Introduction

The Cicely Saunders Institute is committed to pioneering research into palliative care and rehabilitation that feeds quickly into improving care for patients and their families locally, nationally and internationally. The Institute is passionate about ensuring people live better with life-limiting disease, with dignity and choice, and minimal suffering, including to the end of their lives.

We champion the message of Dame Cicely Saunders (1922–2005) ‘you matter because you are you and you matter all the days of your life,’ and her method in putting people not their disease first, in providing total care, and in evidence-based practice, care and education.

The Institute is the world’s only purpose-built Institute dedicated to palliative care, and pioneers the very best in palliative care and rehabilitation through integration of:

• Cutting-edge research – building knowledge and discovering new treatments through robust, world-leading research, informed by patients and families.

• 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 – embedding change in policy and practice nationally and internationally, engaging with patients and families and inspiring tomorrow’s leaders in the field around the world.

The Institute brings together academics, healthcare professionals, community organisations, patients and carers in one dedicated community. It offers high quality palliative care solutions, information and support to patients, as well as providing education. The Institute is truly global in its mission and reach, responding to the clinical, public health and policy challenges faced in high, middle and low income countries. Our strategy of applied research excellence enables ethical, relevant and robust research to feed quickly into care and practice, improving palliative care for all who may benefit, wherever they are in the world. The Institute’s global network and multidisciplinary approach has enabled us to push the boundaries of evidence-based palliative care delivery beyond its initial cancer environment into new fields such as neurology, cardiology, nephrology, HIV and care of the elderly.

Within our local community, of King Health Partners, we offer walk-in support and information services in hospitals and the local area. In a neglected field of research and care that must urgently respond to the changing demographics of our population, we strive to discover effective care for all who need it, irrespective of diagnosis or social position and maximise access to that care. The unique defining features of our Institute are:

• A focus on outcomes and evidence in response to need

In a field that is neglected clinically, and lacking in funding, we have built a large body of high quality evidence that drives forward better care and informs policy. Our tools enable practitioners and researchers around the world to measure and improve patient outcomes using measures tested to high standards of rigour and adapted to local settings.

• Multi-professional research and care

Our Institute and our outputs embody the philosophy of multi-professional discipline, meeting the requirements of a public health strategy through inclusion of medicine, nursing, social work, allied professions, law, social science, the arts, bioethics, and epidemiology.
• **Integration**
  Our building offers a uniquely fertile environment for patients and families to propose and influence research ideas, clinicians to identify challenges, researchers to discover solutions, educators to disseminate, and clinicians to implement.

• **Global health**
  We have developed global partnerships and encouraged learning for all parties involved spanning Europe, Asia, Australia, North and South America and Africa. Our African work has enabled us to learn from low cost innovation, while our partners have been able to develop our outcome measurement science in their own settings. Our global network of partners brings new opportunities to collaborate and utilise commons tools and methods.

• **Patient-centredness and patient preference**
  In line with new thinking for patient-centred care, our work exemplifies patient-centredness, with our outcome tools carefully developed and tested to ensure that they reflect what matters to people. Our ground-breaking studies on patient preferences are driving policy, to ensure care is delivered in the way and the environment that patients wish.

• **New interventions**
  Our methodological advances in outcome measurement, evaluation, design and costing has enabled us to develop, refine, deliver and evaluate accessible and effective interventions for distressing problems across a wide range of groups, including care home residents, people living with HIV or multiple sclerosis, and those experiencing breathlessness.

No other organisation integrates these strands of work in this way. The Cicely Saunders Institute is truly unique in its ability to quickly translate robust scientific research into real improvements in care for patients, alongside world-class teaching for the palliative care leaders of tomorrow.

The Institute is distinctive in its ability to make a lasting impact through its work locally, nationally and internationally.

This resonates with King’s College London’s mission to advance knowledge, learning and understanding in the service of society.

**During 2011–14 we have:**

• **Seen growing use of our person centred outcome measures to aid clinical practice, education, research and service development.** The UK Rehabilitation Outcomes Collaborative (UK-ROC) is supporting improved rehabilitation services. We have validated new modules and translations of the Palliative care Outcome Scale (POS) and launched a dedicated website of free resources (www.pos-pal.org).

• **Extended our academic teams with new lecturers, senior lecturers and fellows with backgrounds in physiotherapy, nursing, statistics, epidemiology, health economics, as well as fostering future leaders from medicine, health and social care research, and social science.**

• **Joined with teams across King’s Health Partners to win the South London NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC).** In this £9 million award palliative and end of life care is a specific theme. We will be working with colleagues to improve care in South London, build capacity and knowledge.

• **Reached out to services across the globe, for example with trials of palliative care in Africa, outcomes collaborations across Europe and Australasia, and multicentre studies and trials across Africa, Asia, Australia, Europe, North and South America.**

• **Launched new models of patient, public and family engagement, and expanded the open access availability of our work, with increasing publications in open access peer review journals and seminars via our U-Tube channel (www.youtube.com/user/CSIKCL).**

• **Developed and evaluated new treatments and services, to tackle difficult symptoms such as breathlessness, or to meet the increasingly complex needs of patients and their families with long term conditions (in our OPTCARE programme of service development).**

• **Expanded our education, capacity building and leadership development.** To drive forward international thinking and care development we convened seminars and workshops, including distinguished speakers in our Annual Lecture series.
Worldwide 107 people die every minute. In the United Kingdom, 69–82% of the half million people dying each year need palliative care (Murtagh et al, 2014) and a 17% rise in annual deaths is expected until 2030 (Gomes et al. Palliat Med 2008;22:33–41). Patterns of dying will change as chronic and progressive diseases coexist, and the boundaries between being ill and dying will be obscured and prolonged. Our unification of palliative care and rehabilitation anticipates this as societies will have to engage with the individual need to ‘live well the final years of life’, realised through symptom management, rehabilitation and/or palliation. The caregivers or family need support, yet societies are obliged to manage competing costs, duties and demands. This can only happen if the changing demography of living and dying is understood, and ways to improve its quality are discovered and developed. Precious and limited human and material resources can then be used wisely.

Our research strategy is to lead the world in ethical and robust research that responds to people and families affected by progressive, far advanced and life limiting conditions. We focus on understanding the needs of the most neglected and disadvantaged groups in societies, and finding solutions that cross health and social, statutory and voluntary care. We aim also to translate our research quickly into care, practice and policy so it can benefit people. Our priorities are to promote dignity and to relieve suffering.

Our research has four main strands to address current and future clinical, public health and methodological challenges (Figure 1). These strands are inter-related and operate across our multi-professional staff, care settings and disease groups. Across strands we hone research methods in our field, collate best evidence to improve practice here and now, and build from these to develop and test interventions, then incorporate our results with existing evidence and into our education programmes.

**Evaluating and improving care:** These are studies to develop, test and evaluate existing and new models of care. Bolstered by our unique interface between palliative care and rehabilitation, we reach beyond the traditional cancer stream to other conditions where palliative care has been neglected. Examples include: Cochrane reviews on specialist palliative care home services showing these double the odds of patients dying at home and improve symptom control; assessment of information needs in South Africa and Uganda, a new intervention in Intensive Care Units to ensure staff give the best support for patients and families at times of uncertainty, and evaluating the cost-effectiveness of a new model of short-term palliative care for patients with multiple sclerosis. We believe it is important not only to describe need, but to find ways to better meet it. New projects will improve and evaluate these models using multicentre phase III trials for older people and long-term neurological conditions.

**Focused clinical research on symptoms:** This includes Cochrane reviews, observational studies and trials to examine symptom burden and its associated factors in the trajectories of non-cancer conditions, especially renal disease in transplant and non-transplant patients, and to test interventions and treatments for breathlessness, pain, spasticity and muscle weakness. New research is now combining effective treatments and testing these in clinical trials, for example a trial of neuromuscular electrical stimulation and a new Breathlessness Support Service.

**Person centred outcome and assessment measures:** Our hallmark is that we place person-centred outcomes as the key outcome in needs and service evaluations. Developing and using short measures for patients, families and observers/staff that capture the highly varied circumstances in complex patients, provides fundamental tools for research and clinical practice. These cover pain and symptoms, psychological
and spiritual need, social, service and rehabilitation concerns and circumstances. Future work is taking forward these tools to aid the assessment of complexity and care commissioning, which is particularly important given the poor or patchy funding of palliative care and rehabilitation. Through global partnerships we are also transforming the evidence base and delivering culturally appropriate palliative care in sub-Saharan Africa and in Asia.

**Living and dying in society:** The suffering and dying, by the very nature of what is happening, are vulnerable. To future-proof palliative care and rehabilitation, the public needs better understanding through better communication. Our mixed methods research on tomorrow’s populations underpins new health care policy by exploring the experience and needs of the very elderly, informal caregivers, diverse cultural groups, and those in care homes. Much of this work is underpinning new health care policy. For example, we have highlighted the need to consider people’s preferences for place of care, in particular the home. We have shown the factors that enable home death, and now are embarking on studies to investigate how to improve the quality of home care, with new programmes in London and across Portugal. To learn from different health systems, our research is extending out to others and comparing care in advanced disease for older people across London, Dublin and New York.

We conduct **methodological development** to improve rigour, ethical standards and ways to understand and support the most profoundly ill populations better, with research to produce guidance and best practice. Our MRC-funded programme refined the MRC framework to develop and test complex interventions and produced guidance of best evidence of research practice in palliative care, including novel ways to classify attrition. The complexity of person-centred care is reflected in our multidisciplinary clinical academic team.

We focus on **disseminating** all our work widely and working collaboratively with many groups, patients, families and service users, clinicians, health and social care services, policy makers and others. We have a strong focus on implementation and dissemination, reflected in our BuildCARE international programme that is enhancing public engagement, empowerment and access to appropriate and effective palliative care and rehabilitation.

![Figure 1 Palliative care and rehabilitation research at the Cicely Saunders Institute](image_url)
This programme strives to improve the care and treatments that patients and families receive by studying and understanding failings in existing services, developing and trialling refined or new models of care that better meet the needs of patients and families, and providing evidence about the effects of care and treatment. Our work spans cancer and non-cancer conditions, is conducted locally, nationally and internationally. Our study designs follow the guidance for the development and evaluation of complex interventions from the Medical Research Council and the MORECARE statement (Higginson et al., 2013a). They include: theory development, systematic reviews, service modelling, feasibility testing and evaluation, including randomized multicentre trials. Collaboration with patients, families and the public is a core component in all phases.
The first randomised controlled trial of the Liverpool Care Pathway

It is well known that the quality of care provided to patients with cancer who are dying in hospital and their families is suboptimal. The UK Liverpool Care Pathway (LCP) for patients who are dying was developed by the Marie Curie Centre in Liverpool with the aim of transferring the best practice of hospices to hospitals. However, robust research into the effects (positive or negative) of the LCP was lacking. In Italy, Professor Costantini (visiting Professor to the Institute) won funding to undertake a robust, adequately powered trial, and Professor Higginson worked on and led components of the trial and analysis. We wanted to find out whether the LCP was effective, and any benefits or disadvantages of its use. The study was planned long before concerns regarding the LCP had surfaced in the UK.

The study was a pragmatic cluster randomised trial. 16 Italian general medicine hospital wards were randomly assigned to implement the Italian adaptation of the LCP (called LCP-I) programme or standard health-care practice. For each ward, we identified all patients who died from cancer in the 3 months before randomisation (pre-intervention) and in the 6 months after the completion of the LCP-I training programme. The LCP-I or standard care in the control wards was slightly different to the UK implementation; the training programme was highly standardised, and throughout the six-month implementation training and afterwards specialists in palliative care supported the ongoing training of staff with joint patient visits, shadowing and supervision.

During the post-intervention assessment, data were 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 relatives who cared for patients in the LCP-I wards (mean cluster size 14·9 [range 8 to 22]) and 113 (70%) of 161 relatives who cared for patients in the control wards (14·1 [8 to 22]) took part. After implementation of the LCP-I programme, no significant difference was observed in 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) (Costantini et al., 2014b).

The lack of significant improvement on the primary outcome supports the recommendation by the UK Neuberger Review to phase out the LCP. However, our study did not find the harms described in the UK reports. In contrast, there seemed to be some closing of the gap between the quality of hospice and hospital care, although not enough to reach statistical significance. This may be because of the different patient groups; only those with cancer were involved in our study, and/or the careful implementation of the LCP-I, which was supported by palliative care experts, who provided continued training. As such, our study underscores the continuing need for specialist palliative care following the principles of the World Health Organisation.

Keeping PACE with communication in situations of uncertainty

Communication and support for patients and families is vital when individuals and families are faced with clinical uncertainty, a situation which is common in the intensive care unit (ICU) where many patients are profoundly ill, with conditions that can quickly change. In these environments clear communication between healthcare professionals, patients and their families is especially important. In a collaborative
project between King’s College Hospital NHS Foundation Trust and King’s College London, we set out to study these issues and to develop ways to improve care and communication with patients and their families in ICU. For further details of PACE and how it was developed see the clinical section (In Focus, page 82).

We conducted face to face interviews with families, and where possible patient, and focus groups to understand their perspective and the main gaps in care. This, along with review of all available interventions, led us to develop a new tool to support psychosocial assessment and communication, called the Psychosocial Assessment and Communication Evaluation (PACE) (Higginson et al., 2013b).

The goal of developing PACE was to improve assessment and communication for all patients in the ICU, both those who may deteriorate and equally those who may recover. PACE comprises the training programme and an assessment, which is recorded in the clinical notes (Figure 2).

Our preliminary evaluation of PACE examined the views of family members of patients on the ICU. From 213 family members, 78% responded to the survey, two-thirds had PACE completed. Those with PACE had a significantly higher and better satisfaction with the honesty and consistency of information from staff and with symptom control of patients compared with those without PACE (Mann-Whitney U-test ranged from 616 to 1247, P-values ranged from 0.041 to 0.010). Survey of ICU staff showed that most found PACE very useful. Ninety-five ICU staff members responded and completed the survey and 89% rated PACE as very or generally useful. Additionally, qualitative interviews with families suggested that PACE helps the staff to get to know the patient and family better, who, in consequence, feel that someone listens to them and is interested in them and their wishes, as well as in the purely biomedical aspects of the disease.

PACE now needs to be evaluated more widely and in a comparative, ideally randomised, trial and across other centres. There are similar needs for good communication and psychosocial care, especially during times of uncertainty, across health care. So PACE might be helpful in other settings, especially hospitals. We are exploring ways in which we might develop PACE in the future (Higginson et al., 2013b).

Supporting and improving dignity for people approaching the end of life

Maintaining dignity is an overarching value, which shapes the delivery of services to patients with advanced diseases and to their families. While there have been many advances in managing the somatic symptoms of people with advanced diseases, less is known about supporting psychosocial, existential and spiritual issues (Hall et al., 2013a).

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**Figure 2 Components of the Psychological Assessment and Communication Evaluation (PACE)**

**Training programme**

The training programme involves collaborative work between the ICU and hospital palliative care team staff to look at ways to improve communication and how the PACE questions might serve as a prompt to improve assessment and help continue communication.

**Record**

The record within PACE asks for assessment of five aspects of care:

1. Family Details; such as children, relationships and guardianships.
2. Social Details; such as language, culture, but also financial concerns and the need for transport and parking for the family.
3. Patient Preferences; including any previously expressed wishes about who they would want to inform their treatment and place of care.
4. Communication and information; how much the patient and the families are aware of the situation and who is key in a family to be involved in communication. It also involves explaining what happens in the ICU and finally any other aspects which the patient, family or staff feel are important. The record then gives space for a continuing log of any communication updates. This is to keep everyone up to date, when the clinical team change during the 24 hour period.
5. Any other issues:
   A list provides circumstances and useful resources as a prompt for staff to receive additional support if needed. PACE is completed by the key worker for the patient, usually a nurse within 24 hours of admission.
In focus

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


We assessed the effectiveness of the Liverpool Care Pathway in the Italian context (LCP-I) to improve the quality of end-of-life care for patients with cancer in hospitals and their family. In this pragmatic cluster randomised trial, 16 Italian general medicine hospital wards were randomly assigned to implement the LCP-I programme or continue standard care practice. For each ward, we identified all patients who died from cancer in the 3 months before randomisation (pre-intervention) and in the 6 months after the completion of the LCP-I training programme or the equivalent period in the standard care wards. The primary endpoint was the overall quality of care using the total Quality of Care Toolkit Scale.

This study did not demonstrate a significant difference in the overall quality of care 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) (see table). Of the nine secondary outcomes reported by family members, two showed improvements – respect, dignity and kindness, as well as control of breathlessness. We noted few differences in the medications that were prescribed and no differences in the period of survival after admission.

The results of our trial show that the effects of the LCP-I programme were smaller than those of the earlier phase II studies and did not reach significance. These results support the UK Neuberger Report conclusion to phase out the LCP. However, the programme did demonstrate potential to reduce the gap in quality of care between hospices and hospitals, with specialist palliative care teams leading the implementation (Table 1). Further research is needed to a wider range of approaches to quality improvement in hospital care for people at the end of their lives and for their families.

Table 1 Cluster-adjusted toolkit mean scores and differences in the post-intervention assessment

<table>
<thead>
<tr>
<th></th>
<th>LCP-I wards (n=119)</th>
<th>CONTROL wards (n=113)</th>
<th>MEAN DIFFERENCES (pre intervention adjusted)</th>
<th>MEAN DIFFERENCES (not pre intervention adjusted)</th>
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<tbody>
<tr>
<td></td>
<td>N. * mean</td>
<td>N.* mean</td>
<td>mean (95% CI) P-value ICC ES mean (95% CI) P-value ICC ES</td>
<td>mean (95% CI) P-value ICC ES</td>
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<tr>
<td>Overall quality of care</td>
<td>118 70·5 111 63·0</td>
<td>7·6 (-3·6 to 18·7)</td>
<td>0·186 0·12 0·33 8·0 (-1·8 to 17·8) 0·110 0·10 0·34</td>
<td></td>
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<tr>
<td>Informing and making decisions</td>
<td>117 73·5 110 64·3</td>
<td>9·2 (-0·9 to 19·3)</td>
<td>0·076 &lt;0·01 0·31 6·6 (-1·3 to 14·6) 0·102 &lt;0·01 0·22</td>
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<tr>
<td>Advance care planning</td>
<td>22 NE</td>
<td>24 NE</td>
<td>NE NE NE NE NE 10·1 (-14·4 to 34·7) 0·424 &lt;0·01 0·24</td>
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<tr>
<td>Respect, dignity and kindness</td>
<td>115 78·8 109 70·4</td>
<td>8·4 (0·3 to 16·6)</td>
<td>0·043 &lt;0·01 0·28 8·5 (0·3 to 16·6) 0·042 &lt;0·01 0·28</td>
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<tr>
<td>Family emotional support</td>
<td>117 46·6 109 38·6</td>
<td>8·1 (-4·3 to 20·4)</td>
<td>0·203 &lt;0·01 0·09 2·0 (-4·3 to 10·1) 0·195 &lt;0·01 0·26</td>
<td></td>
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<tr>
<td>Coordination of care</td>
<td>115 81·4 110 76·8</td>
<td>4·5 (-3·9 to 13·0)</td>
<td>0·296 &lt;0·01 0·19 4·8 (-2·9 to 12·5) 0·221 &lt;0·01 0·20</td>
<td></td>
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<tr>
<td>Family self-efficacy</td>
<td>116 48·9 110 44·4</td>
<td>4·5 (-5·1 to 14·2)</td>
<td>0·360 &lt;0·01 0·16 0·7 (-7·5 to 9·0) 0·863 &lt;0·01 0·02</td>
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</table>

* samples on which the means were estimated
All estimates (means, 95%CIs and ES) are cluster adjusted. Higher score is better quality of care for all variables.
ICC= Intraclass Correlation Coefficient, ES=effect size, NE= not estimable
Building on work described in the previous triennial report we have now completed and published two randomised controlled phase II mixed method trials of Dignity Therapy, one for people with advanced cancer and one for older people in care homes.

Dignity Therapy is a psychological therapy, developed by Dr. Harvey Max Chochinov in Canada. It aims to bolster the dignity of patients approaching the end of life and address their suffering. This therapeutic intervention invites individuals with life-limiting illnesses to reflect on matters of importance to them. Using a specified protocol and following the patient’s cues, we developed a small team of trained therapists who were able to facilitate the expression of thoughts, feelings, and memories and then compile these in a narrative document for the patient to share with family, friends or those important to him or her.

Dignity therapy for people with advanced cancer

To assess the ability of Dignity Therapy to reduce distress for people with advanced cancer we conducted a phase II mixed-method trial, recruiting 45 patients in two UK National Health Service hospitals. The study was difficult to conduct because the group was very ill: only 27/45 (60%) participants remained at 1-week and 20/45 (44%) at 4-week follow-up. We found no differences in dignity-related distress at any time between those randomly allocated to Dignity Therapy plus standard care, or standard care alone. However, the group receiving Dignity Therapy reported more hope than the control group at follow-up, with medium effect sizes (partial $\eta^2 = 0.20$ and 0.15). The Dignity Therapy group were more positive than the control group on all the self-reported benefits ratings (effect sizes (Cohen’s d) ranged from 1.34 (large) for feeling that dignity therapy had helped to 0.31 (modest) for increasing will to live). Differences between groups were statistically significant for finding the therapy helpful at one-week and two-week follow-up and for heightening their sense of purpose at four week follow-up (Hall et al., 2011b). Qualitative interviews with a sub-sample found benefits of Dignity Therapy in terms of: generativity, continuity of self, reminiscence, reflecting on life, maintenance of pride, hopefulness, and supportive care (Hall et al., 2013c).

Although Dignity Therapy has been developed to help reduce distress experienced by people nearing the end of life, many evaluations have largely involved non-distressed samples. The effect of Dignity Therapy on the most distressed individuals had never been reported. We used a case study approach to explore the impact of dignity therapy on distressed patients with advanced cancer. Patients were experiencing very severe physical and psychosocial problems when they received the intervention, most of which would not be expected to be helped by Dignity Therapy. However, all felt that the therapy had helped them and that it had or would help their families (Hall et al., 2013a).

Taken together, this work suggests that Dignity Therapy may have a role for people with cancer, including those who are most distressed. Further work could explore whether Dignity Therapy should be offered as a ‘stand alone’ service, or more integrated into the day to day practice of palliative care teams.
Dignity Therapy for older people in care homes

In this trial, 60 residents aged 65 or more, with no major cognitive impairment, were randomised to one of two groups: intervention (Dignity Therapy plus standard care); or control (standard care only). Outcomes were potential effectiveness (dignity-related distress, depression, hopefulness, quality of life), acceptability (residents’ views) and feasibility (time taken to deliver the intervention). There was a reduction in dignity-related distress in both intervention and control groups, with no significant differences between groups. Residents in the Dignity Therapy group outperformed the control group on all the acceptability items (Hall et al., 2012b). Although it was feasible to deliver Dignity Therapy in this setting, the trial took longer to complete than anticipated.

The qualitative interviews found that residents in care homes greatly valued taking part in the research. Taking part helped participants with refocusing, feeling they were making a contribution, providing diversion and pleasant interaction with the researcher and/or therapist. Residents who received Dignity Therapy were very positive about the generativity document and the value of reminiscence, and the general feeling of producing something from their life that would help others. Interviews with residents’ families showed that they felt that Dignity Therapy had helped residents positively reappraise aspects of their lives (Hall et al., 2013b).

In a further explorative study of what dignity means in care homes, we interviewed 33 care home managers, 29 care assistants, 18 care home nurses, 10 community nurses, 16 residents and 15 members of residents’ families. Dignity was commonly understood as: independence, privacy, comfort and care, individuality, respect, communication, physical appearance and being seen as human. Residents and their families sometimes described incidents where a resident’s dignity had been compromised (Hall et al., 2014). We are now taking forward this work in dignity to explore how to promote dignity in routine care.

The challenge involved in coordinating care

Coordinating patient care is an important yet elusive global challenge, which is set to escalate within the

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**Figure 3** Illustrative quotes from cancer patients and families about Dignity Therapy

... I've not, never really thought a lot of myself, not valued myself ... and because I haven't valued myself other people haven't valued me, it seems ... Now it's made a bit more sense, these things matter more than I thought they did, the things I've talked about ... they have mattered, they do matter .... (Intervention, participant at, one week)

... he's telling people “Oh you should read my life history ...” he's referring it to people and showing them. So quite proud of it ... it's given him a sense of ... self-worth. (Daughter of participant)

... I think that gives you an enormous sense of peace and, and ... well I don't know, some sort of relief really ... it was playing on my mind ...wanting to say things to people that ... I was, I, I felt very difficult to say and sort of quite unable to and ... this has really helped me to do it. (Intervention, another participant at four weeks)

... getting it in her own words was actually very good and also the, the fact that even seeing the positive in her illness, about appreciating people more ... people were amazed how positive she was about life and about her own illness and of course then she talked about her family and her friends and they really appreciated that. It's sort of a lasting legacy and ... I think we're quite lucky that she was selected for the research, in that it is a lasting document to her. (Bereavement Interview, Sister of participant)
midst of a rapidly ageing population living with chronic illness, multiple morbidities and prevailing preferences to die at home. Very few studies have examined what care coordination means from the perspective of patients living with advanced illness and their unpaid caregivers. Commencing in 2011, with our partners at the University of Edinburgh, led by Professor Scott Murray, we conducted a prospective longitudinal, multi-perspective qualitative study to examine care coordination in detail.

Our focus was general, rather than specialist palliative care settings. Using ethnographic observational information, collected over a 22-week period on 56 patients, 25 unpaid caregivers and 17 clinicians, we identified how care is coordinated for patients with advanced progressive conditions in the last year of life (Mason et al., 2013). Disappointingly we found that, despite complex needs and multiple morbidities, few patients had been identified for a general palliative care approach. Unpaid caregivers and specialist nurses often undertook the main roles of care coordinator. We found that these pressures were particularly pressing in emergency contexts.

In a further analysis of serial interviews with 18 patients in three different hospital outpatient clinics, we compared the experiences for those with lung cancer and those with chronic obstructive pulmonary disease (COPD). Those with lung cancer often had a keyworker who provided support and help. The keyworker coordinated care between and within clinical settings, referred patients to community palliative care services, helped them with financial issues, and provided support. Those with COPD experienced a less coordinated package of care. Our findings highlighted the need to further investigate the role of the keyworker in relation to care coordination for both those living with malignant and/or non-malignant conditions, including their unpaid caregivers and especially in relation to older adult patients (Epiphaniou et al., 2014).

Adapting and evaluating a Hospital2Home case conference model for patients with Progressive Idiopathic Fibrotic Interstitial Lung Disease

The needs and experiences of people living with end-stage progressive idiopathic fibrotic interstitial lung disease (ILD) are under-researched. Our research programme in this area is improving the evidence base to help services identify effective treatments and testing new models of care. This programme is in partnership with colleagues at the Royal Brompton and King’s College Hospitals.

