much a part of this programme's greatness, at its heart lays the goal of personal development. This is evident at every step of the way.

Tal Eskol, Paediatric Palliative Care nurse, Israel,
January 2018 intake

Education and training across the CAG

The new Palliative Care CAG provides us with an exciting opportunity to boost our education and training profile across King's Health Partners, and work with other CAGs to facilitate professional development of students and staff across the partner organisations. Our CAG already provides support to education, training and learning opportunities for students and trainees.

MSc, Postgraduate Diploma and Postgraduate Certificate in Palliative Care

Our Master of Science (MSc) in Palliative Care is the longest running multi-professional research-based programme in the world. The philosophy of the MSc and the associated 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 enhance their clinical practice and to develop relevant services and policy.

The Postgraduate Taught Experience Survey (PTES) provides an important opportunity for students to reflect on their time at King's College London and to tell us about their experience of the Palliative Care programme (MSc/PG Dip/PG Cert). In 2016/2017 we were delighted to learn that our course received very positive results, with more than 96% of students reporting they are satisfied with the course, an increase from 90.1% in the previous year (2015/2016).

Undergraduate programmes

The Guy's, King's and St Thomas' School of Medicine is the largest provider of undergraduate healthcare training in Europe, with more than 450 medical students in each year.

The undergraduate palliative care curriculum is taught through seminars, symposia, student selected components, bedside clinical teaching, hospice visits, and Objective Structured Clinical

Examinations (OSCEs). Our programme provides comprehensive coverage of the Association of Palliative Medicine undergraduate curriculum and abides by the recommendations for undergraduate medical education of the European Association of Palliative Care and the General Medical Council. The clinical and academic team extensively teach. Teaching methods include symposia, case based and clinical bedside teaching, the use of video material, clinical vignettes, role-play, and hospice visits where students meet patients (and their families) as part of a 'goldfish bowl' teaching exercise. The early curriculum explores communication skills, sociological theories of loss and grief and medical ethics towards the end of life.

The palliative care approach to holistic patient and family-centred assessment is taught across the undergraduate curriculum to all medical students at King's College London. Understanding the inter-play between psychosocial, spiritual and physical domains to best formulate an individualised care plan for the patient and their families is core to this.

The clinical training is in the long-term conditions block of the new 2020 undergraduate curriculum and is taught by a multi-professional team from the Palliative Care CAG with particular emphasis on integrating with the elderly care curriculum.

Palliative care is also integrated into clinical rotations for core specialities, eg development and ageing, and emergency medicine, so that end of life care, death and dying and the

doctor' role at these times is seen as integral and expected. The Palliative Care CAG also offers a range of student-selected components in year four with optional tutorials and an extended essay. These are often oversubscribed and several of the essays have been entered into external competitions eg conferences held by Association for Palliative Medicine of Great Britain and Ireland. Scholarly projects are offered for undergraduate medical students, with 11–20 placements currently on offer. In the final year, students attend a half-day hospice visit, as part of their General Practice attachment. Again, the hospice visits have been well evaluated by students. Most of our consultants, clinical academics, registrars and clinical PhD fellows examine on the undergraduate programme.

Local training for King's Health Partners staff

At Guy's and St Thomas' we continue to deliver a regular course called 'Transforming End of Life Care'. This has been supported by a funded programme of research to evaluate and further develop training for generalists in palliative and end of life care across acute and community settings. This included evaluating and refining the existing 'Transforming End of Life Care' course, as well as collecting data to inform the development of new course material (e.g. extra modules for specific staff groups) and determine the best way to assess effectiveness of training for non-specialists in

the future. The course was also expanded to include the King's College Hospital Denmark Hill site. Findings from the before-and-after evaluation using 14 self-assessment questions (pre-course and post-course) that examined confidence, understanding and knowledge of EoLC topics identified improvements across a number of important domains including understanding and implementing Fast Track discharge (mean change 3.34, CI 2.6–4.1, $p < 0.001$), confidence managing patients at the end of life (mean change 2.01 CI=1.8 to 2.3, $p < 0.001$) and understanding of grief and bereavement (mean change 1.47, CI=1.2 to 1.7, $p < 0.001$) among others. This work has been published and presented at international conferences including the European Association for Palliative Care congress.

We now deliver a one day Advanced Communication Skills training course at Guy's and St Thomas', open to internal and external staff from across the region. This is in addition to other simulation-based education and training and support for "Sage and Thyme" communication skills training.

In 2016, Dr Jonathan Koffman was awarded funding from Health Education North West London to evaluate a training programme (Difficult Conversations) designed to enable health and social care professionals to identify what a difficult conversation is, and to then provide course participants with the skills and

knowledge to conduct difficult conversations safely with a patient or family member.

Our evaluation from 886 workshop participants shows improvements in confidence and skills, and that they valued the role play and inter-professional learning.

The work programme also included developing six e-learning sessions to accompany/enhance classroom teaching. These e-learning sessions, which are in the final stage of development, include (i) grief and bereavement, (ii) culture and ethnicity, (iii) dementia, (iv) legal issues, (v) advance care planning, (vi) motivational interviewing, and (vi) disadvantaged or socially excluded patient populations.

Work is also underway at Guy's, King's and St Thomas' with the Royal College of Physicians in relation to the "Second Conversation" project, supporting staff with complex decision making and discussions with patients and those important to them.

Electives and placements

Elective placements are regularly undertaken across the Palliative Care CAG 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 Royal Trinity Hospice and St Christopher's Hospice.

Figure 28 | Members of the Palliative Care CAG with visitors from Taiwan



Specialty training in palliative medicine

Dr Shaheen Khan is the Speciality Training Committee chair for the London/Kent Surrey and Sussex Palliative Medicine specialist registrar training programme, the largest programme of its kind in the UK. Dr Polly Edmonds is

deputy chair of the national Specialist Advisory Committee for Palliative Medicine. Professor Irene Higginson is on the exam board for the Royal College of Physicians exit examination in Palliative Medicine. These posts have contributed to substantial local and regional improvements across several domains of the General Medical Council trainee survey, including clinical supervision, handover and workload.

Nursing and allied healthcare professionals

Our clinical teams at Guy's, King's and St Thomas' hospitals provide input into trust induction programmes and provide teaching in palliative care to inpatient and community staff. There is a teaching programme for developing end of life care champions, and another for ward-based teaching, with sessions tailored to suit the needs of different clinical areas. We plan to extend the delivery of this teaching to include colleagues in SLaM via our Mind and Body programme work.

Visitors across the CAG

We regularly have local, national and international visitors to both our clinical and academic teams across the CAG. Visitors will often spend time with both the clinical and academic teams.

Since July 2016 we have hosted over 50 individual and group visits, lasting from one day to several months. Visitors have come from Japan, Singapore, China, South Korea, Taiwan, Canada, USA, Chile, Ireland, France, Italy, Portugal, Germany, Switzerland, Sweden, Denmark, Israel, Lithuania and Australia. Our visitors programme enables us to disseminate our evidence widely and connect with leaders and emerging leaders in palliative care internationally. Several of our individual visitors have resulted in academic collaborations with the Cicely Saunders Institute, and implementation of our outcomes tools into clinical practice internationally.

Education and training initiatives

We have created a number of initiatives to drive our education offering both to our members and also externally to patients, stakeholders and practitioners.

Regular clinical activities

Our clinical teams deliver a highly interactive suite of educational activities for staff in acute and community settings, in particular they host events for General Practitioners (GPs) including:

- Quarterly practice meetings
- An annual South East London doctors event
- On-call teaching session
- Evening tutorials
- Vocational Training Scheme training events
- Lambeth and Southwark Protected Learning Time events
- National "Hot topics for GPs" course

All these are regularly evaluated and modified, where appropriate, in order to maximise learning and teaching satisfaction. We also reach other groups with specialist lectures and events. Recent examples include events held with Speech and Language Therapists, the Guy's and St Thomas' @Home service, and community dentists.

Cicely Saunders Institute 'Knowledge Exchange Seminar'

The Knowledge Exchange Seminar (KES) represents a free-to-attend forum that offers an invaluable opportunity for south London clinicians, researchers and commissioners to consider current research and evidence and how this has potential to influence clinical practice and inform developing future research.