This research started with a systematic review evaluating the evidence for the use of interventions in ILD to improve breathlessness, other symptoms and quality of life. 34 papers described 19 interventions that had been tested with 3,365 patients. Meta-analyses showed that pulmonary rehabilitation (mean difference (95% CI: 27.4 (4.1 to 50.7)) and pirfenidone (a medication with antifibrotic and anti-inflammatory effects used often in ILD) (mean difference (95% CI: 24.0 (4.3 to 43.7)) had a positive effect on six minute walking distance. Both pirfenidone and pulmonary rehabilitation had a mixed effect on breathlessness (Bajwah et al., 2013c).

To help us propose services to better meet the needs of patients and families we reviewed the clinical records of people with ILD. Forty-five patients with ILD in two London hospitals were identified. Nearly all patients (42/45) experienced breathlessness in their last year of life. Additional symptoms included cough, fatigue, depression/anxiety, and chest pain. All patients given opioids (22/45) or benzodiazepines (8/45) had documented benefit from these treatments. Non-pharmacological treatments were rarely used. Few patients had preferred place of care (8/45) or preferred place of death (6/45) documented. Seventeen of 45 patients had specialist palliative care team involvement (Bajwah et al., 2012).

Then we conducted in-depth qualitative interviews with 18 patients, their unpaid caregivers and the health professionals involved in their care. Patients were recruited from the Royal Brompton Hospital and King’s College Hospital NHS Foundation Trust. The interviews showed that patients were severely affected by their symptoms, especially shortness of breath, cough and insomnia. They were frustrated and angry at the way in which their illness severely limits their ability to engage in activities of daily living, and compromises their independence. Both patients and informal caregivers also reported that the disease seriously affected family relationships where strain is pronounced. There was varied knowledge and confidence among health professionals in managing symptoms, and psychosocial needs were often underestimated (Bajwah et al., 2013a).
Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers


Extensive evidence shows that well over 50% of people prefer to be cared for and to die at home provided circumstances allow choice. Despite best efforts and policies, one-third fewer deaths take place at home in many countries of the world. In order to care well for more people at home and thus meet the preferences of more patients and caregivers, the effect of home palliative care services on death at home as well as other outcomes need to be ascertained. We performed a Cochrane review with the primary objectives (1) to quantify the effect of home palliative care services for patients with advanced illness and their family caregivers on patients’ odds of dying at home and (2) to examine the clinical effectiveness of home palliative care services on other outcomes for patients and their caregivers such as symptom control, quality of life, caregiver distress and satisfaction with care.

We identified 23 studies that met the inclusion criteria, including 37,561 patients and 4,042 family caregivers, largely with advanced cancer but also congestive heart failure, chronic obstructive pulmonary disease, HIV/AIDS and multiple sclerosis, among other conditions. Meta-analysis showed increased odds of dying at home (Table 2). In addition, narrative synthesis showed evidence of small but statistically significant beneficial effects of home palliative care services compared to usual care on reducing symptom burden for patients and of no effect on caregiver grief. Evidence on cost-effectiveness (six studies) was inconclusive.

This review demonstrates clear benefits of home palliative care in helping patients, particularly those with advanced cancer, to die at home with reduced symptom burden and without impacting on caregiver grief. This justifies providing home palliative care for patients who wish to die at home. Further meta-analyses on symptom burden and caregiver grief would produce more robust data but for this to happen, future studies need to harmonise measurement and reporting practices.

### Table 2 Death at home: Home palliative care compared to usual care

<table>
<thead>
<tr>
<th>Study or Subgroup</th>
<th>Home palliative care</th>
<th>Usual care (control)</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Events</td>
<td>Total</td>
<td>Events</td>
</tr>
<tr>
<td><strong>Randomized Controlled Trials</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zimmerman 1985</td>
<td>20</td>
<td>28</td>
<td>7</td>
</tr>
<tr>
<td>Jordhøy 2000</td>
<td>22</td>
<td>90</td>
<td>11</td>
</tr>
<tr>
<td>Grande 1999</td>
<td>124</td>
<td>186</td>
<td>25</td>
</tr>
<tr>
<td>Brumley 2007</td>
<td>81</td>
<td>117</td>
<td>54</td>
</tr>
<tr>
<td>Bakitas 2009</td>
<td>69</td>
<td>111</td>
<td>63</td>
</tr>
<tr>
<td><strong>Subtotal (95% CI)</strong></td>
<td>316</td>
<td>532</td>
<td>180</td>
</tr>
<tr>
<td><strong>Heterogeneity:</strong> Tau2 = 0.00; Chi2 = 2.57, df = 4 (P = 0.63); I2 = 0%</td>
<td></td>
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<tr>
<td><strong>Test for overall effect:</strong> Z = 3.60 (P = 0.0003)</td>
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<tr>
<td><strong>Cohort Controlled Trials</strong></td>
<td></td>
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<tr>
<td>Axeisson 1998</td>
<td>13</td>
<td>41</td>
<td>4</td>
</tr>
<tr>
<td>Ahlner-Einqvist 2008</td>
<td>53</td>
<td>117</td>
<td>16</td>
</tr>
<tr>
<td><strong>Subtotal (95% CI)</strong></td>
<td>66</td>
<td>158</td>
<td>20</td>
</tr>
<tr>
<td><strong>Heterogeneity:</strong> Tau2 = 1.32; Chi2 = 5.72, df = 4 (P = 0.02); I2 = 83%</td>
<td></td>
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<tr>
<td><strong>Test for overall effect:</strong> Z = 1.39 (P = 0.16)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total (95% CI)</strong></td>
<td>382</td>
<td>680</td>
<td>180</td>
</tr>
<tr>
<td><strong>Heterogeneity:</strong> Tau2 = 0.33; Chi2 = 20.57, df = 6 (P = 0.02); I2 = 77%</td>
<td></td>
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</tr>
<tr>
<td><strong>Test for overall effect:</strong> Z = 2.98 (P = 0.003)</td>
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</tr>
</tbody>
</table>
Building on work by Dr Julia Riley and colleagues and their Hospital2Home (H2H) – a case conference model of multi-professional care for people nearing the end-of-life developed for cancer – we jointly agreed to test Hospital2Home service for people with ILD. We are now jointly testing this in a randomized controlled trial, results of which will be forthcoming in 2015.

Comparison of palliative care for older people in London, Dublin and New York

Although there are pockets of excellent end-of-life and palliative care globally, huge disparities exist in the care provided to patients and their families. This is sometimes evident despite established palliative care systems in various countries, such as in Ireland, the UK and the US. Building the findings of our earlier studies on evaluating and improving care, in the International Access Rights and Empowerment (IARE) study we are focusing on the largest cities in these three countries; Dublin, London and New York City, with a study arm also in San Francisco. We aim to identify novel ways to improve care, access and quality by examining variations in service provision and access. This large comparative international study is underway currently in partnership with specialist palliative care services from Beaumont Hospital and Mater Misericordiae University Hospital (Ireland), University of California, San Francisco Medical Center and Mount Sinai Medical Center (US), and teams from King’s College Hospital, and Guy’s and St Thomas’ Hospital.

Improving palliative care in sub-Saharan Africa

Following advances in medical care for people living with HIV, which have led to more efficacious and less toxic antiretroviral therapy, international guidelines have changed to lower initiation thresholds for treatment. This has resulted in increasing numbers of people living with HIV taking antiretroviral therapy, and managing HIV as a chronic condition (Lowther et al., 2014). Launched in 2011, TOPCare is a mixed methods, randomised controlled trial of a nurse-led palliative care intervention for HIV positive patients on antiretroviral therapy in Kenya, in collaboration with the University of Nairobi, Bomu Hospital and funded by the Diana Princess of Wales Memorial Fund (Lowther et al., 2012). The study is testing whether receipt of palliative care (in addition to standard HIV care) improves pain scores more than standard care alone, and the results will be available in 2014–15.
Symptom-led Research

Our focused clinical research on symptoms includes Cochrane reviews, observational studies and trials to test interventions and treatments for breathlessness, pain, spasticity and muscle weakness. Our aim is to better understand the symptoms experienced by patients and families towards the end of life, in order to discover more effective ways to prevent and manage the impact and distress they cause. Work is particularly targeted towards symptoms that have been neglected in the past, and extends across multiple patient groups, including those with cancer, chronic respiratory disease, heart failure, HIV/AIDS or long-term neurological conditions such as Parkinson’s disease and multiple sclerosis.
Symptom prevalence

Our research in this period stems from our earlier work, where we found that the prevalence of the 11 common symptoms was equally high across cancer; acquired immunodeficiency syndrome (AIDS); heart disease; chronic obstructive pulmonary disease and renal disease. Pain, breathlessness and fatigue were particularly common and were reported by more than 50% of all patients.

We studied symptom prevalence, severity and palliative care needs assessment using the Palliative care Outcome Scale in patients with long-term neurological conditions. We set out to understand the experiences and needs of people affected by these conditions in order to provide flexible and personalised support through health and social services, the voluntary sector and resources within families living with these conditions. Using a mixed methods approach; with a longitudinal survey and qualitative interviews with patients and carers, we found that physical, emotional, social, healthcare and information needs of people living with Parkinson’s disease, Multiple System Atrophy and Progressive Supranuclear Palsy were as severe as for people affected by cancer, with informal care costs often as high as formal care costs (Saleem et al., 2013). Over time this high level of need usually continued or became more severe. A simple early assessment of symptoms could help predict later difficulties with quality of life and could be used to trigger referral (Higginson et al., 2012c), highlighting a role for early targeted support. This research is being taken forward in Project OPTCARE NEURO, which is designed to test early short term integrated palliative care for people severely affected by neurological conditions.

Projects addressing the palliative care needs of patients with HIV/AIDS across the UK, US and Africa have measured symptom prevalence and burden, particularly in relation to antiretroviral therapy. In 302 patients with HIV/AIDS attending outpatient clinics in Uganda, 47% reported pain in the previous 7 days with 20% reporting moderate and 27% reporting severe pain (Namisango et al., 2012). Increasing pain intensity was associated with greater functional impairment and a poorer quality of life (see In focus, page 25).

“In pain, breathlessness and fatigue were particularly common and were reported by more than 50% of all patients.”
We also explored symptom prevalence in patients with end-stage kidney disease having undergone renal transplantation. In 110 patients from the UK, transplanted more than one year previously, symptom burden was high, with a mean of seven symptoms (Afshar et al., 2012). The most prevalent symptoms were common; weakness (56%, 95% CI 47–65), difficulty sleeping (46%, 95% CI 37–56), dyspnoea (42%, 95% CI 33–51), feeling anxious (36%, 95% CI 28–46), and drowsiness (36%, 95% CI 28–46) and were often reported as severe (Figure 4). A significant inverse relationship between renal function, as measured by eGFR, and number of symptoms emerged (Afshar et al., 2012). This work demonstrated that for renal transplant recipients, symptom burden is similar to patients with dialysis, and that routine symptom assessment should be used to identify unmet need.

**Breathlessness**

Breathlessness is one of the most common symptoms affecting patients. It impairs the ability to undertake the activities of daily living, reduces social contact, and in more advanced disease, becomes more isolating (patients cannot talk) and is a frequent cause of hospital admission. Caregivers often report a feeling of helplessness while watching their nearest ones suffer and clinicians experience similar feelings due to the lack of effective interventions. Our initial work, supported by the Cicely Saunders International ‘Improving Breathlessness’ programme, described types and trajectories of breathlessness, compared experiences across different primary diagnoses and led systematic reviews of pharmacological and non-pharmacological treatments for the symptom. Based on this work, we have developed a classification...
system based on patient experiences, to better characterise the symptom, and examined treatments either alone, e.g. the hand-held fan or neuromuscular electrical stimulation, or in combination as part of a breathlessness service.

**The experience of breathlessness**

We previously explored the experience of breathlessness and its effects on patients and carers across lung cancer, chronic obstructive pulmonary disease, cardiac failure and motor neurone disease. Qualitative interviews with 76 patients and 27 carers showed that distress and disability were experienced as a result of breathlessness regardless of disease state (Gysels et al., 2011a). Patients with COPD revealed that contact with healthcare was postponed to crisis point partly due to a lack of clear prognostic information, underscoring the need for good communication practices. Carers revealed that breathlessness was particularly challenging; they did not have strategies to relieve the symptom and were ill prepared for exacerbations of the symptom (Gysels et al., 2011a).

A further study described and contrasted the experience of 101 people caring for a family member or friend with breathlessness with a diagnosis of heart failure or lung cancer (Malik et al., 2013). We described the caregivers’ sleep patterns and sleep quality, level of burden and quality of life, and explored factors that affected the caregiving experience. Most participants were spouses (72%) and women (80%). Caregiver concerns were generally similar across conditions, and higher caregiver burden was associated with poorer ‘quality of patient care’ and worse carer psychological health. Caregiver depression and looking after patients with more severe breathlessness were associated with fewer positive caring experiences. This work highlighted the high levels of unmet need and burden in caregivers of patients with breathlessness. We are testing new ways to better support careers in our services.

**Episodic breathlessness: a new classification**

In collaboration with Dr Steffen Simon, previously of the Cicely Saunders Institute, we have explored episodic breathlessness. We had observed patients, describing brief episodes of severe breathlessness, but this experience was not described in the research literature. We conducted a systematic review that demonstrated episodic breathlessness is common, experienced by 81% to 85% of patients with advanced disease, but highlighted a need for information about its characteristics and patient experiences (Simon et al., 2013a). We therefore explored the experience of patients with advanced disease suffering from episodic breathlessness using in-depth interviews with 51 patients suffering from advanced stages of chronic heart failure, chronic obstructive pulmonary disease, lung cancer or motor neurone disease. Patients experience clearly distinguishable types and patterns of episodic breathlessness: triggered with normal level of breathlessness, predictable response (e.g. slight exertion), unpredictable response, non-triggered attack-like (quick onset, often severe) and wave-like (gradual onset) (Simon et al., 2013b). Further work characterised the duration, severity, frequency and timing of breathlessness episodes in 129 patients. Episodes were mainly short (75% ≤10 min), severe and occurred daily (Weingärtner et al., 2013). Findings have implications for the treatment of episodic breathlessness since most short-acting drugs in use have a longer onset of action compared to the duration of episodes.

This work has been incorporated into a breathlessness classification system (Simon et al., 2013c) which can be used to describe the intensity, nature and course of the symptom. The system has been refined by an International Delphi Survey (Simon et al., 2013d) and provides a common language for clinicians and researchers to aid clinical assessment and interpretation of research findings.
Neuromuscular electrical stimulation

Breathless patients often become physically inactive, which can lead to deconditioning and a gradual loss of their independence. Exercise can help but even simple forms, e.g. walking, can be difficult when out of breath. In patients who are unable or unwilling to adhere to existing forms of exercise, neuromuscular electrical stimulation (NMES) has been suggested as an alternative method of enhancing leg muscle strength. NMES uses a lightweight stimulator unit which produces a controlled and comfortable contraction and relaxation of the underlying muscles. It can be self-administered at home while seated and as a passive treatment potentially demands less motivation and change in lifestyle than traditional forms of exercise.

We have completed a Cochrane review to examine the effectiveness of NMES to manage muscle weakness in patients with advanced COPD, heart failure or lung cancer. NMES had a favourable effect on thigh muscle strength and exercise performance. We recommended further research to clarify its role in clinical practice by determining the optimal parameters for a programme, the patients most likely to benefit, and its impact on morbidity and service use (Maddocks et al., 2013a) (see In focus, page 23).

Support for people with breathlessness

A previous Cochrane review examined the effectiveness of non-pharmacological treatments, e.g. breathing training, for the relief of breathlessness in advanced stages of disease. Many of the interventions we identified were utilised in a multidisciplinary outpatient Breathlessness Support Service for people with advanced cancer or non-cancer disease. We examined the effectiveness and cost effectiveness in a randomised phase III study aimed to test the hypothesis that the service would improve patient mastery over breathlessness and reduce the use of healthcare resources compared with usual best care alone, at an acceptable level of cost effectiveness.

The Breathlessness Support Service comprised two outpatient clinic visits at the Cicely Saunders Institute and a home assessment, over a six week period. At first, patients were seen by respiratory and palliative care physicians and their carer had access to a social worker. After their appointment patients were followed up by a home visit by both an occupational therapist and a physiotherapist. Interventions provided included; patient education and advice regarding their breathlessness, hand held fan, relaxation CD, breathlessness poem, exercise programme, exercise DVD, patients’ energy conservation techniques, breathing exercises and positional techniques to relieve breathlessness. On their second visit patients were reviewed by palliative care and discharged and, if needed, referred to other services such as hospice, community palliative care or pulmonary rehabilitation.

105 patients took part, the majority of whom had COPD, with the majority of referrals coming from respiratory medicine and physiotherapy. Preliminary findings indicate high patient satisfaction, with 84% of respondents reporting that they definitely found the service helpful, with over half rating the service as excellent. All patients reported that they would recommend the service to someone else. The majority of patients reported that the service helped with their management of their breathlessness along with related symptoms e.g. mood and mobility, and reported it helping them access or receive support from additional services, e.g. social care. It helped to establish a sense of control and understanding of their condition. In qualitative reports patients were able to identify key interventions they found therapeutic; the hand held fan, home exercise, energy conservation techniques, patient education and a poem to help the right sort of breathing. Patients valued not only the provision of these interventions, but the patient-centred tenor of the care environment in which they were delivered.
A full analysis is being completed, including analysis of quantitative data on patient mastery, our primary outcome, and secondary outcomes of health status, quality of life, symptom severity and physical independence. Locally, we are seeking opportunities to continue elements of the Breathlessness Support Service within integrated clinical services.

Pain

Pain is one of the most common and distressing symptoms in patients with cancer. At advanced and terminal stages, the prevalence of pain can be as high as 90%. Pharmacological treatment is the main approach to control cancer pain, following the WHO “analgesic ladder” for cancer pain relief. This approach is effective in relieving pain for approximately 90% of patients with cancer and over 75% of terminally ill cancer patients, yet almost 50% of cancer pain is undertreated. Barriers to effective pain management are multimodal, and may come from healthcare professionals, patients, families and healthcare systems. General Practitioners (GPs) are the second largest group of health professionals involved in the management of cancer pain; they independently prescribe and often function as part of teams to ensure continuity of services via repeat prescriptions initiated by others. With the increased survival of cancer patients, we are likely to see an increased role of GPs in managing cancer pain and end of life care (or cancer pain at the end of life).

To help guide and inform practice, we developed a project with the aim to understand the prescribing practice of analgesics among GPs, factors associated with variation in prescription, and the associations between prescription and the utilization of healthcare services. We used routine GP practice data (General Practice Research Database) for the first time to understand palliative care and end of life care issues and extracted the clinical and social information, as well as over 10 million prescribing records, for almost 30,000 cancer patients (Higginson et al., 2012a; Gao et al., 2011). We have published on prescribing patterns for all three levels of analgesics (Higginson et al., 2012a) and for opioid analgesics (Gao et al., 2011). We found an overall increasing trend in analgesic prescribing, and identified old age as a risk factor for under-prescription of painkillers (Higginson et al., 2012a). The proportion of patients for whom opioids were prescribed decreased sharply with increasing age at diagnosis (Figure 5). For those younger than age 60 years, almost two thirds (60%) were prescribed at least one opioid in the last 3 months of life; however, for those older than age 80 years, the proportion was reduced to less than one third (30%).

“We identified old age as a risk factor for under-prescription of painkillers.”
Neuromuscular electrical stimulation for muscle weakness in people with advanced disease


Patients with progressive diseases often experience muscle weakness, which impacts adversely on levels of independence and quality of life. In those who are unable or unwilling to undertake traditional forms of exercise, neuromuscular electrical stimulation (NMES) may provide an alternative home-based method of enhancing leg muscle strength. Programmes appear to be well tolerated and have led to improvements in muscle function, exercise capacity and quality of life. To provide precise estimates regarding the effectiveness of NMES, we performed a Cochrane Collaboration systematic review with the primary objective to evaluate the effectiveness of NMES for improving muscle strength in adults with advanced disease.

Eleven studies met the inclusion criteria across advanced chronic obstructive pulmonary disease, chronic heart failure and lung cancer. A programme of neuromuscular electrical stimulation (NMES) offered to patients with advanced disease was safe, acceptable and led to significant improvements in quadriceps muscle strength and sub-maximal exercise capacity. Effects appear to be moderate, with pooled mean differences compared to controls of approximately 25 Newton metres (95% CI 9 to 41) in strength and 40 m (95% CI -4 to 84), 69 m (95% CI 19 to 119) and 160 m (95% CI 34 to 287) in exercise performance depending on the walking test used. The mean differences in walking tests equate to the suggested minimum clinically important difference.

NMES appears an effective means of improving muscle weakness in adults with progressive diseases such as COPD, chronic heart failure and cancer. This review highlighted the need for further research to clarify the role of NMES in clinical practice, in particular to determine patients most likely to benefit, and impact on morbidity and service use. In line with this, we are recruiting to a multicentre, placebo-controlled randomised controlled trial of NMES for people with advanced chronic obstructive pulmonary disease who are unable to take part in traditional pulmonary rehabilitation classes. The primary outcome is exercise performance and secondary outcomes include quality of life, health status and use of healthcare services.
Depression

Understanding depression

Work to improve the understanding and treatment of depression continues in collaboration with Professor Matthew Hotopf and colleagues from the Institute of Psychiatry, King’s College London. We undertook a systematic review and meta-analysis to determine the effectiveness of antidepressants in the treatment of depression in patients with neurological disorders. Pooling 20 randomised placebo-controlled trials in patients with Parkinson’s disease, multiple sclerosis, brain injury, epilepsy and stroke, we found 6–8 weeks of antidepressant treatment was associated with a greater than twofold odds of remission (OR 2.23; 95% CI 1.54 to 3.23; number needed to treat=7). (Price et al., 2011b). Fewer data were available for quality of life, and functional and cognitive outcomes, and there was little evidence of improvement with antidepressant treatment. Therefore, evidence for the efficacy of antidepressants in improving quality of life, and functional and cognitive outcomes was limited and inconclusive.

We completed a prospective longitudinal study to explore prospective predictors of non-remission of depression in patients referred to palliative care. Of 76 patients meeting the criteria for ‘any depressive syndrome’ at referral, the reporting of low social support from family and friends was the most powerful risk factor for non-remission. There was also a strong association between improved physical symptoms and remission of depression, providing evidence that effective physical symptom management in palliative care may be a valuable intervention for depressive symptoms (Goodwin et al., 2012). A cross-sectional survey of 301 patients described illness representations and examined the relationship between illness perceptions, adaptive coping, and depression. Feelings of helplessness–hopelessness and fighting spirit were highly correlated with items on the Brief Illness Perception Questionnaire (Brief IPQ) in opposite directions. The Brief IPQ domains of consequences, identity, concern, personal control, and emotion were associated with depression, which supports the assessment of illness perceptions to yield important information about risk of depression and help clinicians to personalize management of advanced disease (Price et al., 2012). We also explored coping in patients with cancer using a Factor analysis of the Mental Adjustment to Cancer Scale, which characterises adaptive coping under the label of ‘fighting spirit’. In a cross-sectional study with 4 week follow up in 275 patients with advanced cancer, we demonstrated good internal consistency and validity of a new scale of ‘acceptance and positivity’. Social support was positively associated with acceptance and positivity, and higher scores were associated with reduced odds of a desire for hastened death (Goodwin et al., 2014).

Decision support tool

Depression is one symptom in a project to develop a Decision Support Tool within the EU-fundedEUROIMPACT project, led by Prof Higginson and Dr Liesbeth Van Vliet, to create more guidance on the routine use of Patient Reported Outcome Measures (PROMs) in clinical care. The project has two arms. In the first, general guidance on the use and implementation of PROMs in clinical care is developed, building on the booklet ‘Outcome Measurement in Palliative Care: The Essentials’ (Bausewein, Daveson, Benalia, Simon & Higginson, 2011) and the EAPC White Paper on Outcome Measures (Bausewein, Daveson, Harding, Higginson among others, 2013). In the second arm, an evidence-based decision support tool is developed on how to respond to different levels of depression, information needs, family anxiety and breathlessness as measured by the Palliative care Outcome Scale. Based on published guidelines and systematic reviews, recommendations on how to respond to identified need are offered. Experts (clinicians, researchers and patient representatives) from all over the world are rating the appropriateness of recommendations in an online Delphi consensus study. The final decision support tool, as well as the general guidance on using and implementing PROMs in clinical care, will be integrated in the C-Change and OACC projects. These are new projects taking forward a funding model for palliative care by studying complexity and outcomes (C-Change) and an new Outcomes, Assessment and Complexity Collaborative (OACC) which is helping to implement Outcomes into routine clinical care.
In focus

Pain prevalence, intensity, associated factors and effect among ambulatory HIV/AIDS patients


This multicentre African study aimed to determine the prevalence, intensity, associated factors, and effect of pain among 302 patients with HIV/AIDS attending outpatient clinics at two teaching hospitals in Uganda. The presence and intensity of pain were self-reported using the Brief Pain Inventory (BPI); symptom data were collected using the Memorial Symptom Assessment Scale (MSAS-SF); and quality of life was assessed using the Medical Outcome Scale-HIV.

A high proportion (47%) experienced pain in the 7 days prior to the survey and pain was a symptom at the time of diagnosis for 68%. On the 0 to 10 numeric scale, 53% reported mild pain (1–4 rating), 20% reported moderate pain (5–6 rating) while 27% reported severe pain (7–10 rating). Pain intensity was significantly associated with advanced HIV disease, number of health comorbidities, increasing number of symptoms, physical symptom distress and reduced functional performance ($P < .04$). Increasing pain intensity was also associated with greater functional ability impairment (BPI functional interference index) and poorer QOL, irrespective of treatment.

Findings also indicated a low level of prescription of opioids. Of the 39 patients who reported severe pain on the day of the survey, only 13 (33%) were prescribed a strong opioid analgesic in line with the WHO pain ladder. Overall, patients expressed a degree of dissatisfaction with their pain treatment, and 57% expressed the need for a stronger type of pain medication. Those receiving pain medication reported an average pain relief of 68%, reinforcing the existence of pain under-treatment in this population.

This research highlighted that pain is highly prevalent among well-functioning ambulatory HIV/AIDS patients and that pain has a debilitating effect on quality of life. These data present important evidence of need for pain relief as HIV treatment is rolled out in Africa and underscore the need for strengthening the quality of pain management in this setting.

Figure 6 Differences in quality of life scores according to pain severity

Differences in quality of life scores according to pain severity. The groups had similar scores on the general health domain but significantly different scores on the domains of physical and role function.
Spasticity

Spasticity is the unwanted over-activity of muscles in those with damage to their brain or spinal cord. It can be exacerbated by other external factors such as poor position or pain. Spasticity is a common symptom in people who have hemiparesis caused by stroke, brain injury or other neurological conditions, and results in reduced function of the affected limb. The main treatment aims for upper limb (arm) focal spasticity are to improve passive function; to make it easier to care for the limb, to restore active function when possible, and to manage related symptoms such as pain.

The main focal treatment options are physical therapy and Botulinum toxin type A (BoNT-A). We have explored the role of BoNT-A in the management of the spastic hemiplegic shoulder and identified common achievable goals for treatment of this symptom. This has led to systematic processes for goal setting and evaluation for upper limb spasticity intervention using Goal Attainment Scaling (Turner-Stokes et al., 2013b). We plan to examine the role of individual physical therapy interventions in spasticity management.

A major component underpinning our research into spasticity has been the development of outcome evaluation systems to be applied alongside the Goal Attainment Scaling method (Ashford et al., 2013a; Ashford et al., 2013c). The importance of measuring the functional impact of treatments from the perspective of patients and their carers has been emphasised in the Department of Health Guidance on the routine collection of Patient Reported Outcome Measures (PROMs). We have developed an upper limb spasticity evaluation index for use in a large international cohort, supported by an earlier cohort study (Turner-Stokes et al. 2013b). In addition, the Arm Activity measure, a patient reported outcome measure for arm function following spasticity intervention has been developed and tested (Ashford et al., 2013a; Ashford et al., 2013b; Ashford et al., 2013c). We are also developing a measure to measure function of the spastic lower limb, which may range from passive caring for the limb in severely disabled patients, to using the limb for active mobility in more able patients. The content of the tool will be drawn from a systematic review of existing measures, together with an analysis of our extensive database of goals for treatment. After consultation with expert clinicians the measurement properties of the tool will be examined in the context of a multicentre observational cohort study, conducted in the context of routine clinical practice.

“We plan to examine the role of individual physical therapy interventions in spasticity management.”

Physiotherapist rehabilitating stepping in a patient with spasticity
Palliative care and rehabilitation are both relatively new fields in healthcare. The focus is on improving quality of life, alleviating symptoms and other problems. But these aspects are difficult to measure. Thus, in the Institute we are leading the development of scientifically rigorous outcome measures that measure what matters most to patients and their families. We see patients and families as people first and foremost, before the disease. To set standards of care we need appropriate tools to measure quality of life, outcomes and provide evidence about the most effective models of care. In developing new measures and evaluating existing measures we employ traditional psychometric approaches as well as modern item response theory methods, e.g. Mokken and Rasch analysis.
Person-centred outcome scales for palliative care

The Institute is at the forefront of the development of patient-reported outcome measures (PROMs) for palliative care. This is important because in 2011, 311 clinicians and researchers across Europe and Africa responded to our survey and identified disharmony in practice. There were 99 tools in clinical care and audit, and 94 in research, that were cited by less than 10 respondents. Further data revealed that respondents required the number of potential tools to be rationalized, and that brief tools were favoured (Harding et al., 2011d). The Palliative care Outcome Scale (POS) was one of the most common measures used, but respondents said that more training and support was needed to promote its use (Downing et al., 2012a). Doctors and nurses both reported the top reasons for not using outcome measures were lack of training and time constraints. Provision of information and guidance influenced their willingness to use measures. Both prioritized brief PROMs, but yet covering both physical and psychological domains. A measure’s comparability with national/international literature, validation in palliative care and easy access to the measure were important components in a tool’s use (Daveson et al., 2012).

To explore these needs around the implementation of PROMs in daily clinical practice further, we held a workshop with 32 professionals from 15 countries and eight different professional backgrounds. The participants identified: 1) the need for standardisation with improvement of existing PROMs, e.g. using modular systems and an optional item pool; 2) the aspects of further development with a multi-professional approach taking into account cultural sensitivity especially for translated versions; and 3) the need for guidance, training, and resources (Simon et al., 2012b).

As a result of these findings, during the period of this Triennial Report, we focussed on improving the Institute’s most widely requested tools – in particular refining and improving the Palliative care Outcome Scale (POS), our main measure, while also supporting use in the Support Team Assessment Schedule (STAS). We developed training materials and guidance to aid the use of all outcome measures.

Support Team Assessment Schedule (STAS)

The Support Team Assessment Schedule (STAS) was developed by Professor Irene Higginson. It assesses the outcomes of palliative care and has good reliability and validity. During the period of this triennial report STAS has been used in studies to compare palliative care services and in clinical audit (Bausewein, et al., 2011a). It has nine core and up to 20 optional items covering physical, psychosocial, spiritual, communication, planning, family concerns and service aspects. The STAS has been translated into seven languages: Dutch, Mandarin Chinese, French, Italian, Japanese, Spanish and Polish (Bausewein, et al., 2011a). It is completed by clinicians mainly in practice to help them assess problems and measure change in symptoms and need.

Palliative care Outcome Scale (POS) and new versions

The Palliative care Outcome Scale (POS) built on the STAS. Both tools have several questions in common, but the POS is shorter and has versions for patient and family self-assessment.

POS is specifically developed for use in palliative care, with a history going back to the late 1990s when it was initially developed. It is a short measure, comprising 10 questions, and an open question where the person can say what is troubling them most. The original POS had extensive work on its validity, reliability and responsiveness to change, with involvement by patients and families in its development. It is quick to complete, taking around 10 minutes. It is validated for use by patients, families and professionals (Bausewein, et al., 2011b).

Refining and improving the POS and STAS

The POS has been considerably developed and improved during the period of this triennial report, especially in our European Collaborative, PRISMA. We completed a systematic review to appraise the use of POS and STAS in clinical care and research. We found 83 papers, 43 on POS, 39 on STAS and one study using both. Eight STAS studies validated the original version, four an adaptation of the STAS; and 20 studies applied the STAS in another
POS papers reported on: 14 adapted POS versions, 12 translations of the POS and 15 studies of its use in different cultures. Both measures had been used in cancer, HIV/AIDS and in mixed groups. POS had also been applied in neurological, kidney, pulmonary and heart disease. Both tools were used in different areas such as the evaluation of care or interventions, description of symptom prevalence and implementation of outcome measures in clinical practice. Overall, the review found that POS and STAS are well accepted tools for outcome measurement in palliative care, in clinical care and in research (Bausewein et al., 2011a).

To improve our measures we evaluated the views of clinicians and researchers on use of outcome measures and which questions are most important in palliative and end-of-life care. An online survey with responses from 392 professionals working in clinical care, clinical audit and research in palliative care across Europe and Africa identified the POS and STAS as among the most common measures used in research and in clinical practice. The main uses were: assessing patients’ symptoms/needs, monitoring changes, evaluating care and assessing family needs. Respondents rated the most important questions as pain, symptoms, emotional and family aspects. There were no differences in the choice of the most important questions between doctors and nurses or between researchers and clinicians (Higginson et al., 2012c).

POS for wider use

Building on our POS version for caregivers, reported in the last triennial report, we developed a further refinement of POS for use with bereaved relatives in a mortality follow-back survey, improving this through cognitive interviewing (Gomes et al., 2013c). We extended the use of POS and the symptom module, POS-S, to help the care of people severely affected by multiple sclerosis and found these were valid (Sleeman et al., 2013c). Our factor analytic examination of the APCA African POS showed how to analyze palliative care outcome data for patients in sub-Saharan Africa (Harding et al., 2013b).

With colleagues in Africa, the world’s first paediatric outcome scale for palliative care is also in the final stages of validation.

Assessing spiritual needs and outcomes using POS

Although assessment of spiritual concerns is a key aspect of palliative care, it is difficult to do well, especially in multicultural contexts. We appraised potential measures that either directly assessed or included assessment of spiritual concerns in systematic review. This identified 191 articles, yielding 26 tools. Three of these – the McGill Quality of Life Questionnaire, the Measuring the Quality of Life of Seriously Ill Patients Questionnaire, and the Palliative care Outcome Scale (POS) – were the best validated tools for assessing spiritual needs and the most promising for use in multicultural palliative care, although all needed further testing (Selman et al., 2011a).

As a result we tested the two questions in POS – ‘peace’ and ‘life worthwhile’ – to see how well they performed as measures of spiritual well-being in African palliative care. The study was conducted at five palliative care services, four in South Africa and one in Uganda, and involved 72 patients in cognitive interviews and a further 285 who completed the POS and other tools. The POS question ‘peace’ was interpreted as ‘perception of self and world’, ‘relationship to others’, ‘spiritual beliefs’ and ‘health and healthcare’, whereas the question of ‘life worthwhile’ was interpreted in relation to ‘perception of self and world’, ‘relationship to others’ and ‘identity’. Peace correlated with an established but lengthier measure of spiritual well-being, but life worthwhile appeared to be different, suggesting this tapped into a distinct construct of spirituality. The study suggested that the two POS questions – ‘peace’ and ‘life worthwhile’ – are brief and simple enough to be integrated into routine practice and can be used to measure this important but neglected outcome in this population (Selman et al., 2013b).
Integrating the improvements – the Integrated Palliative care Outcome Scale (IPOS)

As a result of our improvements and research into POS, we have released a new version of POS – called IPOS – that integrates the best in the POS, POS-S, the APCA African POS and other modules. Cognitive testing and further validation is led from the Institute with several collaborating centres around the United Kingdom and beyond. Parallel translation and validation studies are taking place in Germany, Greece, Portugal, Romania and Sweden, so that several translated versions can be available on release. Updates are regularly posted on the pos website, www.pos-pal.org.

To help support the care of people with myeloma, earlier in care, we are integrating a new myeloma-specific quality of life questionnaire (MyPOS) – a measure of quality of life of people affected by myeloma – using some of the questions and response scales from the POS, POS-S and IPOS. The MyPOS is intended for use in routine clinical practice as well as for measuring the benefit of treatment in ways that are meaningful to patients. In depth interviews with people with myeloma and a systematic literature review (Osborne et al., 2012) have influenced its development.

Using the measures in research to understand need, assess problems and improve care

The main reasons for developing robust and valid measures are to: understand need, assess experience and problems, and discover what treatments and care work best and for whom. Therefore, this strand of measurement underpins all our other research themes. We have used the POS and other measures to better understand and define the trajectories of illness of people with stage 5 chronic kidney disease, (Murtagh et al., 2011c), Parkinson Syndromes (Higginson et al., 2012b; Saleem et al., 2013), heart failure, (Malik et al., 2013), HIV (Simms et al., 2013) and cancer (Malik et al., 2013). We have also used the POS to evaluate palliative care in Africa (Harding et al., 2013c; Lowther et al., 2012), and to assess the longer-term effects of a new model of care for people with multiple sclerosis.

Supporting the introduction of outcome measurement into clinical practice and research

In 2011 our survey of 392 palliative care clinicians across Europe and Africa identified that a lack of training and guidance severely hampered the use of outcome measures in practice (Bausewein et al., 2011b). In response we developed general guidance
on outcome measurement, as part of our EU-supported project PRISMA, and a pocket version of the POS booklet for professionals.

The POS Website (www.pos-pal.org)

In response to our survey showing that ease of access was a key requirement for clinicians and researchers (Daveson et al., 2012a), we launched a bespoke POS website. This website provides downloadable versions of POS and the POS booklets, guidance on its use and publications from clinical and academic groups on POS. In its first 11 months the website had: 251,373 hits (since launch in 2011, average 22,852 hits/month), 10,102 visitors (average 918 visitors/month). 1,274 individuals from 74 different countries are registered POS users (either as individual, group or organisation registration).

POS Translations

The process of linguistically validating measures is lengthy and involves a number of important steps. The POS development team is currently working with teams around the world, who have or are working on translating the POS into over 20 languages, to ensure that all of the required steps for validation are completed. There is also a Thai POS translation being used across the public health sector, and a Vietnamese version being validated. Bárbara Antunes and co-authors developed the Manual for cross-cultural adaptation and psychometric validation in February 2013. This guidance document builds on guidance provided by the European Organisation for Research and Treatment of Cancer (EORTC) and the MAPI Institute, and is available on the website, http://pos-pal.org.

POS training days

The POS development team continues to organise workshops designed for all professionals in palliative and end of life care, having previously successfully hosted them in 2011, 2012 and 2013. The team hosts two separate days aimed at clinical staff and researchers, working in a broad array of settings where participants are able to equip themselves with the necessary skills and knowledge required when implementing POS or other outcome measurements. The workshops are facilitated and run by a mixture of experts from the Cicely Saunders Institute and external speakers and chairs.

The impact of POS on improving care, and on policy and practice

An independent assessment of POS has shown how it leads to changes in how the organisation delivers care (with more emphasis on quality improvement), on the composition and training of staff teams (more holistic/multi-professional) and on the quality of life of patients and families (www.csi.kcl.ac.uk/pos). POS was identified by a European-Commission supported analysis and the European Association for Palliative Care as one of the top four most commonly used measures for clinical care, audit, training and research in Europe and Africa. It is used in clinical practice within at least 44 countries. Its rapid spread has been aided by its translation into 28 languages eg. Brazilian Portuguese, Dutch, Chinese, German, Italian, Khmer, Malayalam, Portuguese, Punjabi, Spanish, Urdu, Afrikaans, SeSotho, isiZulu, isiXhosa, KiSwahili, Dholuo, Kiswahili, Runyankole, Luganda, Runyoro, Setswana, Arabic, French, including the source language of British English.

POS is recommended for use throughout England, including throughout NHS Leeds (formally Leeds PCT), Leeds Teaching Hospitals NHS Trust, St Gemma’s and Sue Ryder Wheatfield’s Hospices, Leeds Adult Social Services and Yorkshire Ambulance Service NHS Trust. The Dutch funding organisation financed by the Ministry of Health and the Dutch Organisation for Scientific Research that emphasises the importance of measuring quality of life in palliative care also recommends POS.

POS is being used within national outcome measurement data collection electronic platforms such as the national Welsh CANISC platform, which forms part of the Welsh patient’s clinical record. POS data has also been used by services to advocate for palliative care.

POS also extends into national and European policy developments, forums, recommendations and is embedded within electronic platforms that improve palliative care quality and access. This includes a coordination project, funded by the European Commission, that highlighted POS as the measure to aid palliative care quality and access across Europe.
In focus

Are we heading in the same direction? European and African doctors’ and nurses’ views and experiences regarding outcome measurement in palliative care


This study aimed to examine and compare doctors’ and nurses’ views and experiences regarding outcomes measurement in palliative care, including patient reported outcome measures (PROMs). A web-based survey was conducted in Europe and Africa with palliative care professionals working in clinical care, audit and research. The overall participation rate was 42% (663/1592) and the overall completion rate was 59% (392/663). Of these respondents, 196 were doctors (51% men, mean 47 years) and 104 were nurses (84% women, mean 45 years).

The results indicate that the doctors and nurses share similar experiences and views regarding outcomes measurement in palliative care, and that this includes favourable outcomes measurement experiences. Both groups preferred brief, multidimensional patient versions of outcome measures that include physical and psychological attributes, both faced similar obstacles regarding outcome measurement practice (lack of training and time) and both were influenced by whether a measure was validated for use in palliative care. When asked to rank tool domains (or elements) in order of priority from most useful to least useful, both doctors and nurses ranked physical and psychological domains as the two most important to include in a measure. The three least important domains were questions about information giving, communication and experiences of services (see Table 4).

This research shows that in palliative care, doctors and nurses are heading in the same direction in relation to outcome measures. Both are influenced by the provision of outcome measurement training, information and guidance. Both prioritise multidimensional and brief patient-reported PROMs, and both are generally willing to use outcome measures. Multidisciplinary outcome measurement education and training is required. An emphasis on competency-based development is encouraged, as well as access to freely available, validated and translated tools that allow for a coordinated and cohesive approach to practice and cross-national research.

Table 4 Doctors’ and nurses’ ranking of tool domains by order of priority; results of survey in Europe and Africa

<table>
<thead>
<tr>
<th>Order of Priority</th>
<th>Domains</th>
<th>Doctors (n=196)</th>
<th>Nurses (n=104)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Median</td>
<td>Quartile (1st–3rd)</td>
</tr>
<tr>
<td>Most important</td>
<td>Physical Symptoms</td>
<td>1</td>
<td>(1–1)</td>
</tr>
<tr>
<td></td>
<td>Psychological</td>
<td>2</td>
<td>(2–3)</td>
</tr>
<tr>
<td></td>
<td>Patient’s insight about their situation</td>
<td>4</td>
<td>(2–6)</td>
</tr>
<tr>
<td></td>
<td>Social</td>
<td>4</td>
<td>(3–6)</td>
</tr>
<tr>
<td></td>
<td>Relative’s concerns</td>
<td>4</td>
<td>(3–6)</td>
</tr>
<tr>
<td></td>
<td>Spiritual</td>
<td>5</td>
<td>(4–7)</td>
</tr>
<tr>
<td></td>
<td>Questions about information giving</td>
<td>7</td>
<td>(4–8)</td>
</tr>
<tr>
<td></td>
<td>Questions about communication</td>
<td>7</td>
<td>(4,5–8)</td>
</tr>
<tr>
<td>Least important</td>
<td>Experience with services</td>
<td>9</td>
<td>(6–9)</td>
</tr>
</tbody>
</table>
The European Cancer Patient Coalition’s President highlighted POS as one of the preferred tools to use with palliative care patients and their families in a policy summit in Brussels. The 2011 Palliative Care Funding Review by the UK Department of Health recommended that future developments of case-mix and assessment be based on POS, to ensure service provision and palliative care benchmarking. POS is named as a measure in the document underlined in item 15 in the Resolution 1649 by the European Parliamentary Assembly for strengthening the palliative care approach throughout Europe. POS is endorsed by the end-of-life Care Horizon Scanning Service website that targets Commissioners and primary and secondary care service-managers in order to ensure best practice and innovation. The England End of Life Care Programme promotes outcome measurement guidance that recommends POS for improved care and access, and has influenced policy development.

Impact of the African Palliative Care Association African Palliative care Outcome Scale

The African Palliative Care Association (APCA) recommends POS as a measure to ensure holistic assessment and care access for all African palliative care patients and as a means to improve quality of African palliative care. POS is used across settings including inpatient hospice, day care, hospital, support team, home care, and primary care environments (A. Downing, Defilippi, 2013). The Hospice Palliative Care Association of South Africa (HPCA) uses the African POS as a measure of quality when accrediting and grading the performance of hospice and palliative care services nationally. These care standards are endorsed by COHSASA (Council for Health Service Accreditations of South Africa), which is responsible for quality improvement and accreditation. In addition, the Handbook of Palliative Care in Africa (produced with US Government collaboration) endorses the POS pain scoring method, with guidance available in English, French and Portuguese for different African regions (www.csi.kcl.ac.uk/pos).

Measures for rehabilitation

Outcome measurement is critical to the evaluation of interventions provided in rehabilitation practice. Since 1995, Professor Turner-Stokes has spearheaded a drive to develop a common language outcome measurement for brain injury rehabilitation in the UK. A common strand for much of the recent work is the development of outcome measures which to assess the effectiveness of rehabilitation interventions, and the exploration of the relationship between different measures in current use in the UK. Evidence has been presented that clearly demonstrates that

“Measuring the quality of care provided was problematic without rigorously validated outcome measures that were suitable for use within the resource-constrained and culturally different African context.”

(Defilippi et al., 2013)
rehabilitation is not only effective, but also highly cost-effective in patients with severe complex disabilities following acquired brain injury. We have developed a set of tools to measure complexity of patient rehabilitation need, service inputs and service outcomes for neurological rehabilitation services. These are undergoing continued testing and refinement, and form part of the national dataset for specialist rehabilitation services, the UK Rehabilitation Outcomes Collaborative (UK-ROC) (Figure 7).

The UK-ROC is hosted by the Regional Rehabilitation Unit, Northwick Park Hospital, an affiliate of the Cicely Saunders Institute and King’s College London. The UK-ROC is closely linked to clinical provision by providing commissioning data for UK specialist rehabilitation across the UK. The measurement tools utilised provide both clinically useful data for patient management and commissioning data to enable the setting of tariffs to pay for services. Key measures utilised in UK-ROC are summarised below:

**Rehabilitation Complexity Scale**

The Rehabilitation Complexity Scale is a simple, easy to use measure of needs for nursing, medical and therapy interventions, which are the principal cost drivers of rehabilitation services. The scale is designed to provide a global assessment of complexity within each of the four patient categories. It has a total score range of 0–15 in four subscales: care (0–3), nursing (0–3), therapy (0–6) and medical (0–3), and has been shown to be psychometrically robust.

**The Northwick Park nursing and therapy dependency scales**

These scales have been developed to provide a more detailed evaluation of needs and service inputs for patients requiring specialised rehabilitation services, and the relative costs of treatment:

- **The Northwick Park Dependency Scale (NPDS)** is an ordinal measure of basic care and skilled nursing needs. Using a computerised algorithm it produces an assessment of the care and nursing hours needed for an individual patient.

- **The Northwick Park Therapy Dependency Assessment (NPTDA)** is an equivalent tool for assessing therapy needs. Using a computerised algorithm it produces an assessment of the therapy hours for each therapy discipline (i.e. physiotherapy, occupational therapy, speech and language therapy, psychology, dietetics, technicians/engineers, social workers, etc) needed for an individual patient.

**UK specialist Rehabilitation Outcomes Collaborative dataset**

The UK-ROC dataset was set up in 2008 to develop a national database for collating case episodes for inpatient rehabilitation. The first five years have focused on neurorehabilitation and include data from all specialist neurorehabilitation services (levels 1 and 2) across the UK. The database has been developed in collaboration with the British Society of Rehabilitation Medicine and the Australasian Rehabilitation Outcome Centre, which is now 10 years into a similar programme. The database provides:

- Casemix and costing data to inform development of complexity-weighted tariffs
- Benchmarking of service quality and outcomes
- Information on rehabilitation requirements, the inputs provided to meet them, outcomes and cost-benefits of rehabilitation for patients with different levels of need.

The dataset represents the inpatient rehabilitation subset of the Long Term Neurological Conditions dataset (downloadable from the NHS Information centre website) and comprises 30 items of demographic and process data for each admitted case episode with measures of:

- Rehabilitation needs – the individual requirements for rehabilitation
- Input – the services provided to meet those needs, so unmet needs can be identified and reasons for variance can be recorded
- Outcomes – the gains made during rehabilitation; recorded using an agreed set of measures.

The hierarchical dataset structure (Figure 7) is designed to minimize data burden for higher
throughput services, whilst capturing a greater level of detail from high cost–low volume specialised services. This scheme has been recommended by the Department of Health’s Expert Reference Panel for Rehabilitation to measure case mix for the purpose of tariff banding under the Payment by Results programme.

**Goal Attainment Scaling**

Measuring effectiveness of brain injury rehabilitation poses major problems due to the heterogeneity of patients’ deficits and desired outcomes. Particularly at the level of function and participation, goals are very much dependent on the individual’s lifestyle and aspirations. Individualised goal-setting has become a routine part of rehabilitation and many multi-disciplinary approaches to clinical care. Goal Attainment Scaling (GAS) supports clinical decision-making and communication between the patient and the treating team, as well as providing a means to evaluate whether the intended goals for rehabilitation were achieved. This department has been exploring the use of GAS as a person-centred outcome measure for rehabilitation since 2006. We have also examined and compared different methods of applying GAS, and have embarked upon an international programme of workshops to train clinicians and researchers to use GAS consistently. Evidence has been presented which clearly demonstrates that GAS is a valid and sensitive outcome measure for rehabilitation. In collaboration with colleagues in Australia, GAS was shown to be a more sensitive measure than existing standardised outcome assessments – providing both qualitative and quantitative evaluation of the benefits of treatment with botulinum toxin for upper limb spasticity. Following on from this work, GAS has now been applied as the primary outcome measure in a large international cohort study conducted across 22 countries, led by Professor Lynne Turner-Stokes.

**Focal spasticity evaluation**

**Upper limb function**

Through related work the need for further assessment of upper limb function has been identified. Assessing functional gain is problematic for three reasons. Firstly the goals for treatment vary widely. Secondly in some cases treatment is aimed at restoring motor control leading to independent function (termed ‘active function’). Thirdly in other cases, where paralysis is more severe, the goals for intervention may be to improve the ease of caring for the person – maintaining hygiene or ease of dressing for example (termed ‘passive function’). The management of spasticity also includes physiotherapy to stretch the affected muscles and where possible to promote motor control through practice of tasks, and is therefore further complicated by incorporating more than one intervention.

While functional scales, which include a standardised task battery, are useful for comparison of different patient groups, they may not reflect accurately the individual goals of each patient, and user-focused outcomes are increasingly regarded as critical to the demonstration of success. There is therefore a need to develop functional outcome measurement tools to use alongside approaches such as Goal Attainment Scaling, which assess both active and passive function from the ecological perspective of the ‘patient’.

- **GASeous (GAS – Evaluation of Outcome for Upper-limb Spasticity)**
  GAS has been further developed and tested in focal spasticity management with botulinum toxin. The approach has been to identify consistent domains for goal setting in this area of practice. This has lead to a structured method of goal setting and outcome evaluation using GAS for upper limb spasticity. This work is being used nationally and internationally by clinicians to document outcome and these aspects of practice.

- **ArmA – Arm Activity Measure**
  The ArmA is a measure of difficulty in passive and active function for application following focal therapy intervention and in particular for spasticity interventions, both physical and with botulinum toxin injection (Ashford et al 2013a). The active and passive sub-scales of the tool are treated as separate constructs, but nevertheless have a relationship and are both important in the achievement of clinically relevant goals. The ArmA has utility in practice for evaluation of spasticity intervention (often for passive function) and possibly other focal interventions such as task practice training for active function improvement. The ArmA has undergone psychometric testing (Ashford et al 2013c) and its utility has been tested in focal spasticity intervention using botulinum toxin (Ashford et al 2014).
• Upper Limb Spasticity Index (ULSI)
  To incorporate both the goal evaluation outcome using GASeous and patient report in the form of ArmA alongside other relevant measures, an index has been developed to record inputs (therapy and medical interventions) and outcomes of focal spasticity intervention. Initial testing of this index has been undertaken and incorporation into a multicentre, international cohort study is underway.

Lower limb function
The importance of measuring the functional impact of treatments from the perspective of patients and their carers has been emphasised in the Department of Health Guidance on the routine collection of Patient Reported Outcome Measures (PROMs). However, there is currently no comprehensive instrument to measure function of the spastic lower limb, which may range from passive caring for the limb in severely disabled patients, to using the limb for active mobility in more able patients. This project builds on our previous work in upper limb spasticity, to develop a measure of lower limb function. The content of the tool will be drawn from a systematic review of existing measures, together with analysis of our extensive database of goals for treatment. After consultation with expert clinicians the measurement properties of the tool will be examined in the context of a multicentre observational cohort study, conducted in the context of routine clinical practice.

• GASLegs (GAS – Leg Spasticity)
  The work undertaken in developing methods for evaluation of upper limb spasticity has resulted in similar work to address outcome in leg spasticity. A structured method of goal setting and outcome evaluation using GAS for lower limb spasticity has also now been developed and is being tested.

• LegA – Leg Activity measure
  Leading directly from the work on the ArmA, Dr Ashford and Professor Turner-Stokes have developed a programme of work undertaking the development and testing of a measure of passive and active lower limb function. This ongoing project and new tool will address patient and carer reported outcome following spasticity intervention in the leg.