Specifically, the KES aims:

1. to consider recent local research and emerging evidence, and evaluate how this might influence clinical practice;
2. to inform clinicians of research initiatives and collaboratives currently working to communicate, disseminate, embed and maintain approaches to research and best practice;
3. to discuss the validity of methodology and practices, both holistic and clinical, used to implement research ideas relating to palliative care.

The most recent KES was in April 2018, and dealt with the topic of multimorbidity in palliative care. More than 60 delegates attended the KES and workshops were held jointly between the South London and East of England NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRC) at the Cicely Saunders Institute. Multimorbidity (living with multiple health conditions) affects a growing number of people in the UK and globally, and severely reduces the quality of life of patients and those close to them, especially toward the end of life. This seminar and workshop aimed to share the latest knowledge, discuss research priorities, and identify opportunities for multimorbidity research in palliative and end of life care. The day began with a series of thought-provoking presentations from clinicians and academics working across different care settings, including, Primary Care perspectives, opportunities and challenges in service change, use of routine data to discover the impact of multimorbidity at end of life,

and national and international progress in patient centred outcomes. Delegates contributed to a lively debate of research priorities highlighting the need for multimorbidity research that spans health and social care systems and coordinates care across settings, draws on specialities like palliative care and General Practice which put the person before their disease and delivers holistic care, and uses existing rich datasets to understand outcomes of routine clinical practice in an efficient manner.

Cicely Saunders Institute Evidence update meetings

Monthly 'Evidence Update' meetings that are aimed at local clinical staff and researchers to supplement the Knowledge Exchange Seminars. These meetings offer an opportunity to share recent research relevant to clinical care and policy.

The Cicely Saunders Institute Seminar and Lecture Series

The Open Seminar Series continues to provide 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. The Institute's YouTube channel (www.youtube.com/

user/CSIKCL) features recordings of seminars and lectures where possible, providing an inexpensive platform for learning and engagement.

The Cicely Saunders Annual Lecture

This is a highlight in our educational programme. An open access event is presented by an international leader in the field of palliative care and hosted at the Cicely Saunders Institute with live outside video-links to sites including Cardiff University, the University of Oxford and the University of San Francisco.

Michal Galazka Study Day

In June 2017, the Institute held an all-day workshop entitled 'Palliative Care in 20 years' time: Future Predictions and Global Challenges' in celebration of the life of Michal Galazka, a pioneer of international hospice education, and friend and collaborator of Dame Cicely Saunders and Professor Higginson. Professor Irene Higginson, Professor Richard Harding, Dame Barbara Monroe (former Chief Executive of St Christopher's Hospice) and other speakers, presented the latest research on future needs for palliative care globally, and the challenges ahead.

Speakers posed the question of how governments will respond to the World Health Assembly call to provide locally appropriate, quality evidence-based palliative care, noting

that as populations age globally, the provision of high quality, effective and affordable care at the end of life presents a major challenge for high, middle- and low-income countries. In 2018, the Michal Galazka Study Day theme will be 'New Frontiers, New Technologies' and will include presentations and discussions on the implications and opportunities that digital change brings for healthcare.

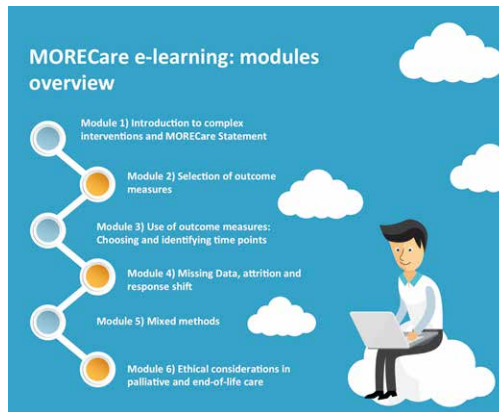
MORECare and e-learning to disseminate research guidance into practice

Despite being a core business of medicine, end of life care (EoLC) 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 are expanding our innovative e-learning platform to enable researchers, clinicians, members of ethical committees, and funders to understand how to conduct high quality, rigorous, and ethical research in end-of-life care.

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 to 10 hours and includes readings, presentations and assessment. So far 202 participants have completed their programme of learning on this platform (see Figure 29).

Figure 29 | Screenshot from the MORECare e-learning platform



The European Palliative Care Academy

The European Palliative Care Academy (EUPCA) (www.eupca.eu) is a joint project of the Robert Bosch Stiftung, Germany, and four academic centres across Europe, King's College London, the Cicely Saunders Institute, the University Hospital of Cologne, Germany, the Nicolaus Copernicus University Toruń, Collegium Medicum in Bydgoszcz, Poland, and the Hospice Casa Sperantei, Brasov, Romania. Together with these institutions, the Cicely Saunders Institute has 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. In May 2017, The European Palliative Care Academy celebrated the graduation of the second cohort of 19 course participants to have completed their Leadership Programme at a ceremony in Brasov, Romania. The students originated from 14 European countries and a wide variety of professional backgrounds.

since

using names

time

eye contact

negotiation

tone of voice

checking understanding

knowing your patient - 'doing your homework'

holistic

trust

LOVE

confidence in situations where you can't make it better

safety

getting out of the 'professional mode'

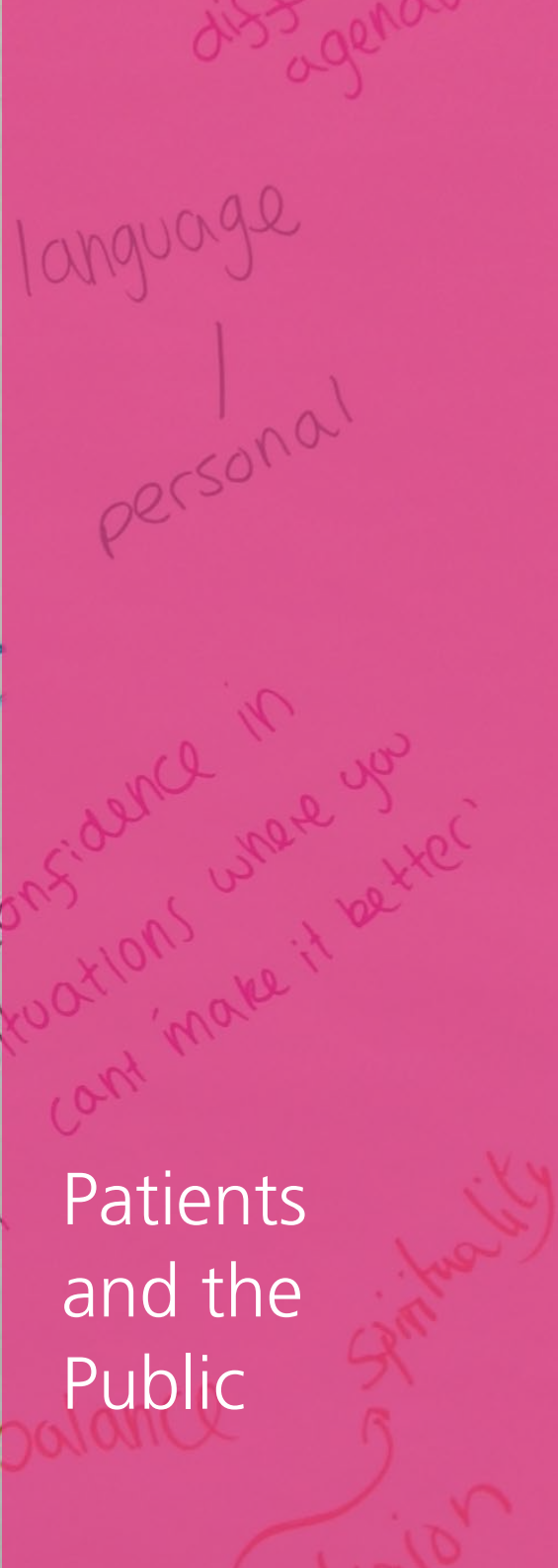
Patients and the Public

Culture

balance

spirituality

union



Having patient experience and perspective added to clinical and research perspectives... gives insight into what is really happening for patients and carers at a healthcare point of delivery... Working together is the perfect combination to gain a balanced perspective to work from.