• Lower Limb Spasticity Index (LLSI)
  The Lower Limb Spasticity Index is under development to incorporate the GASlegs and LegA alongside other relevant measures, to record inputs (therapy and medical interventions) and outcomes of focal spasticity intervention. Initial testing of this index will be undertaken and incorporated into a planned multicentre, cohort study in the UK.

“The active and passive sub-scales of the tool are treated as separate constructs, but nevertheless have a relationship and are both important in the achievement of clinically relevant goals.”
In focus

The Needs and Provision Complexity Scale – a measure of met and unmet needs for health and social care services


Our recent research in patients with complex long-term neurological conditions led to the development of a novel outcome measure that draws on information from both sides of the clinician-patient partnership to determine needs and provision of specialist rehabilitation services in the UK.

The Needs and Provision Complexity Scale (NPCS) is a simple, pragmatic tool that directly evaluates the complexity of needs for care and support in two principal domains, Health and Personal Care and Social Care and Support, and the level of service provision offered to meet these needs. In addition, an algorithm can be applied that expresses met and unmet service needs in terms of costs for the purpose of integrated care planning.

- Part A (NPCS-Needs) is completed by treating clinicians to evaluate each patient’s needs for health and social care in any given period.
- Part B (NPCS-Gets) is a mirror image of the same tool, completed by patients/carers at the end of that period, to report the levels of service that have been provided in relation to those needs.
- The difference between NPCS-Needs and NPCS-Gets indicates the extent of met versus unmet needs at individual service level as well as overall.

The NPCS has been appraised in the context of a multicentre prospective cohort study, which followed up consecutive patients discharged from nine London Specialised Neuro-rehabilitation Units at six months post-discharge (n=211). Psychometric evaluation revealed good overall internal consistency, acceptable repeatability and good concurrent validity.

Needs for medical/nursing care and accommodation were well met. Significant shortfalls in provision were identified in the subscales of Rehabilitation (effect size (ES)=−0.85), Social support (ES=−0.48) and Equipment (ES=−0.44) (all p<0.001). Item-level analysis demonstrated that the frequency of Personal care received exceeded predicted needs (p<0.001). In 80% of cases, this care was provided/paid for by families (Figure 8).

Translated into mean costs per patient per year, the estimated underspends on Rehabilitation (−£2,320) and Social support (−£1,790) were exceeded >3.5-fold by excess costs of Personal care (£10,313) and Accommodation (£4,296). Put simply, the failure to invest the relatively modest sum of approximately £4,000 per year in rehabilitation, equipment and social support services results in increased levels of dependency and ongoing care costs to the tune of approximately £14,000 per annum. The remaining cost of £10,000 per patient per year is largely borne by patients and families themselves.

Figure 8 Proportions of patients whose community service needs were met and unmet (or exceeded) six months after discharge from in-patient rehabilitation

<table>
<thead>
<tr>
<th>Service Category</th>
<th>Needs met</th>
<th>Unmet</th>
<th>Exceeded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation</td>
<td>0.7</td>
<td>0.3</td>
<td>0.0</td>
</tr>
<tr>
<td>Equipment</td>
<td>0.8</td>
<td>0.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Advocacy Needs</td>
<td>0.6</td>
<td>0.4</td>
<td>0.0</td>
</tr>
<tr>
<td>Day Care</td>
<td>0.8</td>
<td>0.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Residential Respite</td>
<td>0.5</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>Family Care</td>
<td>0.7</td>
<td>0.3</td>
<td>0.0</td>
</tr>
<tr>
<td>Social Work/Case Mgmt</td>
<td>0.5</td>
<td>0.5</td>
<td>0.0</td>
</tr>
<tr>
<td>Vocational Rehabilitation</td>
<td>0.7</td>
<td>0.3</td>
<td>0.0</td>
</tr>
<tr>
<td>Therapy Intensity</td>
<td>0.8</td>
<td>0.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Therapy Disciplines</td>
<td>0.7</td>
<td>0.3</td>
<td>0.0</td>
</tr>
<tr>
<td>Personal Enabler</td>
<td>0.8</td>
<td>0.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Carer Frequency</td>
<td>0.7</td>
<td>0.3</td>
<td>0.0</td>
</tr>
<tr>
<td>Number of Carers</td>
<td>0.6</td>
<td>0.4</td>
<td>0.0</td>
</tr>
<tr>
<td>Nursing</td>
<td>0.8</td>
<td>0.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Medical</td>
<td>0.7</td>
<td>0.3</td>
<td>0.0</td>
</tr>
</tbody>
</table>

0.0 0.2 0.4 0.6 0.8 1.0
Societies are changing across the globe. Those who are suffering, have profound disability, or are dying are especially vulnerable. To future-proof palliative care and rehabilitation, we are studying the needs and preferences of key groups and areas: older people, caregivers, preferences and choices, ethnicity and culture, spirituality. Leading the evidence response to the debate over such questions as how to meet the growing ageing population, the diverse cultures in our society, advance directives, and location of dying, the Living and Dying in Society research strand supports the Institute’s non-cancer programme and our expanding health economic focus.
Ageing

The Cicely Saunders Institute has been approved for renewed status as a WHO Collaborating Centre for Palliative Care, Policy and Rehabilitation. In response to global demographic changes, the range of settings in which people are cared for and die, and the methodological challenges of recruitment and data collection among people with impaired physical and cognitive function, our programme of work for older people cross-references to our work on developing and testing interventions.

Older people across settings

Taking forward our collaboration with Professor Harvey Chochinov, our qualitative work has identified the factors that constitute dignity for older people in care homes: “independence,” and “privacy”, followed by “comfort and care,” “individuality,” “respect,” “communication,” “physical appearance” and “being seen as human” (Hall et al., 2014). This informed our trial of a dignity therapy intervention (page 13) (Hall et al. 2012a). Evaluation of the Gold Standards Framework for care homes has identified improvement in communication and symptom control (Hall et al. 2011a). Our research into the needs of older people who present at emergency units found that 57% had palliative care needs (Beynon et al. 2011).

Evidence appraisal and methodological development

Our work in care homes was directed by findings from a Cochrane review that identified only three studies, all USA-based (Hall et al. 2011c). Our international work on long-term care facilities has been underpinned by appraisal of the state of the science in methods to generate evidence in long term care settings, conducted under our pan-European European Commission-funded programme “PRISMA”. This systematic review identified specific problems with population definitions and appropriate outcome measures in the existing evidence (Albers et al. 2012). An investigation of which measures are most appropriate for quantifying quality of life among older people found challenges with tool length concept comprehension, and finding a single-item tool a satisfactory measure (Hall et al. 2011d).

Caregivers

Key work streams in the Cicely Saunders Institute aim to increase understanding of caregivers’ experiences and support needs, and to facilitate the contribution they can make to research through involvement in planning studies that address issues of importance to them and those they care for. Most people with life limiting conditions prefer to receive the care and support they need in their own home and the main source of this care typically comes from within the family. Taking on the role of family caregiver for someone with a terminal illness or chronic condition can be a challenging and distressing experience. While some people derive satisfaction from caregiving in difficult circumstances, others report high levels of burden, with fatigue, worry, stress, loss and social isolation being contributing factors.

Integrating caregiver research across our themes

Increasingly, our studies address the needs and outcomes of both patients and their caregivers, and so the evidence we generate reports on both members of the dyad. For example, we have identified the effect of interstitial lung disease on family relationships from both patient and caregiver perspectives (Bajwah et al. 2013b), and appraised the evidence in a Cochrane review of the effectiveness and cost effectiveness of home palliative care for both patients and caregivers (Gomes et al. 2013a). Cross-cutting with our symptom programmes we have discovered that caregivers of patients with the most breathlessness report fewer rewards of caring (Malik et al., 2013). Importantly, our evidence review found that caregivers report benefits from participating in research (Gysels et al., 2012c).

Measuring and improving the impact of caregiving

As shown in our interventions, inclusion of caregiver outcomes has become standard in our intervention studies, for example we found early palliative care lowered burden among caregivers in our fast track multiple sclerosis trial (Higginson et al. 2011c). This built on our previous work validating short versions of the Zarit carer burden interview. Our evaluation of the PACE (Psychosocial Assessment and Communication Evaluation) has found, in a Phase II trial, that family members were more satisfied with communication in the intervention arm (Higginson et al. 2013b).
Ongoing studies

- QUALYCARE has completed interviews with 500 bereaved caregivers to determine differences in satisfaction costs and bereavement outcomes according to place of death, and the results are currently being analysed.

- As part of project BuildCARE, in an international initiative spanning the UK and USA, services and care in the months before death from cancer were examined in the IARE study. Bereaved caregivers completed postal questionnaires, which helped to determine whether the needs and preferences of their dying relatives had been met, and they identified the impact of death on themselves.

- The OPTCARE older people study is surveying 900 bereaved relatives to find out how health services could be better provided to support people aged over 75, and their caregivers at the end of life. The next phase of this work will evaluate a new palliative care service, incorporating elements recommended by relatives and caregivers, to determine whether it improves well-being and caregiver burden.

- The DINAMO project aims to develop the evidence needed to optimise home palliative care in Portugal. Among the work packages, the preferences of terminally ill patients and families are being elicited.

- The QoL LIVER, a longitudinal mixed-methods study into end-of-life care needs for people in Southern England living with advanced liver disease, and their family caregivers, is also currently underway.

Preferences and choices

A core value for palliative care is to empower patients facing a life-threatening illness by providing individualised care, tailored according to people’s preferences and priorities. The Cicely Saunders Institute carries out a long-term research programme examining people’s preferences for place of care and death, and what helps these to be met. Alongside, we investigate other important research areas to improve choice regarding the care provided towards the end of life. This strand of our research programme provides key information for policy and practice to ensure that we plan appropriate services. In a series of mortality follow-back surveys derived from the QUALYCARE study, we are researching patients’ and family caregivers’ preferences for place of death, assessing changes in the last three months of life, and exploring if and how discussions take place around prognosis and preferences. We are currently studying adults who have died from cancer and older people (75 years and older) living with non-malignant conditions in London and Brighton.

In the European Commission-funded PRISMA population survey of 9,344 adults across seven European countries, we used a mixed methods approach to determine people’s preferences for information and priorities for care, the most concerning symptoms and problems, and preferences for involvement in decision-making and place of death. We have discovered a majority preference for maximising quality of remaining life over extending life in the scenario of serious illness (Higginson et al. 2014). We also found preferences for being fully informed (Harding et al. 2013e) having better access to quality end of life care (Daveson et al. 2013a), self-involvement when a person had capacity (Daveson et al. 2013b), and crucially a preference to die at home (Gomes et al. 2012b). The questionnaire was adapted using a street-survey methodology in two African countries to determine, for the first time, the preferences and priorities for end of life care in developing regions (Kenya and Namibia) (Powell et al. 2014; Downing et al. 2012a).
Two new projects are researching preferences and choice in different ways around the world. DINAMO is developing an optimised model of home palliative care based on patients and caregivers’ preferences, using a discrete choice experiment methodology in Portugal (one of the most ageing countries in Europe). The IARE study is seeking to improve the rights of older patients and their caregivers by generating information regarding access and empowerment of people requiring specialist palliative care in London, Dublin, New York and San Francisco. A novel study to determine patient preferences is embedded within the IARE study. This element also makes use of a discrete choice experiment, which is identifying patient’s preferences for palliative care service characteristics.

Place of care and death

Knowing where people die can be an indicator of where they were cared for, which is important for allocating health-care resources and for assessing related public-health policies. We recommend place of death be incorporated into death-registration data as a health metric. Despite surveys that show a prevailing preference for home death among patients, caregivers and the public, most deaths in Europe still occur in hospital (Gomes et al., 2013b). Our studies identified factors associated with home death, including affluence, patients’ preferences, provision of home care and extended family support (Higginson et al., 2013c). We examined variations in preferences for place of death in 9344 participants cross-nationally (Gomes et al., 2012b). At least two-thirds of people prefer a home death in all but one country studied. Factors associated with a preference for home death in more than one country were: being younger, an increased importance of dying in the preferred place, prioritizing keeping a positive attitude, and wanting to involve family in decisions if incapable (Gomes et al., 2012b). These data have been used to compare the places where people die with population preferences, for example, in Portugal only 29.6% of deaths in 2010 occurred at home, despite 51.2% reporting home as their preferred place of death (Gomes et al., 2013b). In a large systematic review (210 studies, n=100,307) we examined the heterogeneity in preferences for home death and explored, for the first time, changes of preference with illness progression (Gomes et al., 2013b). In 75% of studies most people preferred a home death and around four fifths of patients did not change preference as their illness progressed (Gomes et al., 2013b). This supports focusing on home-based care for patients with advanced illness but urges policy-makers to secure palliative care elsewhere for those who prefer care elsewhere or change their mind (Gomes et al., 2013b).

We have also shown a recent upward trend in the number of patients who die in their preferred place of care, in part as a result of service developments such as community palliative care and advance care planning (Gomes et al., 2012a; Khan et al., 2014; Sleeman et al., 2014). We explored changing time trends of place of death in all cancer deaths in England during 1993–2010 (n=2,281,223) and showed an increased in home (0.87%; 95% CI 0.74%–0.99%/year) and hospice deaths (0.24%; 95% CI 0.17%–0.32%/year, p<0.001) since 2005 (Gao et al., 2013, see In focus). Across all cancer and non-cancer deaths in England and Wales from 2004 to 2010 (n=3,525,564) we showed a steady increase in the proportion of deaths at home, from 18.3% in 2004 to 20.8% in 2010, following trends in the USA and Canada (Gomes et al., 2012a). The rise in home deaths was most pronounced in cancer, and occurred for both genders and across all age groups, except for those younger than 14 years (Gomes et al., 2012a).

Ethnicity and Culture

In response to demographic changes in the UK and beyond, and building on our previous work examining evidence of disadvantaged end of life experiences and dying, we have further developed our theme on ethnicity and culture.

Palliative Care for Black, Asian and Minority Ethnic Communities in the UK

Overall, life expectancy is increasing in European and other developed countries, with more people living beyond 65 years of age. As part of population ageing, the pattern of diseases people experience and die from is also changing. Given that many societies are now multicultural in nature, health and social care professions, regardless of setting, now require a different set of skills and knowledge to be able to ensure both equity and quality of health care provision for all. This situation is further amplified


Most patients with cancer prefer to die at home or in a hospice, but hospital remains the most common place of death (PoD). This study explores the changing time trends of PoD and the associated factors, which are essential for end of life care improvement. The study analysed all cancer deaths in England collected by the Office for National Statistics during 1993–2010 (n=2,281,223). Time trends of age and gender standardised proportion of deaths in individual PoDs were evaluated using weighted piecewise linear regression. Variables associated with PoD (home or hospice versus hospital) were determined using proportion ratio (PR) derived from the log-binomial regression, adjusting for clustering effects.

This large-scale, population-based study found that hospitals remain the most common PoD for patients with cancer (48.0%; 95% CI 47.9%–48.0%). Following a prolonged period of plateau, there was a steady downward trend in hospital deaths (to about 50%) from 2005 onwards. The pattern was mirrored by increasing home death (0.87%; 95% CI 0.74%–0.99%/year, 0.24%; 95% CI 0.17%–0.32% year, respectively, p 0.001). This trend coincides with the launch of a National End of Life Care (EoLC) Programme in November 2004, which was based on research evidence about patient preferences and possible solutions. The programme aimed to reduce hospital deaths and enable more people to die at a place of their choice, usually own home or hospice, through promoting good practice in end of life care. Compared to people with other diseases, patients with cancer had better access to end of life care facilities. One would expect that patients with cancer would be the first beneficiaries of national initiatives on end of life care.

We found that people who died from haematological cancer, who were single, widowed or divorced, and aged over 75 years, were less likely to die in home or hospice. There was little improvement over time in patients with lung cancer dying in home or hospice. Marital status overtook age as the second most important factor associated with PoD, after cancer type. Therefore we concluded that more efforts are needed to reduce hospital deaths. Health care facilities should be improved and enhanced to support the increased home and hospice deaths. People who are single, widowed, or divorced should be a focus for end of life care improvement, along with known at risk groups such as haematological cancer, lung cancer, older age, and deprivation.

Figure 9 Place of cancer deaths in England, 1993–2010, age- and gender-standardised against the United Nations mortality standard population (n=2,281,223)
by growing numbers of older people from Black, Asian and Minority Ethnic (BAME) groups living in developed countries which will continue to increase in coming years.

How we understand the influence of diversity in patterns of advanced disease, illness experiences, responses to treatment, and the use of specialist palliative care services is critical given increasing evidence that we are not all equal in death, dying and during bereavement. Race or ethnic-based disparities in diagnosis, quality of care, referral patterns to specialist palliative care, and treatments for pain and other physical symptoms and location of death have been increasingly documented.

Our growing programme of work examining the relationship between ethnicity and culture and clinical care and policy has focused on macro and micro issues: our European network PRISMA included a detailed work package that examined the influence of culture on end of life care with a focus on global palliative care policy and cultural competence (Evans et al. 2011; Evans et al. 2012a). We have also reviewed concepts of culture in other parts of Europe (Andrew et al. 2013). Our recently commissioned report funded by Marie Curie Cancer Care and Public Health England: Palliative and End of Life Care for Black, Asian and Minority Ethnic Communities in the UK examined ONS statistics in relation to ethnicity and discussed the implications of the growing number of older people and the oldest old among BAME communities living in the UK. Our work has also focused specifically on the patient and carer-centred experience of living with, and dying from, advanced disease. In this area of research we have continued to explore and compare the experiences of advanced cancer among the Black Caribbean and White British communities living in south London and the Asian community (Koffman et al. 2011; Koffman et al. 2012b; Koffman et al 2013b).

**Spirituality**

Spiritual distress is prevalent in progressive, incurable illness and spiritual care is a core component of palliative care, yet it is a domain often neglected in clinical practice and research. Spiritual care aims to support people struggling with questions related to meaning, purpose, and religious and/or non-religious beliefs and values. The Cicely Saunders Institute aims to contribute to research in this field through a multi-component programme of research led by Rev Dr Peter Speck and Dr Lucy Selman. Rev Dr Speck contributed to a recent Cochrane review (Candy et al. 2012) on spiritual and religious interventions in the later stages of disease which identified a dearth of robust science in this area.

Dr Selman’s programme of research began with a systematic review and comprehensive evaluation of measures of spiritual outcomes in palliative care populations (Selman et al. 2011a) and modelling work to describe the place of spirituality and culture in the illness experience (Selman et al. 2013b). Subsequent work in sub-Saharan Africa has demonstrated the high prevalence of spiritual distress (Selman et al. 2011b) and examined the measurement of spiritual outcomes, showing that items relating to feeling at peace and that life is worthwhile from the APCA African POS may be used to screen for spiritual distress in this population (Selman et al. 2013b). Adaptation and testing of the Spirit 8 (Selman et al. 2012a), a tool adapted from a quality of life measure for use in Africa, resulted in a current collaboration with the Medical College of Wisconsin and Hospice Africa Uganda in a longitudinal study of patients’ spiritual well-being.
The EAPC Spiritual Care Taskforce was founded in 2010 with the aim of furthering spiritual care in palliative care in Europe. Dr Selman has been co-chair of the Research sub-group of the Taskforce since 2011. In this role she led an international survey (n=971) of palliative care clinicians’ and researchers’ research priorities in spiritual care (Selman et al., 2014b) With continued support from the Sir Halley Stewart Trust and building on this work, an expert meeting on spiritual care was held at the CSI in October 2012 to work on specific areas for future research in spiritual care. Dr Selman is currently leading InSpirit, an international focus group study to explore patients’ and caregivers’ experiences of and preferences regarding spiritual care, funded by the Sir Halley Stewart Trust.

Our work in spiritual care also intersects closely with our growing theme of research into culture and ethnicity, in which spirituality and religion have been identified as central to the ways people locate meaning in advanced disease, such as cancer. Dr Koffman and colleagues’ work has found that spiritual and religious resources enable some people to cope more effectively with the physical and psychological vicissitudes of their illness (Koffman et al. 2013b).
Progression, symptoms and psychological concerns among those severely affected by multiple sclerosis: A mixed-methods cross-sectional study of Black Caribbean and White British people


Multiple Sclerosis (MS) is now more common among minority ethnic groups in the UK but little is known about their experiences, especially in advanced stages. We examined disease progression, symptoms and psychosocial concerns among 43 Black Caribbean and 43 White British people severely affected by MS with a mixed methods approach. Progression Index (PI) and Multiple Sclerosis Severity Score (MSSS) were calculated. To control for selection bias, propensity scores were derived for each patient and adjusted for in the comparative statistical analysis; qualitative data were analysed using the framework approach.

Disease progression appears to be quicker among Black Caribbean than White British people with MS (p=0.001). This result was consistent when measured in different ways, and after adjusting for demographic and clinical differences across the two ethnic groups.

This work was the first comparative mixed-method study to examine Black Caribbean and White British people severely affected by MS in terms of disease progression, symptoms, and the patient-centered meanings associated with these issues. Findings suggest more aggressive MS disease among Black Caribbean people despite many being in receipt of disease modifying therapy. More rapid disease progression leads to marked difficulties with ambulation, physical function and distress as a result of multiple losses. This study has implications for MS and palliative care services. In particular, we need appropriate interventions to support those people who experience MS as an assault on their identity. Services must be mindful to invest appropriately in training to enhance knowledge and skills in ‘cultural relativism’ or ‘multiculturalism’. As the number of people from Black, Asian and Minority Ethnic communities affected by MS continue to increase, new ways of managing the multiple losses, distresses and symptoms need to be explored, with joint-services between neurology and palliative care and/or cognitive therapy.

<table>
<thead>
<tr>
<th>Table 5</th>
<th>Comparison of disease progression and impact of symptoms among Black Caribbean and White British participants severely affected by MS</th>
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</thead>
<tbody>
<tr>
<td>Progression Index (EDSS/time diagnosis in years):</td>
<td>Black Caribbean (n=43)</td>
</tr>
<tr>
<td></td>
<td>0.74 (0.9)</td>
</tr>
<tr>
<td>Multiple Sclerosis Severity Score</td>
<td>8.80 (1.11)</td>
</tr>
<tr>
<td>Palliative care Outcome Scale</td>
<td>12.79 (6.6)</td>
</tr>
<tr>
<td>Palliative care Outcome Scale – Symptoms</td>
<td>17.48 (10.1)</td>
</tr>
<tr>
<td>Multiple Sclerosis Impact Scale</td>
<td></td>
</tr>
<tr>
<td>Psychological subscale</td>
<td>36.24 (23.6)</td>
</tr>
<tr>
<td>Physical subscale</td>
<td>54.46 (18.9)</td>
</tr>
<tr>
<td>Total score</td>
<td>85.74 (20.7)</td>
</tr>
<tr>
<td>Blessed Orientation Memory Concentration Test</td>
<td>5.91 (4.1)</td>
</tr>
<tr>
<td>Hospital Anxiety and Depression Scale</td>
<td></td>
</tr>
<tr>
<td>Anxiety subscale</td>
<td>5.79 (4.2)</td>
</tr>
<tr>
<td>Depression subscale</td>
<td>6.40 (4.2)</td>
</tr>
<tr>
<td>Total score</td>
<td>12.19 (7.8)</td>
</tr>
</tbody>
</table>

Values are mean (SD), * ANCOVA adjusted for the probability of participating in the study (propensity score)
The challenges to undertaking research on palliative and end of life care are well documented. Problems of patient recruitment, attrition through illness and death, selecting the right outcome measurement and time points are frequently cited as compromising effectiveness studies using either randomised or non-randomised designs. Our methodological innovation work aims to address these challenges. Our Methods of Researching End of Life Care (MORECare) study identified, appraised and synthesised ‘best practice’ methods, to develop and evaluate palliative and end-of-life care, with a focus on complex service-delivery interventions and reconfigurations.
The MORECare Statement

MORECare aimed to develop evidence-based guidance on the best methods for the design and conduct of research developing and evaluating complex interventions in palliative and end of life care. The MORECare study used research methods of systematic review, Transparent Expert Consultation comprising nominal group and consensus survey. The final data synthesis from three systematic reviews and five consultations formed the MORECare Statement. The statement provides 36 best practice solutions to improve study quality in research on end of life care and sets much needed common standards for future research.

The statement provides a framework to develop and evaluate end of life care interventions (Figure 10). It sets a much needed standard for research in the future. We also provided 13 national and international recommendations to improve the environment for the development and evaluation of complex interventions in palliative and end of life care (Tables 6 and 7).

MORECare began with the identification of prominent research challenges through systematic reviews involving: meta-synthesis of research methods (Evans et al., 2013a); the effectiveness of specialist palliative care teams (Evans et al., 2013b); and patient and carer participation in research (Gysels et al., 2012c). This initial work identified five key areas for detailed consideration in the expert consultations including:

- Outcome measurement (measurement properties, time points and proxy data) (Evans et al., 2013a)
- Integrating mixed methods in retrospective study phases (Farquhar et al., 2013)
- Statistical analysis (missing data, attrition and response shift) (Preston et al., 2013)
- Ethical considerations on participation in research and informed consent (Gysels et al., 2013b)
- Economic evaluation (cost methods in EoLC, outcome assessment and equity issues)

The consultations used research methods of nominal group and consensus survey. These methods generate recommendations on the area of study, identify areas of contention/uncertainty and the underpinning debates, and level of agreement on the recommendations posed. Over 140 people attended the workshops and 133 completed the online surveys. Participants comprised researchers, clinicians, members of research ethics committees and patients and carers. The MORECare statement is underpinned by the recommendations with the highest level of agreement and synthesis with the literature. This is extensive work that makes an important contribution to furthering research on palliative and end of life care.

Research underpinning the MORECare statement

The systematic reviews showed patients’ and carers’ desire to participate in research on EoLC, but with the caveats of asking the ‘right’ questions – those important to patients and families, and designing research studies that enable participation by, for example, minimising burden and incorporating participatory research designs (Gysels et al., 2012c and 2013b). Another identified a need for robust evidence on the nature and duration of therapeutic (and potentially confounding) effects of interviewing, when using mixed-method designs (Farquhar et al., 2013). Outcome measurement in palliative and end-of-life care was also considered, highlighting the requirement of psychometrically
robust measures that are clinically responsive, with defined data collection time points to establish a baseline and clear administration guidelines to complete proxy measures (Evans et al., 2013a).

Our recommendations on economic evaluation formed the most controversial area. Strongly opposing debates surrounded the degree of applicability of using the commonly used composite measure of outcomes, Quality-Adjusted Life Years (QALYs) in research on end of life care. Participants argued for incorporation; and against questioning the relevance of QALYs for individuals with life limiting illness and concern of likely failure to demonstrate cost-effectiveness (Higginson et al., 2013a).