Sylvia Bailey, Cicely Saunders Patient and Public Involvement Strategy group Representative

Patients and the public at the centre of everything that we do

The Palliative Care CAG aim to facilitate meaningful patient and public involvement (PPI) which will improve the relevance, quality and impact of our research, and ensure that research is focused on the needs and priorities of patients, carers and families. PPI is especially important for palliative care as it is a person-centred and holistic specialty, and we want our work to reflect this. There are three key principles we follow in our PPI work:

1. Early involvement to improve research productivity, quality and clinical relevance, and to improve quality of clinical services;
2. A model that uses a high degree of flexibility to increase involvement through virtual and face-to-face methods;
3. Promote the contribution that PPI representatives make and evaluate how this affects the research process and improves the quality of clinical services.

Over the past three years we have developed a programme of activities comprising PPI workshops, an online forum, and a series of engagement events to showcase our research, engage people in the area of palliative care, raise our profile, and attract new PPI representatives.

PPI workshops

PPI representatives regularly offer their time at PPI workshops, to advise and collaborate with the Institute at all stages of our research. Our PPI workshops are typically a full day event, providing opportunity for PPI representatives to discuss and learn more about topics within palliative care research. The workshops include a Dragon's Den session, where researchers and clinicians from the Cicely Saunders Institute present new and existing research to PPI 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 PPI representatives to study advisory groups.

To date, we have held eight patient, family and public involvement workshops. Topics are selected by PPI representatives to enhance relevance and create engaging workshops. Topics have included what is meant by a 'difficult conversation', and an overview of the research approvals process.

Cicely Saunders Institute Public Involvement Forum

The Institute's PPI Strategy Group is responsible for developing the organisation's PPI activity, including the Institute's Public Involvement Forum: www.csipublicinvolvement.co.uk.

The aim of this forum is to enable more patients, families, and members of the public to collaborate with researchers and shape palliative care and rehabilitation research. Members can become involved in specific research projects or join general discussions about palliative care. Members help to shape our research, from initial stages, such as research topics, all the way through to how results are disseminated to the public. Since its launch in June 2016, the forum now has approximately 70 members. The PPI Strategy Group has undertaken an evaluation of its online forum by conducting three focus groups to ensure it remains the best possible interface and is

achieving what it set out to do. The results were presented at the National Institute of Health Research Patient and Public Involvement (INVOLVE) conference in November 2017.

A Conversation Starter around Loss, Grief and Bereavement

The Cicely Saunders Institute, in collaboration with the Department of Adult Nursing, King's College London, held their second 'Conversation Starter' event around the topic of grief, loss and bereavement, as part of Dying Matters Week 2018. More than 100 people, including members of the public, patients, carers and healthcare professionals, came together for a theatre performance by Haylo Theatre Company, which explored two sisters' reactions to the death of their father. The performance was introduced by Baroness Ilora Finlay, Professor of Palliative Medicine and cross-bench member of the House of Lords. The evening continued with an expert panel discussion, which included people with a variety of experience relevant to bereavement, research and the arts. The panel and the audience reflected on how the performance resonated with their personal experiences, the role of the arts in starting these discussions, and the importance of being willing to simply listen to others.

Figure 30 | Panel discussion from the Conversation Starter on Grief, Loss and Bereavement



L to R; Linda Magistris, Steve Marshall, Baroness Ilora Finlay, Lucinda Jarrett, Debbie Kerslake

Social media

We continue to actively engage and promote awareness and dissemination of our research, through YouTube, Twitter, blogs, podcasts, and in 2012, we launched the Palliative Care CAG YouTube channel (CSIKCL) (www.youtube.com/user/CSIKCL) which features our research, promotional videos for our postgraduate programmes, and our growing numbers of educational seminars. Our Twitter account (@CSI_KCL) currently has more than 7,000 followers including patients, members of the public, students, health professionals, organisations, journalists, and researchers from all over the world. Our account allows us to communicate our key findings efficiently and reach a large audience.

Open House

In September 2017, the Institute opened its doors to members of the public as part of Open House London. There was a steady flow of visitors throughout the afternoon, with members of the public, as well as friends and family of staff members attending. Visitors had the opportunity to speak with researchers and clinicians to learn more about palliative care and our work.



Research

Some problems such as breathlessness remain difficult to alleviate and need the type of intensive and sustained research that discovered better treatments for pain.

Introduction to research

King's Health Partners is an internationally leading centre for palliative care research. We are second in the world (to Harvard University) based on total number of citations our work has received (see Figure 31) and fourth in the world based on quantity of publications over the last five years (2013–2017). In Europe, King's Health Partners has published more than double the next nearest institution in palliative care (see Figure 32). In the UK, 14.0% of all publications relating to palliative care include researchers from King's Health Partners. Most importantly, the quality of research published by the Palliative Care CAG is high:

- Almost a quarter (23.4%) of the top 10% most cited papers globally for palliative care include a researcher from King's Health Partners;
- In 2017, nearly three quarters (73.3%) of papers from King's Health Partners in palliative care were published in the top 10% of journals (based on Elsevier's CiteScore Percentile);
- The average citations per publication is 12.3, the third highest of the top ten institutions for palliative care research;

- The Field-Weighted Citation Impact (a measure of research quality) score is 2.51 is fourth highest of the global top ten institutions (Harvard University is highest at 3.51);
- Research publications have steadily grown, increasing 5.3% between 2013 and 2017. But more crucially, capacity has grown. The number of people contributing to palliative care research from across King's Health Partners has grown significantly over the same period, increasing by just over a third (37.9%) from 66 in 2013 to 91 in 2017. Given that many of these are early career researchers, being developed by the team, the quality of the publications and Field Weighted Citation Impact is particularly impressive.

Income to support research is primarily from external peer review funding, including from the Medical Research Council (MRC), National Institute for Health Research from the Service Delivery and Organisation, Health Services and Delivery Research, and Research for Patient Benefits programmes, Department of Health, and many national and international charities. The Institute receives a small centre grant

from the charity Cicely Saunders International, initially awarded through open competition for the development of the Institute, reviewed and assessed by an independent scientific panel every two years and now used to enable joint working to gain additional support. The initial partnership between Cicely Saunders International and King's College London raised £10m to build the Institute, with all of the funding coming from external supporters, including the Wolfson, Weston, Dinwoodie and Macmillan charities. There is a small core infrastructure of Higher Education Funding Council for England (HEFCE) support for one professor and a small core team, plus an endowment for a professor and lecturer in Rehabilitation Medicine from the Dunhill Medical Trust. A pledge towards a further endowed chair has been made by Kirby Laing, and Cicely Saunders International and King's College London are actively trying to raise the

remaining funding. All other academic staff (approximately 50–60) are funded by external peer review programmes and projects, with an annual turnover of more than £4 million.

The CAG has and continues to attract a significant amount of funding for research projects, including funding from large health bodies such as the World Health Organisation, who commissioned a call to investigate rapid review of service delivery models for older people at the end-of-life. The CAG also support larger collaborative bids across institutions including being a co-investigator on a multi-million pound research project for the Engineering Science Research Council (ESRC) supporting health research in conflict. The following charts provide an overview of King's Health Partners and the research of the CAG within the Cicely Saunders Institute compared to international and European institutions.