Another important feature of MORECare is the classification of attrition by cause, developed in the consultation on statistical analysis. Attrition in research on end of life care is considered inevitable when involving individuals with life limiting illness, and absence of attrition may indicate involvement of the ‘wrong’ population. Attrition needs to be anticipated and planned. The classification moves beyond a statement on proportion of attrition to describing the causes of attrition (Preston et al., 2013):

- ADD – attrition due to death
- ADI – attrition due to illness
- AaR – attrition at random

The meta-synthesis of research methods incorporated research studies from both specialist and generalist palliative care. This breadth of studies revealed a disparity in the use of randomised designs across the two areas and identified opportunities to widen the use of randomised designs in evaluations of specialist palliative care services and complex interventions.

<table>
<thead>
<tr>
<th>Table 6</th>
<th>International MORECare recommendations to improve the environment for the development and evaluation of interventions in EoLC (Higginson et al 2013a)</th>
</tr>
</thead>
</table>
| **Introduction/background** | 1. Present theoretical framework for the intervention and levels of need established  
2. Present objectives appropriate to the level of intervention development |

**Study design**
3. Indicate and justify stage in MRC guidance for development and evaluation of complex interventions, for example, feasibility, preliminary evaluation, efficacy/cost effectiveness and wider effectiveness  
4. Feasibility stages should test both feasibility of the intervention and of methods of evaluation, including outcome measurement  
5. Justify methods, considering appropriate use of existing data sets and secondary analysis as these may produce rapid information  
6. Justify methods of empirical studies considering mixed methods, observational studies and randomised trials |

**Study team**
7. Ensure involvement from: (i) consumers, patients and caregivers; (ii) relevant clinicians; (iii) relevant methodologists to develop study questions, questionnaires and procedures; and (iv) researchers familiar with the challenges in EoLC studies  
8. Ideally, involvement should be well established and continuing, beyond a specific study, with joint meetings or rotations between clinical and research staff |

**Ethics**
9. Note in ethics committee application MORECare recommends that it is ethically desirable for patients and families in EoLC to be offered involvement in research and MORECare found evidence of patient willingness to be approached  
10. Work within legal frameworks on mental capacity and consent, to ensure that those who may benefit from interventions are offered an opportunity to participate if they wish  
11. Collaborate with patients and caregivers in the design of the study, vocabulary used in explaining the study, consent procedures and any ethical aspects |
| 12. | Attend the ethics committee meeting with a caregiver or patient, as a means to help the committee better understand the patient perspective |
| 13. | Ensure proportionality in patient and caregiver information sheets, appropriate to the study design and level of risk, as excessive information in itself can be tiring/distressing for very ill individuals |
| **Participants** | 14. Adjust eligibility criteria to recruit those patients who may benefit most from intervention, ensuring equipoise |
| **Procedures** | 15. Minimise burden for existing clinical staff for participation in the study |
| 16. | Clearly distinguish between service received and research activity interviews in study arms when multiple interviews with patients are undertaken in trials, for example, using a graphical system [25] |
| **Outcome measures** | 17. Choose outcome measures that meet the following criteria: |
| | • established validity and reliability in relevant population |
| | • responsive to change over time |
| | • capture clinically important data |
| | • easy to administer and interpret (for example, short and with low level of complexity) |
| | • applicable across care settings to capture change in outcomes by location (for example, patients’ home, hospital, hospice) |
| | • able to be integrated into clinical care |
| | • minimise problems of response shift (see below) |
| 18. | Consider including patients’ experience of care, as this is central to many interventions |
| 19. | Select time points of outcome measurement to balance the value of early recording, to reduce attrition, but to allow enough time for the intervention to have had an effect |
| 20. | Consider the potential effect of response shift (that is, a change in a person’s internal conceptualisation or calibration of the aspects measured). Questionnaires that include anchor points or descriptions of each response category may be less problematic in this regard |
| **Missing data and attrition considerations** | 21. Estimate in advance levels of, and reasons for, attrition and missing data, integrating these into sample size estimates and planned collection of data from proxies |
| 22. | Monitor during the study and report all levels of, and reasons for, attrition and other missing data |
| 23. | Assume missing quantitative data NOT to be at random unless proven otherwise |
| 24. | Test results from different methods of imputation – noting that ‘using only complete cases’ is a form of imputation |
| 25. | Use the MORECARE classification of attrition to describe causes of attrition: that is, |
| | • ADD – attrition due to death; |
| | • ADI – attrition due to illness; |
| | • AaR – attrition at random. |
| 26. | Consider reasons for missing data which are not due to attrition, for example missed questionnaire, or missed data item in questionnaire. Consider these in analysis and the potential imputations |
| **Mixed method studies** | 27. Mixed methods can be appropriate in all phases of development and evaluation |
| 28. | Ensure appropriate multi-disciplinary skills mix or training of team |
| 29. | Define the theoretical paradigm and method of integrating results and safeguards to ensure rigour at the outset |
| 30. | Plan investigation to avoid undue burden of qualitative and quantitative questionnaires – perhaps dividing data collection or selecting questions and/or sampling appropriately |
31. Take into account any potential therapeutic effect of qualitative interviews where participants can express their feelings, if these are similar to components of the intervention

32. Ensure that those collecting data are appropriately trained in qualitative data collection

### Implementation

33. Consider implementation implications, including workforce and training needs, in all phases of the study

### Cost-effectiveness

34. Integrate into preliminary evaluations and test feasibility of methods

35. Collect data on use of services including health, voluntary, social and informal care, to take societal approach to care costs

36. Justify appropriate outcome measures to generate cost-effectiveness

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### Table 7 International MORECare recommendations to improve the environment for development and evaluation of interventions in EoLC (Higginson et al 2013a)

<table>
<thead>
<tr>
<th>Recommendations</th>
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<tbody>
<tr>
<td><strong>Ethics</strong></td>
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<tr>
<td>1. Create a Research Ethics Network for Palliative and End of Life Care to further and disseminate best practice</td>
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<tr>
<td>2. Train those working on ethics and research governance committees in the specific issues and wishes of patients in palliative and EoL care and their families</td>
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<tr>
<td>3. Seek to amend the law regarding consent so that advance consent for studies other than clinical trials of medicinal products is legally effective. This would permit research among people who might develop problems with mental capacity later</td>
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<tr>
<td><strong>Clinician/researcher collaboration</strong></td>
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<tr>
<td>4. Increase collaboration and understanding between clinicians and researchers in EoLC through rotations, joint departments and exchanges</td>
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<tr>
<td>5. EoLC organisations to create a research-aware culture for practitioners by informing practitioners and patients on admission to a service that the organisation is actively involved in research</td>
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<tr>
<td>6. Develop specific training for practitioners in palliative and end of life care about research practice, its value and how to recruit</td>
</tr>
<tr>
<td>7. Introduce screening questions about patient/family willingness to be approached for research (as a general principle) in routine initial assessments on entry to palliative care services</td>
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<tr>
<td><strong>Funders</strong></td>
</tr>
<tr>
<td>8. Develop collaboration to ensure that funding supports advancement in knowledge, where one study builds from the finding of another and there is progression to multicentre studies, full evaluations and cost-effectiveness studies</td>
</tr>
<tr>
<td>9. Assess study proposals against the MORECare statement</td>
</tr>
<tr>
<td><strong>National bodies/strategy</strong></td>
</tr>
<tr>
<td>10. Develop repositories of routine data and from specific studies which can be used for secondary analysis to quickly answer current questions</td>
</tr>
<tr>
<td>11. Develop collaboration to take forward the MORECare statement</td>
</tr>
<tr>
<td><strong>Journal editors/referees</strong></td>
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<tr>
<td>12. In statistical assessment take account of the MORECare statement:</td>
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<tr>
<td>• that attrition due to death and ill health is to be expected and should be planned for when designing EoLC studies. It is not an indication of a poor study unless it is markedly different to that planned, but indicates that a relevant population of patients and families have been included, giving external validity</td>
</tr>
<tr>
<td>• that lack of attrition or missing data is not necessarily a positive finding; it could mean the population studied is less relevant to EoLC</td>
</tr>
<tr>
<td>13. Use MORECare statement to consider good research practice for conducting EoLC studies, alongside established checklists for reporting, for example, STROBE, CONSORT</td>
</tr>
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</table>
Follow on work

The MORECare study led to three further research grants: an NIHR School of Social Care Research Methods Review on evaluating complex interventions in palliative and end of life care (Evans C, et al (2013) MRC Guidance on Developing and Evaluating Complex Interventions: Application to Research on Palliative and End of Life Care, SSCR Methods Review 15, NIHR School for Social Care Research, London, see picture); MORECare Capacity, a project to develop research methods on processes of consent; and an MRC Alexander Fleming award to disseminate innovations in effectiveness research into research practice.

NIHR School of Social Care Research Methods Review on evaluating complex interventions

The majority of end of life care is provided by social care services to people living at home or in care homes (with or without nursing). Evaluations of social care services and interventions are, however, uncommon, with research relatively underdeveloped in the discipline. This review focused on social care practice and end of life care to critically consider the potential application of the Medical Research Council Guidance on Developing and Evaluating Complex Interventions. It provided an opportunity to examine the applicability of the MRC guidance and the MORECare statement in the field of social care, and engage with social care researchers and practitioners to disseminate the MORECare findings.

The methods review highlighted that many of the complexities of undertaking research in social care are mirrored in research on end of life care, notably consent for adults with impaired capacity, the selection and use of outcome measures and the imperative to secure research funding to build research capacity and programmes of research. The review illustrated the application of the MRC guidance in research on social care, the complexities associated with this, and ways of incorporating the MORECare statement to address specific challenges. The review is a resource for researchers and practitioners who wish to promote robust research in social care and increase engagement with evidence-based service improvements.

MORECare Capacity

The recruitment and retention of individuals living with advanced illness is a prominent challenge in research on palliative and end of life care. A main barrier is processes of consent for individuals with impaired capacity to consent for themselves associated with cognitive impairment from, for example, dementia disease progression and nearness to death. Our MORECare Capacity study examined how best to include individuals near to death in research on end of life care by identifying solutions and developing best practice guidance on processes of consent for people with impaired mental capacity. The funding enabled detailed examination of this important area, but beyond the scope of the original MORECare study. MORECare Capacity replicated the research methods used in MORECare of systematic review, consultations and a final think-tank workshop. The findings form guidance on processes of consent for adults lacking capacity in research on palliative and end of life care as an addendum to the MORECare Statement.

The study is now complete and two main publications are expected: a systematic literature appraisal identifying the central role of consultees in research on palliative and end of life care; and the final synthesis of the findings from the systematic review, consultations and think-tank to form methods guidance on processes of consent for adults lacking capacity.
The study’s three key achievements are:

1. A systematic review of the literature to identify and synthesise data from 62 studies of often ‘hidden’ disparate evidence to underpin the methods guidance and identify areas of uncertainty for consultation.

2. Engagement of a breadth of expertise representing research, clinical practice, ethicists and lay members in the consensus work to generate 29 recommendations on best research practice and debate and identify solutions in areas of uncertainty/contention.

3. Final synthesis of all the findings to form methods guidance detailing 29 recommendations and best practice solutions on the inclusion of adults near to death in research on palliative and end of life care.

E-learning to disseminate research guidance into practice

Implementation research is one of the weakest and least investigated areas in health services research. Our e-learning project aims to disseminate the MORECare findings using an e-learning format, looking into the development, piloting and evaluation of a short e-learning module on effectiveness research methods in palliative and EoLC for clinicians and researchers. The intention is to maximise the pedagogical value of dissemination of the MORECare Statement, improve learning outcomes, influence practice through using a wide, accessible and interactive format, and evaluate the accessibility and applicability of the resource.

The e-learning study comprises four stages:

1. Development and peer review of the e-learning content

   • Each module consists of a series of reading material/resources, an interactive presentation and a formal assessment (multiple choice questionnaires). The interactive presentations include, for example formative assessment, case studies, and other reflective activities. Six modules: 1) Introduction; 2) Selection of outcome measures; 3) Use of outcome measure; 4) Missing data, attrition and response shift in palliative care; 5) Mixed methods; 6) Ethics

2. Implementation and testing of e-learning modules

   • The course has been tested in King’s College London’s learning management system (Moodle) and among 10 participants (e.g. MSc students). We use a questionnaire to collect feedback on the design, resources, test, content and the learning experience.

3. Piloting the e-learning course

   • The pilot testing involves 10 to 15 participants and aims to identify final minor adjustments to the design and possibly content.

4. First student intake and course evaluation

   • We will evaluate participants’ short term change in knowledge using an online assessment quiz at the beginning and end of the course. On finishing the course, students will complete a brief evaluation exploring perceptions on the extent the course changed or influenced their understanding and confidence to apply research methods in order to develop and evaluate services and treatment in practice.

The first intake is anticipated in September 2014. Our vision for the e-learning course is to form a platform to disseminate future research findings and complement the Institute’s MSc in Palliative Care by widening the teaching resources available to students and staff.
Public Outreach, Engagement and Impact

Our impact and outreach activities enhance the value of our research in national and international policy, clinical and commissioning arenas, the interest and application for education programmes, recruitment of high quality individuals to academic and clinical posts, and the uptake of evidence in clinical care. We undertake considerable engagement with the public, patients and families, professionals, policy makers and the media. The Institute has transformed opportunities for clinical and academic engagement and allowed us to increase our education programmes. It attracts for teams from across the globe that wish to learn about the latest advances in palliative care.

Within King’s Health Partners (KHP) there is a focus on Clinical Academic Collaboration and Integration. This helped to bring our local hospital trusts and clinical services together. We also work closely with many hospices (local, national and international), charities and patient groups.

Why are public engagement, outreach and impact important?

Those living with or dying from progressive disease are vulnerable and society needs to continue to cater for their needs. To future proof palliative care and rehabilitation, the public needs effective understanding through better communication about sensitive and sometimes emotive subjects. In health care science, impact commonly translates into benefits such as disease prevention, improved health, quality of life and care. There can also be economic impacts, such as improving the efficiency of services and doing more or better for the same money, increasing wealth through promoting workforce health or in new treatments that promote industry. An important step to achieving impact is the dissemination and implementation of the research into practice, industry, policy and care. Therefore, public engagement and engagement with clinicians, other professionals, policy makers as well as engagement on an international stage has two important roles: to educate the public, and to improve the research impact.

Our strategy

We integrate different approaches to optimise the reach of our work and its impact on beneficiaries. We combine the following approaches according to context:

- **Active patient and public engagement:** We embed patient and public engagement into all our research projects and programmes.

- **Co-design:** With projects jointly designed by stakeholders and researchers.

- **Fostering clinical/academic talent:** with joint posts and shared working space to increase interaction.

- **Collaboration, consultation, integration and engagement:** Clinicians, policy makers and

Keira Lowther presents to partners in Kenya
other non-academic beneficiaries are integral to designing and disseminating our research.

- **Providing user friendly, free, targeted resources appropriate for the audience, their culture and language:** Our measurement tools are freely downloadable through websites. We complement electronic documents with hard copies, for example 4,400 copies of our guidance booklet “Outcome measures in palliative care: the essentials” were provided free to clinicians throughout Europe.

- **Engaging with social and traditional media:** to increase the awareness and reach of our research.

- **Leadership:** Staff are invited members and/or chair boards of international advisory groups, taskforces, national bodies and professional associations (see Contribution to the discipline).

- Individual and umbrella service-user organisations that influence policy: such as the European Cancer Patient Coalition, the Neurological Alliance, the National Council for Palliative Care, Help the Hospices and locally our Collaboration for Leadership in Health Research and Care (CLAHRC), King’s Health Partners and Academic Health Sciences Network (AHSN) help us to design research for better impact.

**Active patient and public engagement**

Active patient and public engagement is at the core of our research programmes, and is an essential and valued aspect of our work. Service users (patients, carers, and the public) regularly offer their time to advise and collaborate with the Cicely Saunders Institute at all stages of our research. Their involvement improves the quality and relevance of our work.

- **The International Access, Rights and Empowerment (IARE) study**
  As part of the International Access, Rights and Empowerment study, members of the South East London Consumer Research Panel for Cancer (SELCRC) were invited to comment on the structure, content and wording of study materials before these were offered to patients, led discussions to ensure the project is relevant to public need, and consulted to refine our recruitment procedures. Following this consultation, we generated a leaflet to feedback the impact we considered service users had on the study and shared this at their annual event. We were later approached by three SELCRC members interested in becoming more involved in shaping research in the future. All said this was as a result of feeling appreciated and valued.

- **Informing patients and carers about work around breathlessness**
  In May 2013, patients and carers were invited to the Cicely Saunders Institute international conference on breathlessness with speakers from across Europe and North America. Over 120 delegates took part from a wide range of health and social care professions. Opening sessions covered new classifications of breathlessness, physiological models of breathlessness and emerging research which separates the emotional component of the symptom as a target for treatment. In the afternoon, findings from symptom-led breathlessness clinics were presented and discussed in a round-table format with debate and participation among delegates, including patients who participated in the Breathlessness Support Service (see Symptom led research, page 88).

- **BuildCARE seminar series**
  Carolyn Morris, one of our expert user advocates, chaired a seminar presented by Professor Jonathan Tritter from the University of Warwick on the topic ‘Making research count for those that count on research: Patient and public involvement in research’. The event addressed the shift in the role of patients and the public from being passive
to active participants in research projects. In particular, calls for the public to have a say in decisions about how publicly-funded research is awarded have forced shifts in the process of evaluating proposals. Kirstie Newson, another expert user advocate, gave a thoughtful and well received response to the presentation.

The next stage of service user involvement will be focused on developing a cohesive framework in the Institute, with input from BuildCARE patient and carer advocates. We are establishing a service user network to ensure we utilise everyone’s expertise in planning and conducting relevant, high quality research to improve services for patients and their families. We are also systematically searching publications in the field for reports of service-user involvement in palliative care research, to examine the motivations of service-users to participate in research.

What our collaborators say

We asked our collaborators why they wanted to be involved in helping to shape research in the Cicely Saunders Institute:

“I cared for my mum when she died at home. Whilst her wishes were respected I felt that she did not have as good an experience as it should have been, and as mum’s sole carer I did not feel that I was given sufficient advice and support to enable my mum’s last days to be the best they could be. Having worked in the healthcare field for some years, including developing services, I knew things could be better. I wanted to be part of that change ... to provide the inside perspective. So I found the Cicely Saunders Institute and tried to get involved in some relevant research.” (Carer)

“I joined the Advisory Group for a new National Cancer Research Institute Collaborative in Supportive & Palliative Care. The Advisory Group role was very strategic but I wanted to become involved in practical ways too. One of the initiatives we took on was setting up workshops in involvement for researchers, the Compass Masterclass called ‘Collaborate and Succeed’. Irene was co-chair of Compass. She was very supportive of the idea when we proposed it and offered to host the first one at the Institute, which was just in its new building. I was very taken with the fact that practitioners and researchers were in the same building. I think I saw at Cicely Saunders Institute an opportunity to help develop existing terrific work. Irene was very supportive. There was a clear message – this stuff isn’t marginal!” (Patient advocate)

Our response

Professor Irene J Higginson:

“We are lucky in the Cicely Saunders Institute to have many talented and wise people helping and advising us on our research. I would like to formally record my thanks to the many patients, families and members of the public for their help, advice, counsel and critical appraisal that help us to plan, design, deliver and write up the studies. It is a privilege to work with so many people with different experiences and backgrounds. We are also supported across King’s Health Partners in this Clinical Academic Integration and Public Engagement.

It is always a highlight for me and others to learn from patients, families and the public. I always learn something new by listening to their views and experiences. It is inspiring to witness the interest, engagement and enthusiasm in our projects from patients, their families and the public.

Our goal in the CSI is to improve the care for patients and families through cutting edge research. The input from patients and the public helps us keep
focused on what matters most. Palliative care is a public health priority and should help people to live well despite a chronic or progressive condition, and support people and their families, even at the end of life.”

Media engagement

We actively engage with social and traditional media to promote awareness and dissemination of our research, through YouTube, Twitter, blogs, podcasts, and conventional media.

In 2012 we launched the CSI YouTube channel (CSIKCL), which features our research, promotional videos for our postgraduate programmes, and our seminars. Around 20 resources are free to access and to date have been viewed more than 1000 times, allowing people from all over the world to learn about our work and benefit from our international speakers. For example, Dr Amy Abernethy, director of the Duke Cancer Care research Program (Duke University) spoke at the CSI as part of the Open Seminar series on ‘Integrating patient reported outcomes data – real time information for research and clinical care’. This 45 minute video has had more than 290 views since July 2013.

Our Twitter account (@CSI_KCL) has more than 1100 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. In January 2013 the account was named in an editorial in the International Journal of Palliative Nursing as one of the ‘must follow’ accounts for palliative care. A tweet relating to our Cochrane review “Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers”, published in June 2013, had been featured in 213 tweets from 147 different accounts (reaching 169,507 combined followers).

We are making increasing use of modern communication media such as blogs and podcasts. The main aim behind using these media is to increase our outreach, in particular to reaching members of the public. For example, a podcast made in response to the Liverpool Care Pathway review by Professor Higginson, Dr Koffman, Dr Murtagh, Dr Daveson and Dr Sleeman has been listened to more than 500 times, and is one of the most listened to King’s College London comment podcasts.

Our World Health Organisation (WHO) guides are among the most frequently requested of the WHO documents.

The King’s College London press office provides an excellent service for medicine in dealing with the media. Members of the department have featured in numerous radio and television programmes, and in print media. Recent example include:

- BBC Radio 3: Night Waves – Dr Jonathan Koffman, 16th May 2013
- BBC Radio 4: How to have a good death, Prof Irene Higginson, Dr Katherine Sleeman, 21st April 2013
- BBC Radio 4: The Six O’Clock News – report on LCP, Prof Irene Higginson, 15th August 2013
- New Scientist article on LCP report, featured Dr Fliss Murtagh and Dr Katherine Sleeman, 19th July 2013

Engaging with academics and clinicians

In addition to our Open Seminar series we host clinical and academic visitors throughout the year from all over the world. Visitor numbers have increased considerably since the opening of the Cicely Saunders Institute and they continue to rise with many groups now asking to return for second or third visits. The nature of the visits ranges from...
Impact case study: Identifying and achieving preferences for place of care and place of death at the end of life

We have improved how people’s preferences are supported at the end of life through identifying home death as an important yet often unmet preference, then determining influencing factors, barriers and facilitators to achieving that preference. Our research has been integrated into and changed policy in the UK and Europe, with a cascading impact on clinical practice, training and care, helping to reverse trends of increased institutionalisation of death in the UK despite population ageing. Preferred place of care and death now forms an essential part of end-of-life care.

Changing awareness and strategy, leading to place of death as a core policy measure

Achieving home care and death, if preferred, in advanced illness has become a core part of the Department of Health’s (DoH) End of Life Strategy. The National Audit office used our research to highlight the need for home care. As a result, the DoH commissioned the development of the End of Life Care Intelligence Network (ELCIN) to “improve the collection and analysis of information related to the quality, volume and costs of care provided ... to adults approaching the end of life”. Among resources provided is a 2011 ELCIN-commissioned report authored by our researchers regarding local preferences and place of death in England. Place of death has become a key measure reported in ELCIN locality and regional profiles.

Changing where people die and better meeting choice

The NHS has developed a National End of Life Care Programme to implement the End of Life Strategy by “working with health and social care staff, providers, commissioners and third sector organisations across England to improve end of life care for adults”. That adoption of end of life care strategies, as championed by our research, is changing where people die (Gao et al., 2013). A reduction in home deaths is showing a sustained reversal, with increasing numbers of people dying in their place of choice. The latter concluded that “the increase in home and hospice deaths since 2005 suggests that the National End of Life Care Programme has enabled more people to die at their preferred place of death” (Gao et al., 2013).

Shifting the focus of charities, patient-based organisations and funding for care

As well as government-based health services, several independent organisations and patient-based charities use our research on place of care and death.

- The 2012 ‘Independent Palliative Care Funding Review,’ an independent report for the Secretary of State for Health’. This report projected that by 2021 hospital deaths could be reduced by up to 60,000 a year, with a reduction in associated costs, while delivering “optimised provision of services outside the hospital setting”.

- The National Council for Palliative Care, an umbrella charity, cites our research in reports including ‘Commissioning End of Life Care’, ‘A 2030 Vision’, and ‘Policy Roundup’.

- The Dignity in Dying campaign, which has over 25,000 supporters, is advocating our research recommendation of asking preferences for place of death from patients and developing a benefit for caregivers.

International reach

Our research and experts have also been used by International bodies for help in their work. Achieving place of care and death is recommended in the World Health Organization’s 2011 publication ‘Palliative care for older people: Better practices’, aimed at European policy makers. Professor Higginson was selected as Senior Editor on this report and it contains the majority of our references when discussing this recommendation. In Portugal, the Calouste Gulbenkian Foundation is developing a programme of home care support at the end of life in response to our work and the evidence on people’s preferences. In 2011 the Foundation established a formal partnership with the Portuguese Ministry of Health to fund four pilot projects delivering home palliative care.
Public reach and Government reach
Findings from our research received extensive press coverage, most recently of the reversal of trends in place of death, e.g. in The Huffington Post and the Daily Mirror. The House of Lords debated ‘NHS: Death at Home’ and our research was highlighted by both Lord Low of Dalston and Baroness Finlay of Llandaff, to show evidence of the persisting gap between preferences and reality for place of death, and social factors affecting this including lower chance of dying at home amongst Caribbean populations.

An independent report into the effect of our work, which involves review of policy documents and interviews with policy experts, shows how the research galvanised action and thinking as exemplified by this quote:

“For me one absolute tipping point was in 2011 when I was exposed to the work on preferences compared to actual place of death for particular groups in England ... It was readable and linked to the strategy (and) ... highlighted the preferences of older people – how they wanted to get into hospice but didn’t get into hospice. I was struck by the disparity between my beliefs and this data.”

The review concludes: “The early Cicely Saunders Institute research was one key source of evidence that enabled key figures to embark on public debate and discussion of death and dying in a new way ... There is no doubt that the work of the Institute was often dominant in the use of evidence over preferences and that this often drove the public debate.”
individual attachments or exchanges by research fellows (usually over several months) to group requests that involve meetings with staff from both research and clinical services over one day or one week.

Our impact

Our research addresses concerns that affect everyone in society, with its focus on palliative care for chronic and progressive diseases, complex disabilities, death and dying. There are 53 million deaths per year worldwide; around 80% have a period of progressive illness and/or disability as their disease becomes incurable. In these phases, palliative care and rehabilitation are needed to enable people to live as well as possible, and to support them and those who care for them, including in bereavement.

Our multi-professional research, education, public information, support and clinical care strive to identify and raise the profile of patient and family needs, and develop evidence-based solutions to enduring health problems and in the critical phases of life and death. We major on applied health and social care research where findings are critical and directly relevant to policy, clinical practice, patients and families. We produce and advocate for high-quality research to achieve impact. We publish major protocols in advance and results in peer-reviewed, high-impact journals.