Figure 31 | Research output (publications and citations) for the top ten institutions globally based on research area “palliative care” searched in the SciVal Database (Elsevier) for 2013 to 2017

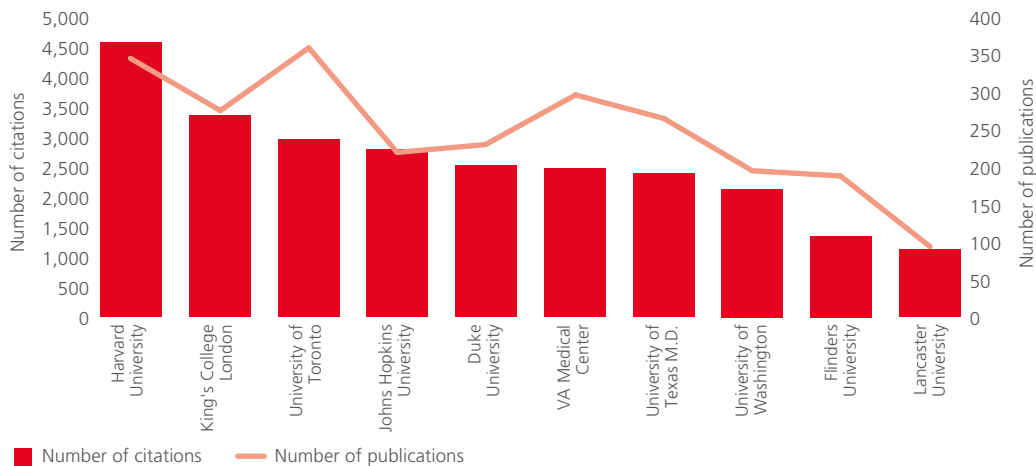
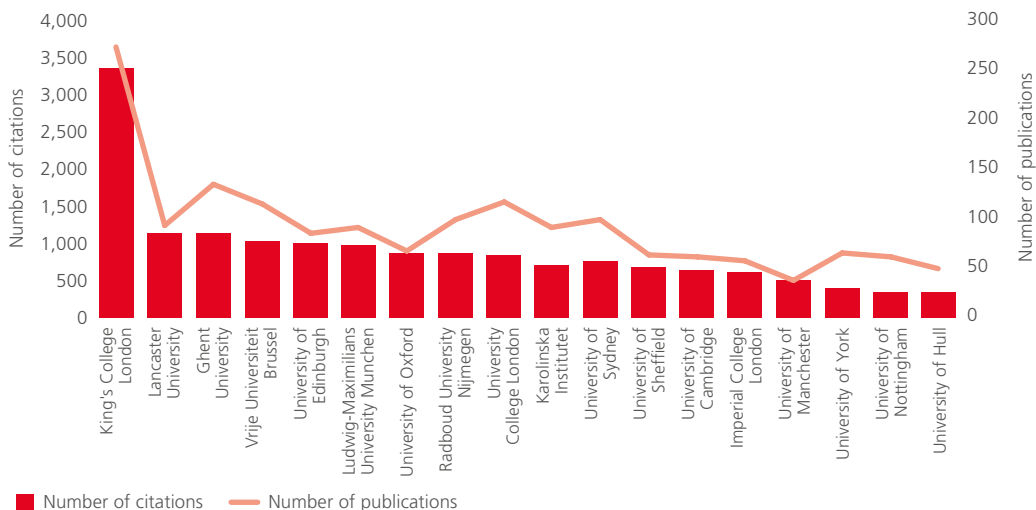


Figure 32 | Research output (publications and citations) for the top ten institutions in Europe and selected others for the United Kingdom and internationally based on research area “palliative care” searched in the SciVal Database (Elsevier) for 2013 to 2017



Early Career Research

PhD students

Since the inception of the Department a total of 23 students have graduated from King's College London with PhDs that examined a wide range of cutting-edge palliative care and rehabilitation issues. They come from a variety of backgrounds, including medicine, nursing, social science, physiotherapy, psychology, and anthropology. Each student develops a bespoke programme in agreement with his or her supervisor.

Our graduates have subsequently progressed their careers in clinical and academic settings, or have combined the two. They are now assuming roles as consultants in palliative medicine, research fellows, lecturers, senior lecturers, readers, and in three cases eventually becoming Professors in palliative care or in rehabilitation in the United Kingdom and overseas. Currently nine PhD students are based at Cicely Saunders Institute, four are from overseas, two of whom are from low to middle income countries.

Case study – building capacity in palliative care through PhD Fellowships and Faculty Scholarships – Project BuildCARE

BuildCARE (Building Capacity, Access, Rights and Empowerment) was aimed to create a 'sea change' in the way palliative and end-of-life care is regarded, implemented and prioritised internationally. Led by Professor Irene Higginson, this four-year project was supported by Cicely Saunders International and The Atlantic Philanthropies. A vital objective of BuildCARE was to develop capacity in palliative care by identifying exceptional individuals with potential, and then develop them into future clinical and academic leaders in palliative care. This has successfully been achieved through Cicely Saunders International PhD Training Fellowships. To date, four outstanding PhD Training Fellows have undertaken their fellowship at the Cicely Saunders Institute, all of whom have now completed their PhDs and have taken up academic and clinical roles as follows:

- Dr Mendwas Dzingina, Lecturer in health services research and health economics at the Cicely Saunders Institute;
- Dr Clare Ellis-Smith, research associate at the Cicely Saunders Institute;
- Dr Lesley Henson, NIHR Academic Clinical Lecturer at the Cicely Saunders Institute; and,
- Dr Pauline Kane, Consultant in palliative medicine, Ireland.

The BuildCARE project has been extended to two more PhD students, Dr Simon Etkind and Anna Bone. Moreover, the BuildCARE project has developed capacity in palliative care via the 'Cicely Saunders International Faculty Scholars' programme. Since becoming BuildCARE's first Cicely Saunders Institute Faculty Scholar, Dr Claudia Bausewein (who also undertook her PhD at the Cicely Saunders Institute) has secured the role of Chair of Palliative Care at the University of Munich. She now leads a clinical and research programme across Germany.

National Institute of Research (NIHR) Academic Clinical Fellows and postdoctoral Clinical Lecturers in Palliative care

The United Kingdom Integrated Academic Training (IAT) is a new pathway to promote the development of clinical academics with time

specifically allocated to develop and advance clinicians' academic skills alongside their clinical specialty training. The NIHR, alongside other funders, supports pre-doctoral Academic Clinical Fellows (ACF) and postdoctoral clinical lecturer (CL) for trainees across all specialties. In palliative medicine, whilst there have been just 14 ACFs from 2008–2014, five of these posts have been hosted by the Cicely Saunders Institute, and of these two (Dr Simon Etkind and Dr Natasha Lovell) have subsequently progressed to undertake their PhDs with us. Of the six clinical lecturers in palliative medicine nationally, two (Dr Lesley Henson and Dr Katherine Sleeman) are based in the Palliative Care CAG. Dr Katherine Sleeman recently became an NIHR Clinician Scientist.

Figure 33 | Some of the 2018 PhD students in the Cicely Saunders Institute



Clinical academics across the CAG

The Palliative Care CAG is committed to fostering clinical academics who we see vital to achieving King's Health Partners tripartite mission. As the pressures of an ageing population intensify, and more people face complex co-morbidities, the clinical academic workforce could never be more important. Positioned at the unique interface of clinical research and medical practice, these are some of the best placed staff to find the most innovative ways of improving our knowledge of how to address challenges and advance solutions in healthcare. The Palliative Care CAG believe it is vital that clinical academia and its workforce continue to be valued and protected. Demand for innovative solutions, delivered at pace, will continue to soar, and the clinical academic workforce needs to be robust, alongside the growing NHS consultant workforce, to ensure these needs can be met.

Although women are equally represented in medicine, they are under-represented in academic medicine. The proportion of women in clinical academic medicine is currently only 28% (Medical Schools Council Clinical Academic Survey 2017). This inequality increases substantially with seniority, with women representing 41.2% of Lecturers, 34.4% of Senior Lecturers/Readers and 17.9% of Professors. Across the Palliative Care CAG, we are leading the way to ensure women in clinical academia are fostered and supported to ensure that career progression continues. We believe that only when we see gender parity throughout clinical academia will we see the full benefits to researchers, research agendas and most importantly the patients we serve.

Our current clinical academics include:



Professor Irene J Higginson, OBE, is Director of the Cicely Saunders Institute, Vice Dean for Research for the Florence Nightingale Faculty of Nursing, Midwifery and Palliative

Care, and a Consultant in Palliative Care at King's College Hospital, Guy's and St Thomas' Hospital and Lewisham Hospital. She has several active research programmes, leads the MSc, Diploma and Certificate in Palliative Care, supervises several PhD students and is active in teaching. Prof. Higginson has published more than 450 articles in peer-reviewed journals, plus several books. Her research interests and publications are in the following areas, quality of life and outcome measurements, evaluation of palliative care, especially of new services and interventions, epidemiology, clinical audit, effectiveness, psychosocial care, symptom assessment, breathlessness, cachexia/anorexia, and elderly care.