Our emphasis on person-centred care strengthens our partnerships with patients and families, and – together with the reputation of our research – ensures the reach and impact with a wide range of beneficiaries:

- Health service providers, clinicians, service managers and directors in hospitals, hospices and community services
- Policy makers in the UK and inter-governmental organisations such as the World Health Organisation and the European Commission
- National/international professional associations
- Non-governmental organisations and major charities
- Individual and umbrella service-user organisations that influence policy such as the European Cancer Patient Coalition, the National Childbirth Trust and the Neurological Alliance.

Our work has:
- Impacted NHS frameworks and guidance, for example the Independent Palliative Care Funding Review for England (2011) and Getting it Right: End of Life Care in Advanced Kidney Disease (2012).
- Improved care for patients and families by transforming services. Our clinical tools both aid assessment and outcome evaluation in routine practice and support service development. These have fed directly into national and international policies.
- Raised the profile, tested solutions and improved access to care in the UK, Europe, Australia, Asia and Africa. We raised the profile of the needs of older people and non-cancer patients leading to policy improvements and attitude changes amongst service-providers.
- Found new ways to improve the experiences and care for people affected by cancer, HIV/AIDS, organ failure, or severe brain injury.
- Led to changes in core training, for example our recommendations on addressing cultural needs are now in the training for British Pain Society members.
Global Partnerships and Programmes

The Institute is a network hub for international research policy influence and education, and our work leads to implementation of local, national, and international programmes. Our global health programme is delivering on our goal of evidence-based palliative care for all (in partnership with Cicely Sanders International) and is a cross-cutting programme that brings together our expertise in outcome measurement, cancer and non-cancer care, culture and ethnicity, spiritual care, and intervention development and testing.

Our global programme spans Africa, Australasia, the Americas, and Europe. Collaborating with partners in over 60 countries we work with governments and decision-makers, presenting research evidence to inform national policies on palliative care (Figure 12). We are a World Health Organisation (WHO) Collaborating Centre and have produced a series of WHO booklets summarising evidence and best practice, for example ‘Palliative care for older people: better practices’ (2011). These are among the most requested WHO booklets on any topic. Our partnerships and evidence are strengthened by a multi-disciplinary approach including anthropology, medicine, epidemiology, philosophy, nursing science and health economics.

Sub-Saharan Africa

We have a highly successfully model of partnership that has flourished in East Africa (e.g. the African Palliative Care Association, Kenyan Hospice Palliative Care Association, Palliative Care Association of Tanzania, University of Nairobi and BOMU Care) and Southern Africa (Universities of Cape Town and of the Witswatersrand, the Hospice Palliative Care TOPCare team at a clinic in South Africa
Association of South Africa and Governmental Health Departments. We work in close partnership with many clinical sites and regional/national associations. This enables us to directly influence guidance such as the ‘Standards for Palliative Care for sub-Saharan Africa’, which advocates the use of the tool we validated, the APCA African POS (see page 31). We have been able to highlight African palliative care in journals such as the Lancet Oncology (Harding et al., 2013c) and Lancet Infectious Diseases (Harding et al., 2012e). We have completed clinical trials in palliative care in East and South Africa in collaboration with both NGO and Public Hospitals, partnering with African Universities (Lowther et al., 2012). In 2013 we launched a new EC-funded programme IMPAQT: Incorporating Palliation through Audit and Quality Training An EC-funded study to measure and improve outcomes for patients with COPD/heart failure in South Africa transferring our outcomes and quality programme into primary and secondary care settings for COPD and heart failure patients in primary care and organ failure patients in acute care settings.

With the creation of a visiting Professorship in Palliative Care at the University of Cape Town (Richard Harding), we have been able to collaborate and publish data demonstrating a cost saving for a novel hospital-based palliative care service (Desrosiers et al., 2013).

US Government-funded evaluation of the US HIV response in Africa

The growth of palliative care in Africa was triggered by the US Government’s response to the HIV epidemic. We were awarded a fellowship via Columbia University to work with the White House in developing the US President’s Emergency Plan for AIDS Relief (PEPFAR) by developing an evidence base. Professor Higginson gave advice to the White House on palliative care. This led to the US Government awarding the Institute the largest ever Public Health Evaluation, investigating care and support in East Africa in partnership with US and African Institutions. This has enabled us to generate new evidence in a previously unexplored field. As the WHO states that palliative care is to be integrated from diagnosis and alongside treatment, we have published the first evidence of need for palliative care following HIV diagnosis (Simms et al., 2013).

The Americas

In 2013 we secured a King’s Health Partners/University of California, San Francisco visiting fellowship to establish global health links across research programmes (Dr Lucy Selman). In the field of academic global health we continue our partnership with the University of North Carolina/Futures Group delivering evidence to the US Government on the President’s Emergency Plan for AIDS Relief (PEPFAR), and provided expert evidence to PEPFAR to inform funding plans.

Within the Americas, we are part of the Canadian-UK HIV rehabilitation collaborative. The visiting fellowship to work alongside the National AIDS Office in Washington DC and Columbia University provided the evidence for the original PEPFAR plans. This involvement has continued in our PEPFAR evaluation roles with the FUTURES group and the University of North Carolina. The IARE project is a new North American partnership (see below), and we have our visiting programme with the University of California San Francisco (see above), enabling us to expand both our HIV and cancer global programmes. Partnerships in Argentina and Cuba have led to the first data reporting outcome measurement, using locally validated POS.

The IARE study, part of project BuildCARE, also contributes to our Global Health Programme, generating comparative evidence across the cities of London, Dublin, New York and San Francisco to inform a sea-change in the delivery of palliative care to older people in these ageing populations. IARE
is a collaboration between King’s Health Partners, Mount Sinai Medical Center, Beaumont Hospital, Mater Misericordiae University Hospital, Trinity College Dublin and the University of California, San Francisco. The study will provide data on access to care and the perspectives of patients, their unpaid caregivers and staff. In this respect, it will bring us one step closer to an integrated working partnership across the country divides and regardless of differences in health structure and systems.

**Australasia**

Our rehabilitation programme has developed costing and outcomes models under an NIHR programme grant and this model is now being used internationally to implement costing tariffs. We collaborate closely with Australian clinical academic services to advance the science of outcome measurement. For example, we are working with Professor Kathy Eagar, Director of the Centre for Health Service Development at the University of Wollongong, to develop a palliative care case-mix classification for England, adapted from her work over the last decade on case-mix in sub-acute and non-acute care in Australia. POS-S renal, our validated renal symptom score, is currently used in renal services across Victoria and New South Wales, and members of our team have conducted workshops, seminars and lectures in Melbourne and Sydney to support the development of renal palliative care. In partnership with Dr Rachael Morton, University of Sydney, we are also helping to test measures of well-being in older people with advanced kidney disease and their family care-givers.

**Europe**

Our pan-European studies have pioneered methodological development and co-ordination across leading clinical and academic centres. Our global health programme truly enhances these programmes, with transfer of lessons and expertise across regions. For example, our Palliative care Outcome Scale (POS) work developed in the UK underpinned the PRISMA programme, which included African partners plus 9 European partners. Lessons learned in African POS implementation were then shared in a South-South exchange between African and Indian palliative care experts.

**‘PRISMA’, an international collaboration**

The PRISMA project, funded by the European Commission and led by the Cicely Saunders Institute, brought together 11 leading institutions across Europe and Africa with patient representatives. The programme aimed to enhance measurement of the end-of-life cancer experience as cancer deaths increase across Europe with an ageing population. The strength of our programme was that the patient experience was at the centre of the work. Bringing together anthropologists to understand cultural difference in the meaning and experience of end-of-life, we conducted large scale population-based surveys in seven European countries plus Africa to determine public preferences and priorities for end-of-life care. We carried out research with clinicians, to determine their priorities for end-of-life research, and research to determine current practice in measurement of end-of-life care across Europe. We held expert symposia on end-of-life care research in Europe, and appraised the evidence, developing resources for free access in European languages for clinicians to implement outcome measurement in
routine practice. The work culminated in a Policy Briefing in Brussels, to inform policy makers, funders and clinicians. The programme has provided around 40 peer-reviewed publications as well as a suite of resources related to POS. (e.g. Daveson et al., 2011b; Harding et al., 2011d; Gomes et al., 2012b). Based on this work, the POS is currently being validated in HIV and cancer across Vietnam by our partners at Harvard Medical School, and in 2013 a national POS conference was convened in Thailand.

We were co-leaders of ECPRC, an EC-funded programme of 60 researchers at 11 centres in six European countries that addressed assessment and guidelines for three symptoms: pain, depression and muscle wasting. We are co-leaders of ‘EUROImpact’, and the EC Marie Curie Initial Training Network. EUROImpact enables 12 early stage researchers and six experienced researchers from across the world to attend the Institute for either extended blocks of time or to attend for specific teaching modules. This has enabled us to provide training to emerging academics in palliative care from across Europe, and employ two early stage and one experienced researcher at the Institute.

Other International programmes that enrich and utilise our environment include BuildCARE, financing, home care, renal and breathlessness programmes. Our USA partnerships include the BuildCARE partners, and the University of North Carolina, partners in our global health programme in Africa, and the Institute for Human Virology, with whom we partnered to test models of HIV care in Tanzania. Our European collaboration continues with Dr Barbara Gomes working to drive forward quality improvement of palliative care in Portugal, and our breathlessness programme across the UK and Germany.

Global alumni

A third of our postgraduate student population resides outside the UK, raising the international profile of the Institution. Our global alumni from our multi-professional and international MSc in Palliative Care have studied with us to produce original publications. This includes data from Bangladesh that examine the use of morphine (Dehghan et al., 2012) and data evidencing the magnitude of palliative care need in an African referral hospital (Uganda) (Lewington et al., 2012). We provide a rich and stimulating learning environment for our learners, and all our students are able to learn a second language through King’s College London’s training and support services.
In focus

The Upper Limb International Spasticity Study-II (ULIS-II): a large, international, prospective cohort study investigating practice and goal attainment following treatment with botulinum toxin A in real-life clinical management

This is the second stage in the ULIS programme (ULIS-II) which has been investigating the real-life practice and outcomes following treatment of post-stroke upper limb spasticity with botulinum toxin A (BoNT-A) and physical interventions. ULIS-II is the first large international cohort study to use Goal Attainment Scaling (GAS) as a primary outcome tool for the person-centered evaluation of treatment with BoNT-A for spasticity (Figure 13).

This large international cohort study was conducted in 84 secondary care centres in 22 countries. The ULIS-II study investigated outcomes of post-stroke spasticity patients (n=456) following one cycle of BoNT type-A (BoNT-A) treatment in routine clinical practice. A published methodology describes the steps taken to ensure the validity of GAS as a tool for the evaluation of functional gains in this context (Turner-Stokes et al., 2012b). Study aims were to quantify and characterise the achievement of person-centered goals following one BoNT-A injection cycle delivered in the context of routine clinical practice, and to describe the variations in clinical practice, including application of physical interventions, and to explore prognostic factors that may impact on outcome.

Despite wide variations in the approach to clinical practice, a large majority (80%) of the patients achieved their treatment goals, mainly in terms of passive or active function and pain reduction (Turner-Stokes et al., 2013e). Our findings provide evidence that BoNT-A injections may contribute to an improvement in the daily life of patients and their carers beyond simple improvement of tone or spasticity (Turner-Stokes et al., 2013e). ULIS-II lays the foundation for larger international longitudinal cohort studies to explore further the characteristics and treatment approaches that predict best outcomes in BoNT-A treatment of upper limb spasticity. From this large dataset, we are currently identifying different trends of response with different combinations of intervention used and in particular explore which categories of patients have the best responses.
Macmillan Information and Support Centre and Wider Support in the Institute

About the Centre

The Macmillan Information and Support Centre is housed on the ground floor of the Cicely Saunders Institute, and provides a welcoming and relaxing environment for patients, carers or family and friends of people with cancer or other long term conditions. People attend the centre with queries, to access support activities, or to make use of the quiet space it offers (Figures 14 and 15).

In 2012, the centre was successful in obtaining a Macmillan Quality Environment Mark award. This prestigious award is a quality framework used for assessing whether cancer care environments meet the standards required by people living with cancer. Specifically, it recognises that the environment is welcoming and accessible to all, respectful of people’s privacy and dignity, supportive to users’ comfort and well-being, gives choice and control to people using the service, and listens to the voice of the user.

“...users will arrive with a welter of needs – physical, mental, emotional and spiritual ... Some will be amazingly buoyant and optimistic, others stunned that suddenly life is short. Yet others will be looking for relief and support while going through a bad patch, yearning to emerge and put life together again. The impressions I have in my mind are about ebb and flow, not being sucked in or blown out, but being held long enough to make good decisions for oneself and others we love ...” Feedback from a user

Having the right kind of information and support, at the right time, is essential, whether a person is newly diagnosed or has been living with a condition for some time. The Macmillan Information and Support Centre aims to offer information and support, both locally and nationally, as well as access to networked computers to encourage patients to self-manage through contacting support groups and obtaining robust, reliable advice online.

The centre is run by a full time Centre Manager, Michelle Goode, and a team of trained volunteers. It is open Monday to Friday, 10.00am to 4.00pm, and was designed to be an integral part of the Cicely Saunders Institute, working alongside both the clinical and academic teams to improve facilities for service users, and to feed into research.

Research

As well as serving the information and support needs of users, the centre is a hub for clinics and research projects, such as our Breathlessness Support Service (see Symptom-led research). This multidisciplinary clinic draws on the expertise of physicians and nurses from respiratory and palliative medicine, as well as physiotherapists, occupational therapists and social workers, and was designed to offer a holistic intervention to palliate this common and devastating symptom.
Crowning Glory Scarves

Led by Gill Thomas (King’s Helpline Advisor), this work represents a collaboration between King’s College Hospital, Stella McCartney, Clive Derby, creative director of the menswear label Rake, and Coutts. The scarves designed by McCartney and Rake, and funded by Coutts, are available for free to any cancer patient attending the centre. Sessions on learning the art of scarf tying are offered, also giving users the opportunity to discuss the physical and psychosocial impacts of cancer.

Looking forward

The Centre is forward thinking and always looking to develop the services offered. Our future goals are to increase the number and breadth of volunteers, continue to increase the number of patients, carers and professionals using the centre, and to support a Benefits Advisor who can be available to all visitors. We hope to introduce patient-centred activities such as dedicated wards visits, make-up workshops, complementary and integrative therapies, with user and patient involvement wherever possible. To fully integrate into the Cicely Saunders Institute we will also explore ways to increase research activity, to help support the evaluation of the services and care we provide.

Patient Support groups

Many patient and carer self-help and support groups now meet in the Institute, using as planned, the Dinwoodie rooms. These are often convened by specialist nurses, and include groups specifically for people affected by many different cancers and other diseases.
### Table 8 Activities supported by the centre

<table>
<thead>
<tr>
<th>Activity</th>
<th>Support Group</th>
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<tr>
<td>Crowning Glory Scarves</td>
<td>Bereavement counselling</td>
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<tr>
<td>Scarf tying</td>
<td>Breast support group</td>
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<td>Wig clinic</td>
<td>Post breast surgery support group</td>
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<tr>
<td>Ward visits</td>
<td>Post stem cell transplant group</td>
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<tr>
<td>Portable bed loaning</td>
<td>Lung support group</td>
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<tr>
<td>Outreach</td>
<td>Myeloid support groups</td>
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<td>Haematology Lymphoid clinic</td>
<td>Haem-oncology benefit group</td>
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<tr>
<td>Lung clinic</td>
<td>Aplasia-anaemia support group</td>
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<tr>
<td>Psychotherapy</td>
<td>Boots No. 7 make-up workshop</td>
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<tr>
<td>King's Cancer Helpline</td>
<td>Post bone marrow support group</td>
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<tr>
<td>Breathlessness Support Service</td>
<td>Awareness events</td>
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**Figure 14** Macmillan Information and Support Centre visitor numbers 2011 and 2013

**Figure 15** Reasons for attending the Macmillan Information and Support Centre in 2013 (n=2621)
Moving into the Institute has allowed us to considerably expand our education programmes, the numbers we can train and the diversity of courses. Our principle remit is to provide high quality evidence-based learning opportunities in palliative care to health and social care professionals, irrespective of their work setting, and to capacity-build staff by working across the Cicely Saunders Institute and its partners. The CSI Executive Education and Training Committee oversees the work of the Department of Palliative Care, Policy and Rehabilitation and King’s Health Partners clinical palliative care services. Links are also being established with the Regional Rehabilitation Unit at Northwick Park Hospital Rehabilitation Service.

PhDs in Palliative Care

The Institute has a vibrant and enthusiastic group of PhD students, who are an integral part of our research and who gain from our internal programme of researcher development. This development programme includes bi-monthly journal clubs, monthly researchers meeting, skills development workshops, evidence update sessions, and an Open Seminar series with national and international speakers. There is also a departmental PhD peer-support group to provide mutual support, exchange experiences, and foster rapid learning. Our PhD students also benefit from the extensive range of training and support provided throughout King’s College London, which they access and use according to their individual training and development needs. Doctoral students who choose the Cicely Saunders Institute to undertake PhD research studies are given the opportunity to be at the heart of latest developments in the field. At any one time, there are around 8–10 professionals studying with us for their PhD from a wide range of backgrounds – currently medicine, nursing, social science, physiotherapy, psychology, and anthropology graduates are represented. Each student develops a bespoke programme in agreement with their supervisors.

Dr Jonathan Koffman, Ms Christina Ramsenthaler, Ms Constanze Remi and Dr Lucy Selman, 2012
PhDs completed and awarded during 2011–14

- **DESPINA ANAGNOSTOU** Ethnographic study of cancer patients’ experience of their illness and care at the end of life in Greece. Supervisors: Teresa Wiseman, Alison Richardson, Irene Higginson

- **BARBARA GOMES** Post bereavement survey to improve understanding of where cancer patients die and to discover ways of empowering patients to die in the place of their choice, with quality care, dignity and support for their families. Supervisors: Irene Higginson, Paul McCrone, Sue Hall

- **LUCY SELMAN** Spiritual well-being and its assessment among patients receiving palliative care in South Africa and Uganda. Supervisors: Richard Harding, Irene Higginson, Marjolein Gysels

- **STEPHEN ASHFORD** Assessment of functional improvement in the hemiparetic arm following focal rehabilitation intervention. Supervisors: Lynne Turner-Stokes, Mike Slade

- **VICTORIA SIMMS** A longitudinal outcomes study of HIV palliative care provision in Kenya and Uganda. Supervisors: Richard Harding, Irene Higginson

- **FARIDA MALIK** Breathlessness in patients with advanced disease: the experiences of caregivers. Supervisors: Irene Higginson, Marjolein Gysels

- **LAUREN RAYNER** The clinical epidemiology and management of depression in palliative care. Supervisors: Matthew Hotopf, Irene Higginson

Current PhD students

- **EMMA MURPHY** A cohort study to describe the trajectory of illness and care received during the last year of life for those people with ESRD who die following withdrawal of dialysis. Supervisors: Fliss Murtagh, Teresa Wiseman, Irene Higginson


- **SABRINA BAJWAH** Developing and evaluating a Hospital2Home palliative care service for patients with severe Progressive Idiopathic Fibrotic Interstitial Lung Disease. Supervisors: Irene Higginson, Jonathan Koffman, Julia Riley, Athol Wells

- **LESLEY HENSON** Exploring and understanding factors associated with emergency department attendance by patients with advanced cancer towards the end of life: a mixed methods study. Supervisors: Barb Daveson, Gao Wei, Irene Higginson

- **KEIRA LOWTHER** A mixed method evaluation of the effectiveness of a nurse-led palliative care intervention for HIV positive patients in Mombasa, Kenya. Supervisors: Richard Harding, Lucy Selman, Irene Higginson

- **STEPHEN KRIESE** Understanding and improving the end of life care for patients with end-stage liver disease and their carers: a longitudinal study of symptoms and experience. Supervisors: Irene Higginson, Fliss Murtagh, Wendy Prentice, Michael A Heneghan

- **MENDWAS DZINGINA** Development of a preference-based outcome measure for use in economic evaluations of palliative care services. Supervisors: Irene Higginson, Paul McCrone, Fliss Murtagh

- **CLARE ELLIS-SMITH** The Palliative care Outcome Scale for Dementia (POS-Dem): an intervention for people with dementia living in residential care homes. Supervisors: Barb Daveson, Catherine Evans, Irene Higginson

- **PAULINE KANE** Needs and Education for Access: the NEAS study. Improving access to palliative care for patients with heart failure in Ireland. Supervisors: Fliss Murtagh, Barb Daveson, Irene Higginson

- **TOM OSBORNE** Quality of life in people with multiple myeloma and follicular lymphoma. The development and validation of a questionnaire for use in the clinical setting to aid the assessment of quality of life in people with multiple myeloma. Supervisors: Irene Higginson, Sue Hall, Richard Siegert
MSc, Postgraduate Diploma and Postgraduate Certificate in Palliative Care

Our Master of Science (MSc) in Palliative Care is one of the most highly acclaimed programmes in palliative care in the United Kingdom and the world. The underpinning philosophy of the MSc and the 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 in order to inform their clinical practice and to develop relevant services and policy.

The course aims to develop a deeper knowledge and understanding of the many clinical, social, psychological, spiritual and ethical issues in palliative and end of life care, and their assessment and effective management. In addition to being able to critically appraise evidence of new and existing treatments, our students are taught how to formulate important and feasible research questions relevant to the specialty, and then to design and conduct their own rigorous research studies to address these issues. Students are taught by world-leading experts from King's College London, St. Christopher's Hospice and other prestigious centres of excellence in the United Kingdom and elsewhere.

Our international reputation attracts high calibre and highly motivated students from all over the world. The range of countries currently and historically represented in the student body is very diverse including those from Colombia, Uganda, South Africa, Portugal, Germany, the United States of America, Brazil, Italy, Spain, the Netherlands, Norway, Iceland, Israel and many others. This student mix brings with it unique opportunities for students to share experiences on how palliative and end of life care has developed across the world and also to reflect on the social and cultural approaches to death, dying, caring and bereavement. The MSc has also been designed to closely complement the training requirements of UK specialists training registrars in palliative medicine. Many students attending the course are attracted to modules that directly fulfil their training needs as consultants in palliative medicine in the making. We frequently refer to the training curriculum to ensure we continue to develop and modify the course to ensure it matches the needs of the specialty.

Since its inception in 1999, over 450 students have successfully graduated from the course. They have had a direct effect on the assessment and effective management of distressing symptoms associated with advanced disease, have cared for family members during this process and in bereavement, and have influenced local, national and international policy on the provision of palliative and end of life care. Many former students have gone on to achieve significant promotion within their respective professions and countries. Of these students a large number attribute their progression directly to the course experience. We are proud to list two Professors of Palliative Care (Drs Claudia Bausewein from Munich and Gerhild Becker from Freiburg) amongst our alumni. Our students also have a strong track record of sharing the findings from their research study projects, and in some instances their course assignments, in peer-reviewed scientific journals that include *Lancet Infectious Diseases, British Medical Journal, Journal of Pain and Symptom Management, Palliative Medicine, Journal of Palliative Care, BMC Public Health and Social Science and Medicine* to name a few.

PhD students Ms Claire Ellis-Smith, Dr Lesley Henson, Dr Mendwas Dzingina, Dr Pauline Kane
An increasing number of former students have gone on to conduct PhD research either at King’s College London or elsewhere and to grow the evidence base in new and important areas. We have also assisted in developing the careers of ‘emerging researchers’ recognised for their international contribution to palliative care; Dr Barbara Gomes and Dr Lucy Selman are both recent graduates, were awarded the prestigious ‘European Association of Palliative Care (EAPC) Early Researcher Award’ at the scientific meetings held in Trondheim in 2012 and Prague in 2013 respectively.

**Successful MSc in Palliative Care alumni**

All students attending the MSc in Palliative Care are required to conduct a research study project. This is a significant undertaking that typically involves the collection of primary data, analysis of secondary data or a systematic review. Research study projects titles from students who have graduated from the course between 2011–2013 are detailed below:

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**MSc alumni 2011 and their research dissertations**

- **SHARON BEATTY** Assessing the spiritual concerns of care home residents using the FACIT-SP
- **MAGALI VAN DEN EYNDE** Pain assessment tools for older people with dementia in hospital or the community: A systematic review
- **ROSALYN FOO** Explorative study on the views of hospice staff nurses on clinical supervision
- **CONSTANZE REMI** The pharmacists’ role in palliative care, literature review and survey among German pharmacists
- **KATE SHEPHERD** Exploring the feasibility and acceptability of the Kidney Care Plan in patients with chronic kidney disease who are being managed conservatively: a pilot study
- **LOUISE HISTON** A qualitative study to explore the views of patients with head and neck cancer of a new pro-active pain management programme and to understand barriers to pain control
- **CHRISTINA RAMSENTALER** Principles and practice in reporting exploratory or confirmatory factor analyses in palliative care research – a systematic review and recommendations for future research
- **LISA SHEEHY** Are you at peace?: A qualitative analysis of the views of older people in care homes
- **REBECCA JENNINGS** Meaning of pain for patients with advanced cancer and how it influences behaviour: a qualitative research study
- **KATE CRITCHLEY** The prevalence of and the factors associated with awareness of dying for patients with cancer and their relatives
- **RENAME PRAXMARER** The challenges and barriers healthcare professionals are faced with in communicating about end of life issues with terminally ill patients and their families: a systematic review
- **TREENA SAINI** A pilot study to examine the effectiveness of hypnotherapy in the management of anxiety and its associated symptoms in patients with cancer receiving palliative care

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**MSc alumni 2012 and their research dissertations**

- **CORDULA ZEHNDER-KIWORR** Prevalence of physical and psychological symptoms in patients with head and neck cancer – a systematic review
- **SARAH KLINGER** Caregiver assessment of patients with ‘Parkinson’s Plus Syndromes’: the effect of burden and other factors on concordance and discrepancy with patients
- **CLAIRE ZANE** Breakthrough cancer pain – the experience of informal carers: a qualitative study
• MARY CLANCY  Nurses’ experiences of delivering spiritual care to palliative care patients: a meta-ethnography

• ALEXANDRA ROGERS  What are the training needs of medical registrars in assessing and managing pain in patients with dementia in the acute hospital setting?

• CATHERINE THOMAS  Exploring stress and resilience in hospice volunteers: a qualitative study

• LUCY COOMBES  Potentially useful outcome measures in paediatric palliative care: a systematic review

• CLAIRE MAGEE  The role, confidence and educational preferences of general practitioners providing out-of-hours palliative care in England: a postal survey

• EDITH UBOGAGU  Home or Away – factors influencing the management and delivery of end of life care in patients with a preference for home death, discharged from hospital in the last days of life: semi-structured interviews with general practitioners in the outer London boroughs and surrounding counties

• MAY WUNG  A systematic review and meta-analysis to identify the efficacy of non-invasive ventilation in managing myasthenic crisis

• HELEN SCOTT  An exploratory qualitative study of end of life care nursing on hospice and acute hospital wards: can hospice ward nursing practice transfer to the acute sector?

• MICHELLE ROLLINSON  Assessing dignity related distress in older people in care homes using the Patient Dignity Inventory: a cognitive interviewing study

• NIMISHA PANCHMATIA  The effectiveness and acceptability of the Goal Attainment Scale on acute wards with patients with advanced metastatic disease

• HELDER AGUIAR  Impact of Home Palliative Care Team (HPCT) on place of death, chemotherapy and NHS resource and use and costs for terminal cancer patients in the Portuguese metropolitan area: a retrospective cohort study

• EILEEN ANDREWS  Exploring the lived experience of adults with lower limb lymphodema secondary to Kaposi’s sarcoma: a phenomenological study

• LAURA COTTINGHAM  How do palliative care doctors care for patients who are hoping for a miracle? A pilot qualitative study

• HELEN BREWERTON  The recognition of dying in the hospital setting. A retrospective cohort study
MSc alumni 2013 and their research dissertations

- **TUSHTI BHARDWAJ** Qualitative study of illness attribution, physical and psycho-social concerns of Asian people severely affected by multiple sclerosis

- **ANGELA BURDEN** Healthcare professionals’ perspectives of the role of specialist palliative care in a major trauma ward: a qualitative study

- **RYAN CABIDA** Voicing the challenges in end of life care: Exploring the impact of the Schwartz Centre Rounds on hospice staff

- **MIRIAM CAPPELLI** Why are haematological cancer patients less likely to be referred to palliative care and to die at home? A qualitative study on the views of Italian health care professionals

- **NORAH FAGAN** Living with advanced cancer: Rural Irish patients’ perspectives

- **LOUISE FREE** Identifying the learning needs of palliative medicine trainees in the assessment and management of pain in patients with moderate to severe dementia

- **ANDREW GOODHEAD** Pastoral care of the dying: What pastoral and religious support is offered to dying people by Christian clergy? A study among ordained clergy working in Lambeth and Southwark, South East London.

- **NICOLA HETHERTON** Decision aids facilitating the discussion of Advance Care Planning with people living with dementia – A systematic review

- **SARAH-JANE IVEY** How can we best support people who are living with and dying from life-limiting illnesses? The perceptions of representatives from South Asian communities.

- **KEVIN KOUNG** Safety and effectiveness of levosimendan on symptoms and quality of life in advanced heart failure: A systematic review from palliative care reviews

- **ANA DOMINGUES DE ALMEIDA FORJAZ DE LACERDA** Cause and place of death of children and adolescents in Portugal (1987–2011): an epidemiological study

- **SUSAN MARTIN** Exploring the experiences of nurses carrying out last offices, including their views regarding the involvement of significant others in the process

- **ANNABELLE MAY** Factors that impede older palliative care patients dying alone at home

- **SABRINA CARVAJALINO PALACIO** Needs and symptom profile of patients with fibrotic interstitial lung disease: A systematic literature review

- **SHUCHITA PATEL** Non-conventional interventions in pain management in advanced, progressive, non-malignant respiratory disease: A systematic review of literature

- **TARANJIT SINGH** Palliative care in South Asia: A systematic review of the evidence for care models, interventions and outcomes

- **VERA PAIVA BRANDAO NAPOLES SARMENTO** Key components of home palliative care according to patients and family caregivers’ experiences: a meta-ethnography.

- **FEMKE SPORENDUNK-BUUR** Service users experience of a new out-patient breathlessness support service: A qualitative study

- **FABIA WEISSER** Experience of burden, needs, rewards and resilience in informal carers of patients suffering from motor neurone disease, secondary analysis of longitudinal qualitative data

- **CHRISTINE ZOBRIST** When grief goes somatic- The relationship between grief, somatic symptoms and poor bereavement outcomes; a systematic literature review
Undergraduate education

King’s College London School of Medicine at Guy’s, St Thomas’ and King’s Hospitals is the largest provider of undergraduate healthcare training in Europe, with over 450 medical students in each year. The undergraduate palliative care curriculum, led by Dr Rachel Burman, is designed to spread throughout the five-year MBBS through seminars, symposia, student selected components, bedside clinical teaching, hospice visits, and Objective Structured Clinical Examinations. Our programme provides comprehensive coverage of the Association of Palliative Medicine undergraduate curriculum and abides by the recommendations for undergraduate medical education of the EAPC and the General Medical Council.

Teaching is jointly by the clinical and academic team. It includes symposia, case-based and clinical bedside teaching, the use of video material, clinical vignettes and role play, and hospice visits where students meet patients as part of a ‘goldfish bowl’ teaching exercise (Edmonds, Burman & Sinnott, 2004). The early curriculum explores communication skills, sociological theories of loss and grief and medical ethics towards the end of life. Palliative care is also integrated into clinical rotations for core specialities, e.g. development and ageing; emergency medicine, so that end of life care, death and dying and the doctor’s role at these times is seen as integral and expected.

The palliative care team also offers a range of student-selected components in year 4 with optional tutorials and an extended essay. These are often oversubscribed, several of the essays have been entered for external competitions e.g. from Association for Palliative Medicine of Great Britain and Ireland, and are always well evaluated. 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 and registrars examine on the undergraduate programme. Dr Teresa Beynon co-ordinates the examiners and is a clinical advisor in the School of Medicine. In 2013 she was involved in the ‘Giving and receiving feedback’ teaching session.

Electives and placements

Elective placements are regularly undertaken at Guy’s, King’s and St Thomas’ by overseas medical, nursing and allied health students. Programmes of study are individually tailored with time shared across the clinical and academic departments as well as Trinity Hospice and St Christopher’s Hospice. A new initiative has also established a regular elective exchange programme, in memory of Dr Rob Buckman who worked in Canada and the UK. These fellowships support elective exchanges between students at Toronto University and King’s to give exposure to palliative care and psychosocial oncology.

King’s College London Palliative Care Society

Two medical students enjoyed their palliative care student-selected component so much that they approached their supervisors, Dr Rachel Burman and Dr Wendy Prentice, to set up an undergraduate palliative care society. The Society’s aim is to promote understanding of palliative care amongst
students at King’s College London and to create an opportunity to strengthen input and contributions that undergraduate students can make to palliative care research and impact. It is the world’s first undergraduate palliative care society and its inauguration in 2012 was overseen by Professor Rick Trainor, Principal of King’s College London. Usman Yusuff, the society’s president, recently returned from an elective period in South Africa with another doctor on an elective with the palliative care team sponsored by the Royal College of Physicians.

**Postgraduate medical education**

Postgraduate medical education is led by Dr Shaheen Khan (Guy’s and St Thomas’ NHS) and Dr Polly Edmonds (King’s College Hospital). We are the lead provider in postgraduate palliative medicine training for north-west London, south London, and Kent, Surrey and Sussex. Dr Khan has recently been appointed as Training Programme Director for Palliative Medicine for King’s Health Partners. Dr Edmonds is Quality Assurance lead for the palliative medicine faculty, chairs the regional Specialty Training Committee, and is a member of the Royal College of Physician’s Standard Setting Group and Specialty Advisory committee for Palliative Medicine. Professor Higginson is on the exam board for the Royal College of Physicians examination in Palliative Medicine.

**Specialty training in palliative medicine**

Across King’s Health Partners there are five specialty registrars and two academic clinical lecturers in palliative medicine; Dr Fliss Murtagh and Dr Katherine Sleeman. These posts have contributed to positive improvements in several domains of the General Medical Council trainee survey including clinical supervision, handover and workload.

**Nursing and allied healthcare professionals**

We provide input into the King’s Nurse Induction programme and provide teaching in palliative care to surgical and disease specific wards. Kate Shepherd, practice development nurse, actively supports the development of palliative and end of life care across all clinical areas for all grades of 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.

**Principles of Care for the Dying Patient**

With the phasing out of the Liverpool Care Pathway for the Dying Patient, clinical teams have responded actively in supporting ward teams deliver individualised care through an electronic notification system. This initiative provides ward-based training as the need arises around the care of patients and their families. Our Clinical Nurse Specialists and Practice Development Nurse signpost front line staff to our formal skills-based training programmes to strengthen their knowledge and confidence.

**Sage and Thyme® workshops**

The Sage and Thyme® model helps train all grades of staff how to listen and respond to patients/clients or carers who are distressed or concerned. It places published research evidence about effective communication skills within a memorable structure for clinical practice. Vicky Robinson, Consultant Nurse, has been running the half-day training monthly and presented a plenary presentation at the inaugural King’s Health Partners Nursing and Midwifery Conference in 2013. The training is being included in the Florence Nightingale School of Nursing and Midwifery undergraduate training and the workshop is mandatory for all newly-qualified nurses on the preceptor programme.

**Transforming End of Life Care**

Developed by Vicky Robinson in 2012, this two-day training course brings together front line staff from hospital, community and the care home sectors at Guys and St Thomas’ to learn together about the common issues faced by patients and families as death approaches. This multidisciplinary environment has served to integrate organisations, professions, and grades of staff. The course is highly evaluated, two posters were presented at the EAPC in 2013, and we plan to turn this into a shared initiative during 2014.
Clinical education

Our clinical teams deliver a regular series of educational activities for staff in the acute and community setting, in particular events for General Practitioners (GPs) including:

- quarterly practice meetings
- an annual South East London Doctors On Call teaching session
- evening tutorials
- Vocational Training Scheme training events
- Southwark Protected Learning Time events
- National “Hot topics for GPs” course

We also reach other groups with specialist lectures and events, for example Speech and Language Therapists, the Southwark and Lambeth Integrated Care team and community dentists.

Education multidisciplinary meeting

Our education multidisciplinary meetings were introduced to provide a forum to discuss cases identified as representing an educational need or opportunity. As well as drawing up action plans to meet the educational needs, the forum provides an opportunity to look at the team’s professional development needs, and to process requests for clinical visits and teaching. Key themes arising from these meeting have included procedural issues e.g. late referrals, symptom control and complex discharge planning issues.

The Cicely Saunders Institute Seminar and Lecture Series

This series aims to facilitate and optimise opportunities for local, national and international networking within palliative care and rehabilitation in order to improve practice, education and policy and the integration of research and clinical endeavours. Speakers have included:

2011

- **DR SARAH DEAN** University of Exeter: ‘The process of patient and public involvement in research: the example of stroke rehabilitation’

- **DR JOAN TENO** Brown University, USA: ‘Transitions and place of care: A national study of Medicare decedents between 2000 to 2007’

- **DR PETER FENWICK** King’s College London, Institute of Psychiatry: ‘End of life experiences’

- **VICKY ROBINSON** King’s College London and Mike Connolly, University of Manchester: ‘Sage & Thyme®: addressing emotional and psychological distress in palliative care’

- **DR FRANSISCO LUIS PIMENTEL** Universidade de Aveiro, Portugal: ‘Improving the measurement of quality of life in palliative care using research analysis’

- **PROFESSOR JANE SEYMOUR** University of Nottingham: ‘…Commission the service and then walk away’: Findings from a study examining access to resources for end of life’

- **DR SURESH KUMAR** Institute of Palliative Medicine, Kerala, India: ‘Palliative care in the developing world’

- **PROFESSOR MICHAEL BENNETT** University of Leeds ‘Neuropathic cancer pain’
2012

- **DR RACHAEL MORTON** The University of Sydney, Australia: ‘Why plans for conservative care rather than dialysis, and what factors influence patient choice?’

- **PROFESSOR MARTIN ORRELL** Department of Mental Health Sciences, University College London: ‘Improving quality of life in dementia’

- **DR BRIAN CASSELL** Virginia Commonwealth University, USA: ‘The financial sustainability of palliative care’

- **PROFESSOR SARA CARMELO** Ben-Gurion University of the Negev, Israel: ‘End of life care in Israel: preferences of the public and physicians’ & ‘The will-to-live: structure, empirical findings and suggestions for practice’

- **PROFESSOR JONATHAN TRITTER** Warwick Business School, Coventry: ‘Making research count for those who count on research: Patient and public involvement in research’

- **PROFESSOR JOHAN BILSEN** Ghent University & Vrije Universiteit Brussels, Belgium: ‘Medical end-of-life care decisions and practices: the Belgian perspective’

- **PROFESSOR SARAH TYSON** University of Manchester: ‘Using outcome measures in clinical practice: Theory to reality’

- **PROFESSOR CHRISTINA PUCHALSKI** George Washington Institute for Spirituality and Health (GWish), USA: ‘Improving the quality of spiritual care as a dimension of palliative care: learning from the U.S. experience’

- **PROFESSOR ALICIA O’CATHAIN** University of Sheffield: ‘Mixed methods in effectiveness research: understanding process to inform implementation’

- **DR KIRSTY BOYD** Centre for Population Health Sciences, University of Edinburgh: ‘Time for palliative care in end-stage liver disease: using a clinical indicators tool (SPICT ™) to identify patients for supportive & palliative care’

2013

- **DR CLAIRE BUTLER** Pilgrims Hospices in East Kent: ‘Evaluation of Pilgrims Hospices Rapid Response Hospice at Home Service’

- **PROFESSOR ROB GEORGE** King’s College London, Cicely Saunders Institute & Dr Carolyn Johnston, King’s College London: ‘What are the key ethical, legal & clinical considerations in withdrawing or withholding treatment in palliative care for patients with impaired capacity’

- **DR JONATHAN KOFFMAN** King’s College London, Cicely Saunders Institute: ‘The place and meanings of happiness in end-of-life care’

- **PROFESSOR NADINE FOSTER** Keele University: ‘Stratified primary care for patients with low back pain’

- **DR LIZ GWYTHER** Hospice Palliative Association of South Africa, Cape Town: ‘How is palliative care part of the right to health? Evidence from South Africa’

- **PROFESSOR JOAN TENO** Brown Medical School, Rhode Island: ‘Hospice in the USA: time to confront our variation’

- **DR AMY ABERNETHY** Duke University, North Carolina: ‘Integrating patient reported outcomes data – real time information for research and clinical care’

- **DR THOMAS J. SMITH** Hopkins’ Sidney Kimmel Comprehensive Cancer Center, Baltimore U.S.: ‘Bending the cost curve in cancer care – dreams and reality’
78 / Cicely Saunders Institute

The Cicely Saunders Annual Lecture

This is a highlight in our educational programme. This 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.

- **PROFESSOR ANN MOORE** University of Brighton: ‘Development of research priorities using a Delphi process’

- **PROFESSOR MARIA EKSTRAND** University of California, San Francisco: ‘The role of stigma in HIV prevention and treatment: Implications for interventions’

- **DR JULIA RILEY** National Heart and Lung Institute, Imperial College London: ‘Coordinate my care: An electronic palliative care coordination system across London’

- **DR AUGUSTO CARACENI** Fondazione IRCCS National Cancer Institute, Milan, Italy: ‘Delirium: Acute confusional states in palliative medicine’

- **PROFESSOR MOGENS GROENVOLD** Bispebjerg Hospital, Amsterdam: ‘Using outcome measurement in health research’

- **DR JENNY VAN DER STEEN** VU University Medical Center, Amsterdam: ‘EAPC white paper on palliative care in dementia’

- **PROFESSOR MARIA EKSTRAND** University of California, San Francisco: ‘The role of stigma in HIV prevention and treatment: Implications for interventions’

- **DR FLORIAN STRASSER** St Gallen, Switzerland: ‘Development of effective multi-dimensional interventions for patients with cancer cachexia’

- **DR ANDREW EPSTEIN** Memorial Sloan-Kettering Cancer Center, New York: ‘Person-Centered Oncology Care and Choices’

- **DR JENNY VAN DER STEEN** VU University Medical Center, Amsterdam: ‘EAPC white paper on palliative care in dementia’

- **PROFESSOR DIANE MEIER** Icahn School of Medicine at Mount Sinai, USA: ‘Can (or should) palliative care meet the challenge of care for persons with long term chronic illness versus remaining in our end-of-life corner?’

- **2014: PROFESSOR STEIN KAASA** Norwegian University of Science and Technology, Trondheim, Norway: ‘Integration of palliative care into public health and cancer care: a vision for the future’

- **2013: PROFESSOR DIANE MEIER** Icahn School of Medicine at Mount Sinai, USA: ‘Can (or should) palliative care meet the challenge of care for persons with long term chronic illness versus remaining in our end-of-life corner?’

- **2012: PROFESSOR KATHY FOLEY** Memorial Sloan Kettering Cancer Center, USA: ‘International & national policies for palliative care: can they make a difference?’

- **2011: PROFESSOR DAVID CURROW** Flinders University, Australia: ‘Palliative Care Research – what is the return on investment’

- **2010: PROFESSOR DAVID CURROW** Flinders University, Australia: ‘Palliative Care Research – what is the return on investment’
BuildCARE Study Days

These are multi-disciplinary events that encourage national and international networking between researchers and clinicians and usually include an element of training or skill development. Each year, we host over 400 delegates at our BuildCARE study days from across the world countries.

2011

- International Breathlessness Conference: Innovations and controversies in clinical management
- User-Friendly Research Training for Specialty Registrars in Palliative Medicine
- Advanced Renal Care study day
- Improving outcome measurement: Palliative Care Outcome Scale (POS) workshops to advance clinical care and research

2012

- Psychological distress in palliative care: Advances in clinical management
- Homecare: evolution, evidence and experience

2013

- Improving Outcome Measurement – Palliative care Outcome Scale (POS) workshops to advance clinical care and research
- International Breathlessness Conference: development in management in advanced disease

2014

- Improving Outcome Measurement – Palliative care Outcome Scale (POS) workshops to advance clinical care and research
- Access, Equity and Innovation in Palliative Care: Can we really afford and deliver quality for all in the future?
Clinical Services

Clinical palliative care services affiliated to the Institute are delivered across King’s Health Partners in King’s College Hospital (Denmark Hill and Princess Royal hospitals), Guy’s and St Thomas’ hospitals as well as in the communities of Lambeth, Southwark and Lewisham. Clinical and academic colleagues learn from each other and work together to develop research that is grounded in and can impact on patient care. Several clinical consultants have honorary academic appointments and vice versa. These and a growing number of joint clinical-academic posts including chairs, clinical lecturers and research fellows, project managers and research nurses, have helped to further integrate our research and clinical activities.

A programme of joint journal clubs, clinical academic division and forum meetings and evidence updates/team meetings allows regular exchange of information and ideas. Knowledge Exchange Seminars are held six monthly for all team members as well as our academic partners for clinical and academic initiatives to be discussed and disseminated widely. As well as providing day to day clinical services, the clinical teams are involved in service development and innovation, translational research and leading the provision of relevant undergraduate and postgraduate education and training (see Education and Outreach).

Palliative care services

Across King’s College Hospital NHS Foundation Trust (Denmark Hill and Princess Royal), Guy’s hospital & St Thomas’ hospital our clinical teams receive over 4,200 referrals each year, of which approximately 70% have a cancer and 30% a non-cancer primary diagnosis.

Palliative care services for in-patients are provided by multi-professional teams at King’s College NHS Foundation Trust (Denmark Hill and Princess Royal), Guy’s hospital & St Thomas’ hospital. A 24/7 telephone advice service for health professionals is provided across all three sites, as well as with colleagues at Lewisham hospital, supporting 7 day a week visiting (excluding Princess Royal Hospital). Patients are seen in an advisory capacity and remain under the admitting team.

Clinical team at King’s College Hospital NHS Foundation Trust: (left to right) Fliss Murtagh, Wendy Prentice, Chris Bridges, Louise Free, Rachel Burman, Polly Edmonds, Ann Southwell, Kate Shepherd, Sarah Spencer-Adams, Xan Neethling and Leanne Boyle
The Guy’s and St Thomas’ Community Palliative Care team provides 24/7 support for patients, their carers and healthcare professionals in the community across Lambeth, Southwark and Lewisham. The team hold quarterly meetings at General Practice surgeries to discuss palliative and end of life care issues with colleagues in primary care and work closely with nursing colleagues in the vertically-integrated community nursing service. The team has close working relationships with colleagues in organisations including care homes, hostels and local hospices including Trinity Hospice, St Christopher’s Hospice and the Greenwich and Bexley Hospice.

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

Service innovation

- **Patient outcomes/Department of Health funding pilot**
  Both acute Trusts participated in data collection for the national pilot on specialist palliative care funding. As part of the implementation of a new electronic system, the King’s team have now integrated the recording of outcome measures (phase of illness, performance status and POS) into routine clinical practice and are currently working to develop outputs that will support the delivery of quality clinical care.

- **End of life care**
  Both acute Trusts have withdrawn the Liverpool Care Pathway following the independent review published in July 2013. Our approach to end of life care acknowledges the time needed to support staff caring for the dying. King’s College Hospital introduced a trust-wide notification system that identifies dying patients and triggers support for ward staff with overarching principles of care. We offer education and support with individualised care planning, communication and documentation as well as senior out of hours support. A similar approach has been implemented at Guy’s and St Thomas’ from early 2014. This approach is being evaluated and fed back nationally to the Leadership Alliance for the Care of Dying People. Each of our Trusts also has executive-led Trust-wide end of life care governance committees overseeing care delivery and patient and family experience within the hospitals and the community.

- **Transforming End of Life Care in Acute Hospitals**
  Guy’s & St Thomas’ NHS Foundation Trust is a wave one hospital in this national programme aiming to transform hospital-based end of life care. Tools in development to improve the care offered to patients, include the AMBER care bundle, Coordinate my Care (CMC), an Electronic Palliative Care Co-ordination System (PaCCS), the PEACE advance care planning documentation, and a focus on rapid discharge that is facilitated by systems change to enable safe and timely access to injectable medications on discharge.

- **The AMBER care bundle**
  The AMBER care bundle was developed at Guy’s & St Thomas’. It is an approach used in hospitals when clinicians are uncertain whether a patient may recover and are concerned that they may only have a few months left to live. It encourages staff, patients and families to continue with treatment in the hope of a recovery, whilst talking openly about people’s wishes and putting plans in place should the worst happen. It consists of four elements:
    - talking to the person and their family to let them know that the healthcare team has concerns about their condition, and to establish their preferences and wishes
    - deciding together how the person will be cared for should their condition get worse
    - documenting a medical plan
    - agreeing these plans with all of the clinical team looking after the person.

The person’s condition is then monitored closely and followed up on a daily basis to record any changes and address any concerns that they or their family may have. By having conversations about preferences and wishes ensuring that everyone involved is aware of care plans, the aim is that people are more likely to have their needs met.
Development and evaluation of the feasibility and effects on staff, patients, and families of a new tool, the Psychosocial Assessment and Communication Evaluation (PACE), to improve communication and palliative care in intensive care and during clinical uncertainty


We aimed to develop and evaluate an interventional tool to improve communication and palliative care, using the ICU as an example of where this is difficult with a phase I-II study following the Medical Research Council Guidance for the Development and Evaluation of Complex Interventions and MORECare statement. The Psychosocial Assessment and Communication Evaluation (PACE) was produced using a literature review, qualitative interviews, and focus groups with 40 staff and 13 family members. PACE provides individualized assessments of all patients entering the ICU. It is completed within 24 to 48 hours of admission, and covers five aspects (key relationships, social details and needs, patient preferences, communication and information status, and other concerns), followed by recording of an ongoing communication evaluation (Figure 16). Implementation is supported by a training program with specialist palliative care. The feasibility and effects of PACE were evaluated using observation, record audit, and surveys of staff and family members across two ICUs. PACE was acceptable and feasible for staff to use. The close working relationship between palliative care and ICU staff in its development and implementation led to sustained working. It was mainly completed by nurses, which is not unexpected, as other work has suggested the central role of nurses in ICU care. A post-implementation survey of 95 ICU staff found that 89% rated PACE assessment as very or generally useful. Of 213 family members, 165 (78%) responded to their survey, and two-thirds had PACE completed. Those for whom PACE was completed reported significantly higher satisfaction with symptom control, and the honesty and consistency of information from staff (p-values 0.041 to 0.010) compared with those who did not.

PACE is a feasible interventional tool that has the potential to improve communication, information consistency, and family perceptions of symptom control. PACE may also be relevant for other hospital circumstances where there is a high level of clinical uncertainty.

Figure 16 Model of how Psychosocial Assessment and Communication Evaluation (PACE) may be acting to improve care in the intensive care unit (ICU) and achieve the desired outcomes

![Diagram showing the model of how PACE may be acting to improve care in the ICU and achieve the desired outcomes](image_url)
This tool is supported in practice across Guy’s & St Thomas’ and King’s College hospitals by the work of facilitators. Through the national network, the care bundle is also now being tested in hospitals across the United Kingdom and is being piloted in New South Wales. Mindful of the need for prospective evaluation, a feasibility evaluation study is underway to help inform work to examine the effectiveness of the intervention, and its effects on patients and families.

- **Specialist palliative care pharmacy**
  Guy’s and St. Thomas’ has appointed Steven Wanklyn as Consultant Pharmacist for palliative and end of life care. This post leads on clinical, educational, patient safety and service development innovations within the field of pharmaceutical sciences as they relate to this specialist area. Planned research in medicine optimisation will address national requirements and will be taken forward through the integration of work between pharmacy and palliative care clinical academic departments. As one of the first pharmacy consultant posts in this specialist field it will lead across the profession in driving quality improvement in the use of medications for palliative and end of life care patients. This will have a positive impact in developing the pharmacy workforce across the organisation and nationally.

- **Practice Development Nurse**
  The newly established Practice Development Nurse role at King’s College Hospital is breaking new ground. Taking a multidisciplinary approach, this post delivers palliative and end of life education for all clinical areas and all grades of clinical staff across the Trust. Education is a core activity of the team and as such continues to be a high priority. Exciting developments in the Trust’s strategy for education in end of life care for all relevant staff members are now starting to be realised. In 2012/13 The Trust Quality Account included End of Life Care as a key area, within which education of staff was a priority. End of Life Care e-learning modules are now mandatory for all clinical staff across the Trust and a face to face teaching session to support these has also been developed and implemented. The first roll out of training was successfully implemented to staff within liver, renal and haematology departments. This is now being rolled out Trust-wide.

- **Cross discipline integration**
  We have established close working relationships with specialties across our clinical teams. Examples of established working practices and outputs from integration include:

  - **Renal medicine:** an across sites Cause of Concern Register identifies patients with palliative care needs early on, so more tailored information about patient choices and better symptom management can be delivered (In focus, page 86).
  - **Skin services:** Professor Rob George and Dr Teresa Beynon input into services with joint ward rounds, multidisciplinary team meetings, and provides consultation on inpatients and outpatients nationally.
**Intensive care medicine:** A joint project at King’s College Hospital led to the development and implementation of a routine psychosocial assessment and communication evaluation tool, PACE. This aims to support patients and families at times of uncertainty (In focus, page 82). Intensive care referrals and activity has since increased and a second palliative care social worker has just been appointed to support this increase in activity.

- **Neurology:** Dr Rachel Burman is an integral part of the motor neurone disease service at King’s College Hospital providing a weekly joint clinic with the neurology team. Palliative care principles are embedded within the patient pathway. New services for people with Long Term Neurological Conditions will be launched in 2014 as part of the OPTCARE Neuro research project.