Professor Lynne Turner-Stokes

was appointed to the Herbert Dunhill Chair of Rehabilitation at Kings College London in 2001. She has spearheaded development of a two-site academic department of rehabilitation between Kings College London and Northwick Park. Professor Turner-Stokes set up the Regional Hyperacute Rehabilitation Unit (RHRU) at Northwick Park Hospital in Harrow. The unit provides a tertiary specialist rehabilitation service for younger adult patients with severe complex disabilities, mainly resulting from acquired brain injury. The RHRU acts as a central focus for research and training for all professionals involved in rehabilitation, and has a national and international reputation as a leading service in the field of neurological rehabilitation.



Dr Katherine Sleeman

is an NIHR Clinician Scientist and Honorary Consultant in palliative medicine. Her research investigates the use of routinely collected data to understand and improve patterns of care before the end of life, particularly for people with dementia. She has expertise in public and policy engagement in palliative and end of life care, and she chairs the CAG Reach and Impact Group.



Dr Sabrina Bajwah is a Clinical Senior Lecturer and Honorary Consultant in palliative medicine. Her research is focused on respiratory palliative care and finding the best models of care including trialling different models of palliative care. She is passionate about gender equality across all protected characteristics and chairs the CAG Diversity and Inclusion Committee.



Dr Stephen Ashford is an Honorary Clinical Lecturer and Consultant Physiotherapist. His research investigates rehabilitation approaches in complex neuro-disability and palliative care. He has particular expertise in outcome measurement, guideline development, physical symptom management and rehabilitation treatment planning. He currently chairs the national guideline group for management of spasticity.



Dr Catherine Evans is a Senior Clinical Lecturer and Honorary Nurse Consultant in Palliative Care. Her research work focuses on developing and evaluating palliative care services and interventions for older people with non-malignant conditions in community settings. She has particular interest in the use of mixed methods in trials in palliative care, and Patient and Public Involvement, seeking to tailor research to the priorities of those it is intended to benefit. Catherine is the senior lead for the Patient and Public Involvement executive group.



Dr Lesley Henson is an NIHR Academic Clinical Lecturer and specialist registrar in Palliative Care. Her research area of interest relates to the aggressiveness of end of life care for people with cancer and builds on prior research conducted during her PhD that explored emergency department visits towards the end of life.

In addition, many members of the Cicely Saunders Institute have clinical training, including in medicine, nursing, physiotherapy, occupational therapy, social work and psychology. Some will enter clinical or joint roles when their specific research projects end, others will continue academic careers informed by their clinical practice, and some will become clinical academics.

Leading the way in best practice and service optimisation

In addition to addressing King's Health Partners' mission of research, clinical services, education, we also contribute more widely to policy both nationally and internationally.

Our policy work includes leading reviews of scientific evidence to support best practice recommendations in Palliative Care and Rehabilitation. On a national level, the CAG has been invited to chair several key committees for the National Institute of Health and Care Excellence (NICE) and the Department of Health, which enables our research findings and clinical experience to directly affect the policy making process. The Cicely Saunders Institute is collaborating with the Florence Nightingale School of Nursing and Midwifery to develop guidance on Supportive and Palliative Care for Patients with Cancer in England and Wales, funded by NICE. The Guidance forms a central part of the supportive care strategy

announced as part of the National Cancer Plan. This Guidance both complements and extends the site-specific guidance published as part of the Improving Outcomes series (e.g. in relation to breast, lung, colorectal, gynaecological and upper gastrointestinal cancers).

Under the management of Professor Irene J. Higginson, an Evidence Review Manual has been launched. This contains the evidence of effectiveness underpinning a comprehensive set of recommendations for action at national and local level, focussing on the configuration, design, and delivery of services.

Professor Lynne Turner-Stokes was the editor and lead author of a number of National Clinical Guidelines published through the Royal College of Physicians including:

- Management of spasticity using Botulinum Toxin – UK clinical guidelines;
- Rehabilitation following acquired brain injury;
- Complex Regional Pain syndrome; and
- Prolonged Disorders of Consciousness.

On an international level, the Cicely Saunders Institute is one of the five collaboration centres that make up the World Health Organisation (WHO) Expert Advisory Group which was formed in response to a World Health Assembly resolution on Palliative Care in 2014 (WHA67.19 Resolution). We take part in regular exchanges with the other Collaborating Centres relevant to palliative care to share materials (the London, Oxford and Barcelona Collaborating Centres) and have exchanged materials and expertise, and we also collaborate with the WHO Copenhagen office on an ad-hoc basis. As a WHO collaborating centre, we support synthesis and dissemination of evidence, relating to Palliative care and Rehabilitation, into evidence-summaries and policy briefs, for the WHO website.

In response to the WHA resolution on palliative care, we have collaborated with WHO in their response. This has involved a number of activities as follows:

1. Conducted a rapid scoping review (Oct–Dec 2017) on service delivery models for older people at the end of life. This was a competitive award commissioned by the

WHO Centre for Health Development Kobe, Japan. This work has been published on the WHO website, details of which can be found via the following links. www.who.int/entity/kobe_centre/mediacentre/news/eol_report.pdf?ua=1 http://www.who.int/kobe_centre/mediacentre/news/EOLC_report/en/

2. Contributed to the WHO booklet on humanitarian crisis which will soon be published.
3. Contributed to a paper on WHO public health palliative care approach led by Joachim Cohen and Richard Harding.
4. Professor Lynne Turner-Stokes is a member of the WHO guideline development group on Rehabilitation which was set up following the publication of WHO report on disability in 2007. This work has now been completed and the guideline was published in 2017 titled "Rehabilitation in Health Systems". This guideline incorporated evidence on both the effectiveness and cost-effectiveness of integrating rehabilitation services into health systems. It is noteworthy that the guideline recommendations leaned heavily on evidence produced from research conducted at the Cicely Saunders Institute, for example Professor Turner-Stokes' work on the cost efficacy of specialist inpatient rehabilitation (Turner-Stokes, L., et al., *BMJ Open*, 2016. Doi:10.1136, 6(2)). Further details on this guideline can be found at the following link. www.who.int/rehabilitation/rehabilitation_health_systems/en/
5. Currently writing a chapter on palliative care for people with tuberculosis (TB) for the WHO "End TB" strategy.

Research in focus

To provide a focus on the research endeavours of the CAG, below are abstracts from some of the highlighted publications produced by the CAG that have shaped the development of clinical guidelines, imparted education outcomes and best practice.

Outcomes measurement

European Association of Palliative Care White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services – Recommendations from the European Association for Palliative Care (EAPC) Task Force on Outcome Measurement

Palliative Medicine, 2016

Bausewein, C., Daveson, B.A., Currow, D.C., Downing, J., Deliens, L., Radbruch, L., Defilippi, K., Ferreira, P.L., Costantini, M., Harding, R., Higginson, I.J.

Background: Outcome measurement plays an increasing role in improving the quality, effectiveness, efficiency and availability of palliative care.

Aim: To provide expert recommendations on outcome measurement in palliative care in clinical practice and research.

Methods: Developed by a European Association for Palliative Care Task Force, based on literature searches, an international expert workshop, development of outcome measurement guidance and international online survey. A subgroup drafted a first version and circulated it twice to the task force. The preliminary final version was circulated to wider expert panel and 28 international experts across 20 European Association for Palliative Care member associations and the European Association for Palliative Care Board of Directors and revised according to their feedback. The final version was approved by the European Association for Palliative Care Board for adoption as an official European Association for Palliative Care position paper.

Results: In all, 12 recommendations are proposed covering key parameters of measures, adequate measures for the task, introduction of outcome measurement into practice, and national and international outcome comparisons and benchmarking. Compared to other recommendations, the White Paper covers similar aspects but focuses more on outcome measurement in clinical care and the wider policy impact of implementing outcome measurement in clinical palliative care. Patient-reported outcome measure feedback improves awareness of unmet need and allows professionals to act to address patients' needs. However, barriers and facilitators have been identified when implementing outcome measurement in clinical care that should be addressed.

Conclusion: The White Paper recommends the introduction of outcome measurement into practice and outcomes that allow for national and international comparisons. Outcome measurement is key to understanding different models of care across countries.

Liverpool Care Pathway for patients with cancer in hospital: A cluster randomised trial

Lancet, 2014

Costantini, M., Romoli, V., Leo, S.D., Beccaro, M., Bono, L., Pilastrri, P., Miccinesi, G., Valenti, D., Peruselli, C., Bulli, F., Franceschini, C., Grubich, S., Brunelli, C., Martini, C., Pellegrini, F., Higginson, I.J.

Background: The quality of care provided to patients with cancer who are dying in hospital and their families is suboptimum. The UK Liverpool Care Pathway (LCP) for patients who are dying was developed with the aim of transferring the best practice of hospices to hospitals. We therefore assessed the effectiveness of LCP in the Italian context (LCP-I) in improving the quality of end-of-life care for patients with cancer in hospitals and for their family.

Methods: In this pragmatic cluster randomised trial, 16 Italian general medicine hospital wards were randomly assigned to implement the LCP-I programme or standard health-care practice. For each ward, we identified all patients who died from cancer in the three months before randomisation (pre-intervention) and in the six months after the completion of the LCP-I training programme. The primary endpoint was the overall quality of care toolkit scale. Analysis was by intention to treat. This study is registered with ClinicalTrials.gov, number NCT01081899.

Findings: During the post-intervention assessment, data was gathered for 308 patients who died from cancer (147 in LCP-I programme wards and 161 in control wards). 232 (75%) of 308 family members were interviewed, 119 (81%) of 147 with relatives cared for in the LCP-I wards (mean cluster size 14.9 [range eight to 22]) and 113 (70%) of 161 in the control wards (14.1 [eight to 22]). After implementation of the LCP-I programme, no significant difference was noted in the distribution of the overall quality of care toolkit scores between the wards in which

the LCP-I programme was implemented and the control wards (score 70.5 of 100 vs 63.0 of 100; cluster-adjusted mean difference 7.6 [95% CI -3.6 to 18.7]; $p=0.186$).

Interpretation: The effect of the LCP-I programme in our study is less than the effects noted in earlier phase 2 trials. However, if the programme is implemented well it has the potential to reduce the gap in quality of care between hospices and hospitals. Further research is needed to ascertain what components of the LCP-I programme might be effective and to develop and assess a wider range of approaches to quality improvement in hospital care for people at the end of their lives and for their families.

Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data

Alzheimer's and Dementia, 2018

Sleeman, K.E., Perera, G., Stewart, R., Higginson, I.J.

Introduction: A fall in hospital deaths in dementia has been interpreted as indicating an improvement in end-of-life care. Whether other indicators of quality of end-of-life care, such as emergency department (ED) attendance, show a similar trend is unclear.

Methods: Retrospective cohort study using electronic medical records from a large mental health care provider, linked to national mortality and hospital use data (2008–2013).

Results: Of 4,867 patients, 78.6% (3824) had at least one ED attendance during their last year of life (mean 2.13, standard deviation 2.34, range 0–54). ED attendance increased over the time period (incidence rate ratio 1.62, 95% confidence interval 1.46–1.80 for 2012–2013 compared with 2008–2009).

Discussion: ED attendance in the last year of life for people with dementia is common and is increasing. Policy makers must pay attention to a broader range of indicators of poor end-of-life care alongside the place of death.

Understanding Palliative Care requirements

How many people will need palliative care in 2040? Past trends, future projections and implications for services

BMC Medicine, 2017

Etkind, S.N., Bone, A.E., Gomes, B., Lovell, N., Evans, C.J., Higginson, I.J., Murtagh, F.E.M.

Background: Current estimates suggest that approximately 75% of people approaching the end-of-life may benefit from palliative care. The growing numbers of older people and increasing prevalence of chronic illness in many countries mean that more people may benefit from palliative care in the future, but this has not been quantified. The present study aims to estimate future population palliative care need in two high-income countries.

Methods: We used mortality statistics for England and Wales from 2006 to 2014. Building on previous diagnosis-based approaches, we calculated age- and sex-specific proportions of deaths from defined chronic progressive illnesses to estimate the prevalence of palliative care need in the population. We calculated annual change over the nine-year period. Using explicit assumptions about change in disease prevalence over time, and official mortality forecasts, we modelled palliative care need up to 2040. We also undertook separate projections for dementia, cancer and organ failure.

Results: By 2040, annual deaths in England and Wales are projected to rise by 25.4% (from 501,424 in 2014 to 628,659). If age- and sex-specific proportions with palliative care needs remain the same as in 2014, the number of people requiring palliative care will grow by 25.0% (from 375,398 to 469,305 people/year). However, if the upward trend observed from 2006 to 2014 continues, the increase will be of 42.4% (161,842 more people/year, total 537,240). In addition, disease-specific projections show that dementia (increase from 59,199 to 219,409

deaths/year by 2040) and cancer (increase from 143,638 to 208,636 deaths by 2040) will be the main drivers of increased need.

Conclusions: If recent mortality trends continue, 160,000 more people in England and Wales will need palliative care by 2040. 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. Countries with similar demographic and disease changes will likely experience comparable rises in need.

How empowering is hospital care for older people with advanced disease? Barriers and facilitators from a cross-national ethnography in England, Ireland and the USA

Age and Ageing, 2017

Selman, L.E., Daveson, B.A., Smith, M., Johnston, B., Ryan, K., Morrison, R.S., Pannell, C., Mcquillan, R., De Wolf-Linder, S., Pantilat, S.Z., Klass, L., Meier, D., Normand, C., Higginson, I.J.

Background: Patient empowerment, through which patients become self-determining agents with some control over their health and healthcare, is a common theme across health policies globally. Most care for older people is in the acute setting, but there is little evidence to inform the delivery of empowering hospital care.

Objective: we aimed to explore challenges to and facilitators of empowerment among older people with advanced disease in hospital, and the impact of palliative care.

Methods: We conducted an ethnography in six hospitals in England, Ireland and the USA. The ethnography involved: interviews with patients aged ≥ 65 , informal caregivers, specialist palliative care (SPC) staff and other clinicians who cared for older adults with advanced disease, and fieldwork. Data were analysed using directed thematic analysis.

Results: Analysis of 91 interviews revealed substantial challenges to empowerment: poor communication and information provision, combined with routinised and fragmented inpatient care, restricted patients' self-efficacy, self-management, choice and decision-making. Information and knowledge were often necessary for empowerment, but not sufficient: empowerment depended on patient-centredness being enacted at an organisational and staff level. SPC facilitated empowerment by prioritising patient-centred care, tailored communication and information provision, and the support of other clinicians.

Conclusions: Empowering older people in the acute setting requires changes throughout the health system. Facilitators of empowerment include excellent staff-patient communication, patient-centred, relational care, an organisational focus on patient experience rather than throughput, and appropriate access to SPC. Findings have relevance for many

high- and middle-income countries with a growing population of older patients with advanced disease.

Which patients with advanced respiratory disease die in hospital? A 14-year population-based study of trends and associated factors

BMC Medicine, 2017

Higginson, I. J., Reilly, C.C., Bajwah, S., Maddocks, M., Costantini, M., Gao, W. on behalf of the GUIDE_Care project.

Background: Strategies in many countries have sought to improve palliative care and reduce hospital deaths for non-cancer patients, but their effects are not evaluated. We aimed to determine the trends and factors associated with dying in hospital in two common progressive respiratory diseases, and the impact of a national end of life care (EoLC) strategy to reduce deaths in hospital.

Methods: This population-based observational study linked death registration data for people in England dying from chronic obstructive pulmonary disease (COPD) or interstitial pulmonary diseases (IPD). We plotted age- and sex-standardised trends, assessed during the pre-strategy (2001–2004), first strategy phase (2004–2008), and strategy intensification (2009–2014) periods, and identified factors associated with hospital death using multiple adjusted proportion ratios (PRs).

Results: Over 14 years, 380,232 people died from COPD (334,520) or IPD (45,712). Deaths from COPD and IPD increased by 0.9% and 9.2% annually, respectively. Death in hospital was most common (67% COPD, 70% IPD). Dying in hospice was rare (0.9% COPD, 2.9% IPD). After a plateau in 2004–2005, hospital deaths fell (PRs 0.92–0.94). Co-morbidities and deprivation independently increased the chances of dying in hospital, with larger effects in IPD (PRs 1.01–1.55) than COPD (PRs 1.01–1.39) and dose-response gradients. The impact of multimorbidity increased over time; hospital deaths did not fall for people with two or more co-morbidities in COPD, nor one or more in IPD. Living in rural areas (PRs 0.94–0.94) or outside London (PRs, 0.89–0.98) reduced the chances of hospital death. In IPD, increased age reduced the likelihood of hospital death (PR 0.81, ≥ 85 versus ≤ 54 years); divergently, in COPD, being aged 65–74 years was associated with increased hospital deaths (PR 1.13, versus ≤ 54 years). The independent effects of sex and marital status differed for COPD versus IPD (PRs 0.89–1.04); in COPD, hospital death was associated with being married.

Conclusions: The EoLC strategy appeared to have contributed to tangible reductions in hospital deaths, but did not reach people with multimorbidity and this gap widened over time. Integrating palliative care earlier in the disease trajectory especially in deprived areas and cities, and where multimorbidity is present, should be boosted, taking into account the different demographic factors in COPD and IPD.

'My body's falling apart.' Understanding the experiences of patients with advanced multimorbidity to improve care: Serial interviews with patients and carers

BMJ Supportive and Palliative Care, 2016

Mason, B., Nanton, V., Epiphaniou, E., Murray, S.A., Donaldson, A., Shipman, C., Daveson, B.A., Harding, R., Higginson, I.J., Munday, D., Barclay, S., Dale, J., Kendall, M., Worth, A., Boyd, K.

Objective: Multimorbidity is increasingly common in the last year of life, and associated with frequent hospital admissions. The epidemiology is well described, but patient perspectives are less understood. We report the experiences and perceptions of people with advanced multimorbidity to inform improvements in palliative and end-of-life care.

Design: Multicentre study including serial, multiperspective interviews with patients and their family carers; an interpretive analysis of experiences and understanding of living with advanced multimorbidity. Participants: We recruited patients and their family carers using established UK clinical guidance for the identification of people anticipated to be in their last year of life.

Settings: An acute admissions unit in a Scottish regional hospital; a large English general practice; a London respiratory outpatient clinic.

Results: We analysed 87 interviews with 37 patients and 17 carers. They struggled with multiple changing medications, multiple services better aligned with single conditions such as cancer, and a lack of coordination and continuity of care. Family carers spoke of physical, mental and emotional exhaustion and feeling undervalued by professionals. Patients and carers frequently saw deteriorating health as part of 'growing old'. Many used a 'day-to-day' approach to self-management that hindered engagement with advance care planning and open discussions about future care. 'Palliative care' and 'dying soon' were closely related concepts for many patients, carers and professionals, so rarely discussed.

Conclusions: Patients with advanced multimorbidity received less care than their illness burden would appear to merit. Some people did restrict their interactions with care providers to preserve autonomy, but many had a limited understanding of their multiple conditions, medications and available services, and found accessing support impersonal and challenging. Greater awareness of the needs associated with advanced multimorbidity and the coping strategies adopted by these patients and carers is necessary, together with more straightforward access to appropriate care.

The Myeloma Patient Outcome Scale is the first quality of life tool developed for clinical use and validated in patients with follicular lymphoma

European Journal of Haematology, 2017

Davies, J.M., Osborne, T.R., Edmonds, P.M., Schey, S.A., Devereux, S., Higginson, I.J., Ramsenthaler, C.

Objectives: The development of novel agents and an ageing population has led to an increasing number of patients with follicular lymphoma (FL) living longer with their disease. Health-related quality of life (HRQOL) is a priority for patients and should guide clinical decisions. The Myeloma Patient Outcome Scale (MyPOS), originally developed for myeloma, was validated in a cross-sectional survey recruiting 124 FL patients.

Methods: Content and construct validity, structural validity using confirmatory factor analyses, reliability and acceptability were evaluated.

Results: Three subscales were indicated: symptoms and function, emotional response, and healthcare support. MyPOS symptom and function scores were higher (worse) in participants with poorer performance status (F=26.2, P<.000) and discriminated between patients on and off treatment. Internal consistency was good, a coefficient 0.70–0.95 for the total MyPOS score and subscales.

Conclusion: The MyPOS is valid, reliable and acceptable, and can be used to support clinical care of FL patients. This is the first measurement tool developed specially for use in clinical practice that has been validated for use in people with FL. Further longitudinal validation is now required to support its use in outcome measurement.

Innovative practice and learning

Introducing namaste care to the hospital environment: A pilot study

Annals of Palliative Medicine, 2017

Davies, J.M., Osborne, T.R., Edmonds, P.M., Schey, S.A., Devereux, S., Higginson, I.J., Ramsenthaler, C.

Background: The rising prevalence of dementia is impacting on acute hospitals and placing increased expectations on health and social care professionals to improve the support and services they are delivering. It has been recommended that good practice in dementia care relies on adopting a palliative approach to care and meeting people's physical, psychological, social and spiritual needs. Increased dementia training for staff that includes initiatives that promote dignity, enhancing communication skills and recognising that a person with dementia may be approaching

the end of their lives are needed. Our study aim was to explore whether Namaste Care is an acceptable and effective service for people with advanced dementia being cared for on an acute hospital ward.

Methods: This was an exploratory qualitative interview, pilot study. Individual, semi-structured, face-to-face interviews were conducted with hospital healthcare staff working in an area of the hospital where Namaste Care had been implemented. Data were analysed using the framework approach.

Results: Eight interviews were completed with members of the multidisciplinary ward team. Two themes were identified: (I) difficulties establishing relationships with people with dementia in hospital (subthemes: lack of time and resources, lack of confidence leading to fear and anxiety), (II) the benefits of a Namaste Care service in an acute hospital setting (subthemes: a reduction in agitated behavior; connecting and communicating with patients with dementia using the senses, a way of showing people with dementia they are cared for and valued).

Conclusions: This small-scale study indicates that Namaste Care has the potential to improve the quality of life of people with advanced dementia being cared for in an acute hospital setting. However, further research is required to explore more specifically its benefits in terms of improved symptom management and wellbeing of people with dementia on acute hospitals wards.

An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: A randomised controlled trial

The Lancet Respiratory Medicine, 2014

Higginson, I.J., Bausewein, C., Reilly, C.C., Gao, W., Gysels, M., Dzingina, M., McCrone, P., Booth, S., Jolley, C.J., Moxham, J.

Background: Breathlessness is a common and distressing symptom, which increases in many diseases as they progress and is difficult to manage. We assessed the effectiveness of early palliative care integrated with respiratory services for patients with advanced disease and refractory breathlessness.

Methods: In this single-blind randomised trial, we enrolled consecutive adults with refractory breathlessness and advanced disease from three large teaching hospitals and via general practitioners in south London. We randomly allocated (1:1) patients to receive either a breathlessness support service or usual care. Randomisation was computer generated centrally by the independent Clinical Trials Unit in a 1:1 ratio, by minimisation to balance four potential confounders: cancer versus non-cancer, breathlessness severity, presence of an informal caregiver, and ethnicity. The breathlessness support service was a short-term, single point of access service integrating palliative care, respiratory medicine, physiotherapy, and

occupational therapy. Research interviewers were masked as to which patients were in the treatment group. Our primary outcome was patient-reported breathlessness mastery, a quality of life domain in the Chronic Respiratory Disease Questionnaire, at six weeks. All analyses were by intention to treat. Survival was a safety endpoint. This trial is registered with ClinicalTrials.gov, number NCT01165034.

Findings: Between Oct 22, 2010 and Sept 28, 2012, 105 consenting patients were randomly assigned (53 to breathlessness support service and 52 to usual care). 83 of 105 (78%) patients completed the assessment at week 6. Mastery in the breathlessness support service group improved compared with the control (mean difference 0.58, 95% CI 0.01–1.15, $p=0.048$; effect size 0.44). Sensitivity analysis found similar results. Survival rate from randomisation to six months was better in the breathlessness support service group than in the control group (50 of 53 [94%] vs 39 of 52 [75%]) and in overall survival (generalised Wilcoxon 3.90, $p=0.048$). Survival differences were significant for patients with chronic obstructive pulmonary disease and interstitial lung disease but not cancer.

Interpretation: The breathlessness support service improved breathlessness mastery. Our findings provide robust evidence to support the early integration of palliative care for patients with diseases other than cancer and breathlessness as well as those with cancer. The improvement in survival requires further investigation.

Benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases in adults

Cochrane Database of Systematic Reviews, 2016

Simon, S.T., Higginson, I.J., Booth, S., Harding, R., Weingärtner, V., Bausewein, C.

Background: Breathlessness is one of the most common symptoms experienced in the advanced stages of malignant and non-malignant disease. Benzodiazepines are widely prescribed for the relief of breathlessness in advanced diseases, despite a weak evidence base for their use.

Objectives: The primary objective of this review was to determine the efficacy of benzodiazepines for the relief of breathlessness in people with advanced disease.

Search methods: This is an update of a review published in 2010. We searched 14 electronic databases up to September 2009 for the original review. We checked the reference lists of all relevant studies, key textbooks, reviews, and websites. For the update, we searched CENTRAL, MEDLINE, and EMBASE and registers of clinical trials for further ongoing or unpublished studies, up to August 2016. We contacted study investigators and experts in the field of palliative care asking for further studies, unpublished data, or study details when necessary.

Results: Overall, we identified eight studies for inclusion: seven in the previous review and an additional study for this update. We also identified two studies awaiting classification in this update. The studies were small (a maximum number of 101 participants) and comprised data from a total of 214 participants with advanced cancer or COPD, which we analysed. There was only one study of low risk of bias. Most of the studies had an unclear risk of bias due to lack of information on random sequence generation, concealment, and attrition. Analysis of all studies did not show a beneficial effect of benzodiazepines for the relief of breathlessness (the primary outcome) in people with advanced cancer and COPD (8 studies, 214 participants) compared to placebo, midazolam, morphine, or promethazine. Furthermore, we observed no statistically significant effect in the prevention of episodic breathlessness (breakthrough dyspnoea) in people with cancer (after 48 hours: risk ratio of 0.76 (95% CI 0.53 to 1.09; 2 studies, 108 participants)) compared to morphine. Sensitivity analyses demonstrated no statistically significant differences regarding type of benzodiazepine, dose, route and frequency of delivery, duration of treatment, or type of control. Benzodiazepines caused statistically significantly more adverse events, particularly drowsiness and somnolence, when compared to placebo (risk difference 0.74 (95% CI 0.37, 1.11); 3 studies, 38 participants). In contrast, two studies reported that morphine caused more adverse events than midazolam (RD -0.18 (95% CI -0.31, -0.04); 194 participants).

Conclusions: Since the last version of this review, we have identified one new study for inclusion, but the conclusions remain unchanged. There is no evidence for or against benzodiazepines for the relief of breathlessness in people with advanced cancer and COPD. Benzodiazepines caused more drowsiness as an adverse effect compared to placebo, but less compared to morphine. Benzodiazepines may be considered as a second- or third-line treatment, when opioids and non-pharmacological measures have failed to control breathlessness. There is a need for well-conducted and adequately powered studies.

International Research

Nurse-led palliative care for HIV-positive patients taking antiretroviral therapy in Kenya: A randomised controlled trial

The Lancet HIV, 2016

Lowther, K., Selman, L., Simms, V., Gikaara, N., Ahmed, A., Ali, Z., Kariuki, H., Sherr, L., Higginson, I.J., Harding, R.

Background: People with HIV accessing antiretroviral therapy (ART) have persistent physical, psychological, social, and spiritual problems, which are associated with poor quality of life and treatment outcomes. We assessed the effectiveness of a nurse-led palliative care intervention on patient-reported outcomes.

Methods: We did this randomised controlled trial at a clinic in Kenya for adults with HIV, established on ART, and reporting moderate-to-severe pain or symptoms. We randomly assigned participants (1:1) either to a palliative care intervention (including assessments of physical, emotional, and spiritual wellbeing and quality of life) given six times over four months, or to usual care. Participants and investigators were not masked to allocation. The primary outcome was pain (scored on the African Palliative Care Association's African Palliative Outcome Scale). This trial is registered with ClinicalTrials.gov, number NCT01608802.

Findings: We screened 2070 patients, of whom we enrolled 120:60 allocated to each group. In the control group, median pain score improved from 1.0 (IQR 0.0–2.0) at baseline to 5.0 (3.0–5.0) at 4 months; in the intervention group, it improved from 1.0 (0.0–2.0) at baseline to 4.5 (3.0–5.0) at 4 months. Compared with standard care, the intervention had no significant effect on pain (coefficient -0.01, 95% CI -0.36 to 0.34, $p=0.95$).

Interpretation: A nurse-led palliative care intervention was not effective in reducing pain. However, person-centred assessment and care delivered by staff who have received additional training had positive effects on self-reported mental health related quality of life and psychosocial wellbeing.

Palliative care service in Cyprus, a population-based needs assessment based on routine mortality data

Progress in Palliative Care, 2017

Aristodemou, P.A., Speck, P.W.

Background: Cyprus is currently forming its public healthcare system aiming to accompany people from cradle to grave. This population-based palliative care service needs assessment was performed under increasing demographic, economic, and societal pressures.

Objectives: The primary aim was to assess the palliative care service needs in Cyprus using routine mortality data and this was achieved by: (a) analysis of mortality death registration statistics making inferences to palliative care needs; (b) reviewing existing palliative care service provision in Cyprus.

Methods: Data derived from death registrations from January 2011 to December 2013 were analysed using specific International Classification of Diseases and Related Health Problems –10th Revision codes. The method developed by Rosenwax and Murtagh with further refinement of the disease categorisations was used to give a population-based estimate of palliative care needs at a minimum and at a maximum value, combined with symptom prevalence.

Results: Out of the 5,500 people on average dying in Cyprus annually, a minimum 2,634 and a maximum 3,927 could benefit from a palliative care service. Palliative care provision in Cyprus today focuses almost exclusively on cancer, depending largely on philanthropic funding with some services being reduced despite evidence of increasing need.

Conclusion: Palliative care should be integrated into the public healthcare system with appropriate resource allocation. Recommendations are made to facilitate this.

Funding models in palliative care: Lessons from international experience

Palliative Medicine, 2017

Groeneveld, E.I., Cassel, J.B., Bausewein, C., Csikós, A., Krajnik, M., Ryan, K., Haugen, D.F., Eychmueller, S., Keller, H.G., Allan, S., Hasselaar, J., Merino, T.G.-B., Swetenham, K., Piper, K., Fürst, C.J., Murtagh, F.E.M.

Background: Funding models influence provision and development of palliative care services. As palliative care integrates into mainstream health care provision, opportunities to develop funding mechanisms arise. However, little has been reported on what funding models exist or how we can learn from them.

Aim: To assess national models and methods for financing and reimbursing palliative care.

Design: Initial literature scoping yielded limited evidence on the subject as national policy documents are difficult to identify, access and interpret. We undertook expert consultations to appraise national models of palliative care financing in England, Germany, Hungary, Republic of Ireland, New Zealand, The Netherlands, Norway, Poland, Spain, Sweden, Switzerland, the United States and Wales. These represent different levels of service development and a variety of funding mechanisms.

Results: Funding mechanisms reflect country-specific context and local variations in care provision. Provider payment is rarely

linked to population need and often perpetuates existing inequitable patterns in service provision. Funding is frequently characterised as a mixed system of charitable, public and private payers. The basis on which providers are paid for services rarely reflects individual care input or patient needs.

Conclusion: Funding mechanisms need to be well understood and used with caution to ensure best practice and minimise perverse incentives. Before we can conduct cross-national comparisons of costs and impact of palliative care, we need to understand the funding and policy context for palliative care in each country of interest.

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King's Health Partners
Ground Floor
Counting House
Guy's Hospital
London SE1 9RT

Tel: 44 (0)20 7188 4058

Email: kingshealthpartners@kcl.ac.uk

Website: www.kingshealthpartners.org

Twitter: @kingshealth



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