- **Institute of Liver Studies:** We have developed an integrated approach to the management of patients with end stage liver disease, which includes a weekly joint morbidity and mortality meeting, and the development of models of care to support patients with advanced disease. A research project is underway to assess further the needs of this group.

**Rehabilitation services**

Specialised neurorehabilitation following trauma and complex neurological illness/injury is provided across London by a network of eight provider units, two of which are integrated with the Institute:

- **The Regional Rehabilitation Unit (RRU) at Northwick Park Hospital**, directed by Professor Lynne Turner-Stokes, is an affiliated unit of King’s College London. It provides inpatient and outreach neurorehabilitation for a catchment population of over 15 million people, spanning London and the Home Counties. The consultant-led rehabilitation teams in both services provide fully coordinated inter-disciplinary rehabilitation in a range of different service models including inpatient and outreach rehabilitation. They support district specialist rehabilitation services and community-based teams, as well as linking with specialist nursing homes to provide life-long residential care for patients with long term conditions resulting in complex neurological disability.

- **The Frank Cooksey Rehabilitation Unit (FCRU)** based at Lewisham Hospital, is the King’s Health Partners specialist neurorehabilitation service.

**Service innovation**

- **Specialist Community Outreach Team**
  The RRU provides a Specialist Community Outreach Team service providing specialist assessment, management advice and support to teams, patients and carers. The service provides advice, support and spasticity intervention for management of people with complex neurodisability and support to their carers. The team of four clinicians works with nearby community rehabilitation teams and the inpatient service at Northwick Park Hospital Harrow (covering a population of approximately 20 million people). Input to other London boroughs, and nationally is also available.

- **Complex Physical Disability Management**
  The Specialist Community Outreach Team have developed close working relationships with rehabilitation units and community rehabilitation services across the region. The team provides advice to these services through the patient pathway, from acute management post injury to long term disability management and palliative care when required. The team has more recently been developing systems to review and re-evaluate patients with prolonged disorders of consciousness. The team has been involved in the development of the recent guideline on this subject produced by the Royal College of Physicians.
• Spasticity Management
Spasticity management is currently provided through the Specialist Community Outreach Service by the consultant physiotherapist who is supported by the rehabilitation medicine consultants. This involves administration of botulinum toxin to both patients in our own regional unit and in other hospitals, nursing homes and at home. Advice on systemic spasticity medication and onward referral to other services for regional intervention (either intrathecal baclofen pumps or intrathecal phenol) is also provided. We have been one of the first services to provide administration of botulinum toxin by a Physiotherapist through use of a Patient Group Direction (approximately 10 years ago). We now also use supplementary prescribing to enable the provision of botulinum toxin and adjustments to dosage of other systemic anti-spasticity medications (e.g. Baclofen and Tizanidine). Now that Independent Prescribing is a clinical reality for physiotherapists, implementation of this is planned in the coming year.

• Use of botulinum toxin in the management of spasticity
A number of studies have been conducted using both retrospective and prospective data. The RRU have developed an integrated care pathway for focal spasticity treatment using botulinum toxin and have been able to use data from this to inform the future development of more holistic spasticity management. The pathway provides a systematic method of recording the process and outcome of intervention. Key elements include systematic recording of intervention and outcome, implementation of Goal Attainment Scaling and outputs including National guidelines for management of spasticity.

• Shoulder pain
Within the RRU a clinic for hemiplegic shoulder pain has been established which has developed a model of pain management for patients post stroke and acquired brain injury. This clinical work has been evaluated through research projects looking at systems for evaluating and recording patient reported pain for those with communication difficulties. This work has utilised a Patient Reported Outcome measure, the SPIN, which was developed by Dr Diana Jackson and was used to evaluate clinical practice.

• Integrated Care Pathway for management of hemiplegic shoulder pain:
Shoulder pain is a common and distressing problem for many patients with neurological conditions such as stroke. It may not immediately be evident in people with communication impairments who have difficulty conveying information about pain. To improve management of this problem, we introduced a proforma and associated evidence based guidelines which prompt timely assessment of hemiplegic shoulder pain, guide the choice of intervention and enable the course of management to be followed.

Three rounds of audit have been carried out to assess performance on 18 quality standards. We have found that introducing the proforma has improved standards of documentation and demonstrated a positive outcome in over half of our patients. A key output of this work is an information pack designed for rehabilitation professionals, which is available on request from the RRU. Further outputs include publications in peer-reviewed journals and presentations to rehabilitation professionals, both locally and at national and international conferences.

• Depression
An integrated care pathway has been developed for the management of depression in patients with acquired brain injury. This has been implemented in practice and has been tested within our service, leading to consistent structured management of patients in our care.
Advanced Renal Care Project 2010–2012

This was an innovative project to develop and implement improved care for those with advanced kidney disease. It was conducted in close collaboration with nephrology and palliative care clinicians, and was very much informed by patients and families.

The patient perspective
A questionnaire survey of dialysis and conservatively managed Stage 5 Chronic Kidney Disease patients early in the project, identified that symptom management and attention to quality of life are a high priority for the patients themselves. While patients were highly satisfied with management of their kidney disease, they reported that symptom management, and psychological, social and practical aspects of their care, were often neglected by renal teams. In addition, planning ahead for future care is something which patients and families considered infrequently, and this was not prompted by their renal team (Kane et al., 2013).

The Cause for Concern Register
The project determined that a “Cause of Concern” or GOLD Register is invaluable in identifying advanced kidney disease patients with high palliative and supportive care needs, many of whom will be in the last year of life. Age, underlying renal diagnosis, the presence of co-morbid conditions, and the ‘surprise’ question were clinically appropriate and acceptable indicators to identify patients for the Register. Patient-reported outcome measures (symptom and quality of life scores) markedly improved such identification, focusing the Register on patient needs as well as on prognosis.

The value of patient-reported outcome measures
Patient-reported outcomes measures helped move the focus of clinical care away from disease-orientated care towards more patient-centred palliative and supportive goals. They provided an excellent foundation for holistic assessment of palliative and supportive care needs, as recommended for all patients with far advanced disease by the national End of Life Care Programme.

Numbers of patients with palliative and supportive needs
In this project, which was undertaken in two renal units with 1,350 prevalent CKD5 patients, we identified 96 patients (7% of all dialysis and conservatively managed Stage 5 CKD patients) as suitable for entry onto the Register. This was using three identification criteria: high symptom scores, poor quality of life, and the surprise question (the first two reported by patients themselves, and the last assessed by professionals). Because prognosis is uncertain, and professionals tend to over-estimate survival, this 7% likely encompasses patients with shortest survival (< 6 months) – re-focusing the Register on those with longer prognoses (< 12 months) but with high symptom burden and poor quality of life increases the capacity of the Register to improve quality of life for a greater number of patients with high palliative and supportive needs, and will increase the proportion on the register.

Achieving better care
The high symptom burden and other concerns seen among patients on the Register, plus the priority patients give to symptom relief and improvements in quality of life, underlines the need for systematic steps to address palliative and supportive needs for these patients (Murtagh et al., 2014). Improvement in patient care and quality of life outcomes for these patients can be achieved with relatively limited resources applied systematically, with good leadership and a detailed implementation plan (Kane et al., 2013).

There are challenges in implementing a shift in emphasis from primarily disease-centred care include more palliative and supportive goals, and something of a culture shift was needed. However, these changes are largely welcomed by renal staff, many of whom recognise the lack of palliative and supportive care provision for their patients. The specific steps we took to achieve change included:

• Education and awareness-raising amongst all renal professionals, and among the wider network of primary and palliative care providers, about recognising and assessing palliative and supportive needs.
Education and awareness-raising amongst all renal professionals, and among the wider network of primary and palliative care providers, about recognising and assessing palliative and supportive needs

Renal-specific Advanced Communication Skills training for those staff with key roles in this work (Bristowe et al., 2014)

Adopting routine patient-reported measures (POS-S renal and EuroQol, EQ5D) in the CKD5 population

Routine and regular assessment of all CKD5 patients for inclusion on a Cause for Concern Register, using these measures as well as other predictors of survival

Renal staff with dedicated responsibility to follow up those on the Register, to undertake holistic assessment and implement palliative and supportive interventions, and support other renal staff in doing so

Creation of a toolkit of resources, including symptom management guidelines, and clinically-applicable outcome measures

Integration of care provision, identifying and coordinating care across providers so that it is patient needs, rather than service constraints, which drive delivery of care
Contribution to the Disciplines

External committees

Academic and Independent Researchers

Professor Irene J Higginson

Awards
• Fellowship, Academy of Medical Sciences, April 2013
• Floriani Award for important scientific and cultural contribution, October 2011
• NIHR Senior Investigator, renewed 2013

Chair
• Scientific Committee EAPC 2015 Conference

Membership
• Association for Palliative Medicine (Treasurer 2010–2014)
• Association for Palliative Medicine (Executive Board Member 2009–2014)
• British Psychosocial Oncology Society (Awarded life membership in recognition of outstanding contribution to palliative care and services to BPOS)
• EAPC
• Royal Society of Medicine (including: Palliative Medicine and Gerontology sections)
• Association for Palliative Medicine (Member of Science Committee, 2002–2005)

Professor Lynne Turner-Stokes

Chair
• London Neurorehabilitation Specialised Commissioning Consortium – Clinical Advisory Group
• Research and Clinical Standards Subcommittee, British Society of Rehabilitation Medicine
• Healthcare Resource Group Expert Reference Panel for Rehabilitation
• Guideline Development Group for Low Awareness States
• BSRM/RCP
• CRG for Rehabilitation National Transition of Specialised Services Commissioning

Professor Lynne Turner-Stokes

Membership
• British Society of Rehabilitation Medicine – President Elect 2012–2014

Membership
• Royal College of Physicians (RCP) Joint Specialist Committee for Rehabilitation Medicine
• Medical Defence Union Council and Cases Committees
• RCP Joint Specialist Society Clinical Effectiveness Forum
• Expert Working Group: Payment by Results. Chapter A (Nervous System)
• National Council for Palliative Care, Long Term Conditions Group
• Clinical Advisory Panel for Payment by Results
• Major Trauma Network Group (National): Rehabilitation Subcommittee

Dr Richard Harding

Awards
• The Board of the African Palliative Care Association made a personal award at the APCA triennial conference 2013 for ‘dedication to increasing evidence base for palliative care in Africa’ as ‘best publisher on palliative care in Africa’

Membership
• Member of the Advisory Council of the African Palliative Care Research Network
• Member of the Steering Committee: EAPC Task Force on Palliative Care in Africa: Fostering collaboration and partnership
• Bright Sparks UK
• Member of the Program Council for the International Palliative Care PhD Programme hosted by Norwegian University of Science and Technology (NTNU), Norway
• Member of the core organising committee of the AIDS Impact conference
• Member of the Research Committee for the International Children’s Palliative Care Network
• Member of the Ethics Committee of the Hospice Palliative Care Association of South Africa. Chaired by the University of the Witswatersrand
• Palliative Care Research Association
• European Partnership Against Cancer – European Commission Health Directorate
• WHO Group “Decent Care Values in Palliative Care”
• UK Forum for Hospice & Palliative Care Worldwide
• International Association for Hospice and Palliative Care
• African Palliative Care Association
• International AIDS Society
• National Hospice Palliative Care Organisation
• European Association of Palliative Care
• International Association of Hospice Palliative Care
• GMFA
• Office of the U.S. Global AIDS Coordinator Palliative Care Indicators Group
• International Palliative Care Family Carer Research Collaboration
• Society for Social Medicine
• Associate member COMPASS Collaborative
• European Public Health Association
• Canada-UK HIV Rehabilitation Research Collaborative (CUHRRC)
• External expert on evidence review panel for the US Government’s five year planning for new carer support technical working group under the President’s emergency plan for AIDS relief

Dr Jonathan Koffman
Chair
• Sub-Dean for postgraduate teaching in the School of Medicine, King’s College London (2008–2013)
• Chair of Educational Quality for the Academic Academy, King’s Health Partners (2013–present)

Membership
• Palliative Care Research Society

Dr Gao Wei
Membership
• The Royal Society Statistics, The Palliative Care Research Society
• The Higher Education Academy, Chinese Preventive Medicine Association

Dr Fliss Murtagh
Membership
• London Cancer Alliance Palliative Care Pathway group member (2012–current)
• Workgroup lead for KDIGO (Kidney Disease: Improving Global Outcomes) International Consensus conference on Renal Palliative Care (2012–2014)
• Fellow of the Royal College of Physicians of London (2013–2014)
• Membership Royal College of General Practitioners (1995–2014)
• Treasurer of the Royal Society of Medicine Palliative Care Section (2012–2014)
• President of the Royal Society of Medicine Palliative Care Section (2011–2012)
• End of Life Care for Advanced Kidney Disease Project Board for NHS Kidney Care (2009–2011)
Dr Katherine Sleeman
Chair
- President of Palliative Academic Clinical Trainees Society

Dr Roxana Alexandrescu
Membership
- Fellow Faculty of Public Health
- Associate Member The Society for Research in Rehabilitation

Dr Catherine Evans
Award
- NIHR Clinical Lectureship

Membership
- International Collaborations Community Health Nursing Research (Executive Committee)
- Royal College of Nursing
- National Council of Palliative Care
- Palliative Care Research Society
- Sussex Palliative Care Research Speciality Group
- Kent, Surrey and Sussex Palliative Care Research Speciality Group

Dr Barbara Gomes
Awards
- EAPC, Early Researcher Award 2013 runner-up

Chair
- Scientific Committee of the Portuguese Society of Studies in Psycho-Oncology

Dr Matthew Maddocks
Awards
- EAPC, Early Researcher Award 2012 runner-up


Chair
- Rehabilitation Subgroup of the NCRI Palliative and Supportive Care Clinical Studies Group

Membership
- NCRI Palliative and Supportive Care Clinical Studies Group
- European Association of Palliative Care – Physiotherapy Taskforce
- Allied Health Professions Research Network – London Hub Facilitator
- Association of Chartered Physiotherapists in Oncology & Palliative Care, Public Relations, Education & Research Officer
- Scientific Committee of 10th Palliative Care Congress
- Advisory Board of 8th World Congress of the European Association of Palliative Care

Professor Rob George
Membership
- Royal College of Physicians Working Party on Prolonged disorders of Consciousness; Resuscitation Council UK Guidance group on Cardiovascular Implanted Electronic Devices in people towards the End of Life, during Cardiopulmonary Resuscitation and after Death;
- Ethics Committee of the Association for Palliative Medicine;
- Ethics Committee of the National Council for Palliative Care
- External Expert Clinical Advisor to the ‘More Care Less Pathway’ Review Panel for Sec State for Health

Chair
- Vice President Association for Palliative Medicine, 2013–2015, President 2015–2017
- Hon Secretary Committee for Ethical Issues in Medicine, Royal College of Physicians 2010

Researchers

Dr Lesley Henson
Membership
- Member of the Royal College of Physicians
- Member of the Association of Palliative Medicine

Dr Pauline Kane
Membership
- Non-Consultant Hospital Doctor (NCHD) representative on Irish Medical Council June 2008–June 2013
Dr Stephen Kriese
Membership
- Advisory panel to NHS Liver Care and the National End of Life Programme in the production of the strategy document “Getting It Right: Improving End of Life Care for People Living with Liver Disease” (2013)

Diana Jackson
Membership
- Society for Research in Rehabilitation

Dr Liesbeth van Vliet
Membership
- Patient Provider Interaction network, Netherlands/Flanders
- The European Association for Communication in Healthcare
- EAPC
- Palliative Care Research Society

Polly Edmonds
Chair
- Specialty Certificate Examination Standard Setting Group

Membership
- Royal College Physicians Specialty Advisory Committee;
- London Provider Shared Services Palliative Medicine Leads Meeting;
- KHP Palliative Medicine Specialty Faculty Meeting

Susanne De Wolf-Linder
Membership
- EAPC

Editorial roles

Professor Irene J Higginson
Journal of Palliative Medicine (US) – Senior Associate Editor (UK) (1999– )
BMJ Supportive and Palliative Care – Associate Editor (2012–2014)
Palliative Medicine (UK) – Editorial Advisory Board (1999– )
Palliative and Supportive Care (UK) – Editorial Board (2003– )
Palliative and Supportive Care (UK) – Editorial Board (2003– )
Quality of Life and Health Outcomes – Editorial Board (2004– )

Professor Lynne Turner-Stokes
Clinical Rehabilitation – Editorial Board
Journal of Rehabilitation Medicine – Editorial Board

‘Concise guidance series’ in Clinical Medicine – Editor

Dr Richard Harding
Journal of Pain & Symptom Management – Editorial Advisory Board Member
AIDS Care – Editorial Board Member
BMC Research Methods – Associate Editor

Dr Gao Wei
Journal of Palliative Care and Medicine (2011– )
The Open Epidemiology Journal (2011– )

Dr Fliss Murtagh
End of Life Care Journal Editorial Board (2010–2012)

Dr Jonathan Koffman
End of Life Care Journal Editorial Board (2010–2012)

Dr Roxana Alexandrescu
Journal of Environmental and Occupational Science

Dr Barbara Gomes
BMC Palliative Care – Associate Editor
Portuguese Palliative Care Journal – Scientific Committee Member

Barb Daveson
Australian Journal of Music Therapy Editorial Board
Christina Ramsenthaler
End of Life Care Journal Editorial Board (2010–2012)

Dr Stephen Ashford

Referee work for peer-review journals and funding bodies

Journals
Acute Cardiac Care
Acute Medicine
African Journal of Microbiology Research
Age and Ageing
AIDS Care
American Journal of Kidney Diseases
American Journal of Public Health
American Journal of Respiratory and Critical Care Medicine
American Nephrology Journal
Archives of Physical Medicine and Rehabilitation
Australian Music Therapy Journal
BioMed Central
BMC Health Services Research
BMC Medicine
BMC Palliative Care
BMJ Supportive & Palliative Care
Brain Injury
British Journal of Cancer
British Journal of Sports Medicine
British Medical Journal
Bulletin of Economic Research
Chronic Illness
Clinical Ethics
Clinical Interventions in Aging
Clinical Nephrology
Cochrane
COPD: Journal of Chronic Obstructive Pulmonary Disease
Critical Reviews in Oncology & Haematology
Dialysis & Transplantation
Disability and Rehabilitation
European Journal of Cancer Care
European Journal of Epidemiology
European Journal of Neurology
European Journal of Public Health
Health and Quality of Life Outcomes
Health Trends
Journal of Cancer Research & Therapy
Journal of Clinical Nursing
Journal of Clinical Oncology
Journal of Environmental and Occupational Science
Journal of Epidemiology and Community Health
Journal of Health Services Research & Policy
Journal of Medical Ethics
Journal of Neurology, Neurosurgery and Psychiatry
Journal of Palliative Care
Journal of Palliative Care & Medicine
Journal of Palliative Medicine
Journal of Psycho-Oncology
Journal of Public Health Medicine
Journal of Social Science and Medicine
Journal of Surgery
Journal of the International AIDS Society
Journal of Wound Care
Korean Journal of Political Economy
Nephrology
Nordic Journal of Music Therapy
Pain
Palliative Medicine
Patient Education and Counseling
Physical Therapy Reviews
PLOS Medicine
PLOS ONE
Primary Health Care Research and Development
Psychological Assessment
Psycho-Oncology
Quality in Health Care
Quarterly Journal of Medicine
Respirology
Sexually Transmitted Infections
Social Science and Medicine
Supportive Care in Cancer
The Cochrane Collaboration
The Lancet
The Lancet Oncology
The Lancet Respiratory Medicine
The Open Epidemiology Journal
Thorax
Funding Bodies

Academy of Medical Sciences
AIDS Fonds
British Heart Foundation
British Renal Society
Cancer Research UK
Department for International Development
Department of Health
Dutch Cancer Society (KWF Kankerbestrijding)
Economic and Social Research Council
German Cancer Aid – Physical Exercise & Cancer Patients’ Programme
Kidney Research UK
Marie Curie Cancer Care
Medical Research Council
Singapore Ministry of Health – Health Services Research
MS Society
National Cancer Institute of Canada
National Institutes of Health
National Research Programme for Ireland
NHS Executive (National and regional offices programmes)
NIHR Programme Grants for Applied Research
NIHR Health Technology Assessment
NIHR Public Health Research
NIHR Services and Delivery Research
Physiotherapy Research Foundation
Research Grant Council (RGC) of Hong Kong
Scottish Office
Social Science and Humanities Research Council of Canada
The Prostate Cancer Charity
Wellcome Trust
Welsh Office of Research and Development for Health and Social Care

Keynote presentation highlights

Academic and Independent Researchers

Professor Irene J Higginson
9th Palliative Care Congress (UK). 2012 – Closing Plenary. ‘Palliative care research: its landscape and laments’.

7th World Research Congress of the EAPC, Trondheim. 2012. Closing Plenary. Dying at home – is it better: what have we learned and where are we going?


World Cancer Congress and COSA Annual Scientific Meeting, Melbourne, 2014. Outcome measures in survivorship.

World Cancer Congress and COSA Annual Scientific Meeting, Melbourne, 2014. Symptom management in lung cancer.

**Professor Lynne Turner-Stokes**
Royal Melbourne Hospital, Melbourne. Grand Round, 2011
When is a neurogenic bladder not neurogenic?

International Workshop to prepare Special Issue for Disability and Rehabilitation, centred on Connecting People and Technologies. Auckland. 2011 Engaging clinicians in outcome measurement.


International Workshop. Optimising management of spastic patients, Nice, France 2011 The patient-centred approach – ULIS-II.


British Society of Rehabilitation Medicine, Southampton 2012 Plenary lecture – Update on Payment by Results.

Department of Health: Rehabilitation Prescription Workshop. London 2012 National audit for rehabilitation following major Trauma: specialist commissioning for Complex rehabilitation.


Grand Round. Royal Melbourne Hospital. Melbourne 2013 Met and unmet needs for rehabilitation in the community – counting the cost of not providing services.


**Dr Richard Harding**
AIDS Impact Conference 12th meeting, Botswana 2009 Plenary – Beyond virology: are we enhancing quality of life and the patient experience of HIV disease?


2nd International Seminar on Palliative Care Research, European Palliative Care Research Centre & The EAPC, Gent 2012. Outcome measurement in palliative care.


Hospice Palliative Care Association of South Africa Congress Johannesburg, South Africa. 2011, Using patient outcomes to improve care.

12th Congress of the European Association of Palliative Care, Portugal, 2011. PRISMA, a Pan-European EC Co-ordinating Action: Reflecting the Positive Diversities of European Priorities for Research and Measurement in End-of-Life Care.

**Dr Jonathan Koffman**

40th EDTNA/ERCA International Conference, Ljubljana, Slovenia, 2011. Servicing multi-cultural needs at the end of life “getting it right, getting it wrong.


Progress in Palliative Medicine Conference, 15–16 March 2013 Gdańsk, Poland How to research the desire to live or die and Translational research in palliative care: experience from the Cicely Saunders Institute.

Servicing multi-cultural needs at the end of life – “getting it right, getting it wrong” Palliative and end of life care for all – is everybody equal? A joint meeting
of Marie Curie Cancer Care and the Palliative Care Section of the RSM, 2013, Royal Society of Medicine, London.

National End of Life Care Intelligence Network and Marie Curie Cancer Care Grand Connaught Rooms, London: 2013 Delivering inclusive end of life care services that meet the expectations, preference and needs of people from Black, Asian and other Minority Ethnic (BAME) backgrounds.

International Conference on Palliative Care, Ministry of Health, Brdo pri Kranju, Slovenia, 2013 Barriers to dying at home.

20th Anniversary Meeting for the Irish Association of Palliative Care, Dublin, 2013 Going beyond cancer... extending palliative care to non-malignant disease.

**Dr Fliss Murtagh**


EDTNA Conference, Ljubljana, Slovenia, 2011 Symptom management in advanced kidney disease.


Primary Care National Conference, Birmingham, UK, 2012 Palliative and end of life care for patients with advanced kidney disease.


American Society of Nephrology Conference, Atlanta, USA, 2013 Geriatric nephrology-dialysis withdrawal.

**Dr Catherine Evans**

Marie Curie Cancer Care and the Palliative Care Section of the Royal Society of Medicine meeting, 22 March 2013 ‘I can’t tell you I want to participate’; mental capacity and the processes of consent in research on end of life care’.

**Dr Barbara Gomes**

Help the Hospices Conference, Bournemouth, 2011. Where and how people die: new evidence, new ideas.


13th World Congress of the EAPC, Prague, 2013. Social Diversity in Palliative Care: Ways Forward for a Rising Challenge.


**Dr Matthew Maddocks**

World Congress of Physical Therapy, Amsterdam, Netherlands 2011 Factors limiting exercise capacity in patients with thoracic cancer.


13th World Congress of the European Association of Palliative Care, Prague, Czech Republic 2013 Neuromuscular electrical stimulation for adults with advanced disease: a Cochrane systematic review.

4th International Conference on Cancer Nutrition Therapy, Zagreb, Croatia 2013: Therapeutic exercise for cancer cachexia: optimizing uptake of nutrients to build lean tissue mass.

**Dr Lucy Selman**

Osher Center for Integrative Medicine, University of California San Francisco, San Francisco, 2013 Using qualitative research in intervention development and evaluation.

Department of Pain Medicine and Palliative Care, Beth Israel Medical Center, New York, 2013 Spiritual care: generating an international evidence base.

13th Congress of the EAPC, Prague, 2013. Spiritual care – what does this mean in a secular society?


Barb Daveson
Help the Hospices National Conference. Bournemouth, UK, 2011. Outcome measures – showing the difference we make.

Dr Diana Jackson
Rehabilitation Conference, Nelson, New Zealand 2013 Have respite – be happy?

Dr Stephen Ashford
Anglia Heart and Stroke Network 2011 Measurement in spasticity management.
Anglia Heart and Stroke Network 2012 Goal Attainment Scaling in rehabilitation.

Bárbara Antunes
The 2nd International seminar on palliative care research of the PRC and EAPC RN, Ghent Belgium 2012 “Implementing patient reported outcome measures (PROMs) in clinical practice”.

Representation at conferences

2011
6th Cachexia Conference, Milan
7th National Cancer Research Institute Cancer Conference, Liverpool
12th World Congress for the EAPC, Lisbon
British Renal Society, Renal Association – Joint Conference, Birmingham
Compass Collaborative Conference, Edinburgh
European Association of Palliative Care Conference, Lisbon
European Conference on Health Economics, Helsinki
Help the Hospices Conference, Bournemouth
Help the Hospices National Conference. Bournemouth
International Conference on Communication in Healthcare (ICCH) conference, Chicago
Palliative Care and Liver Disease – Current Issues in Palliative Care Conference, London
Palliative Care Research Society Conference, Belfast
World Congress of Physical Therapy, Amsterdam

2012
2nd International Seminar of the PRC and EAPC RN, Ghent
6th European Public Health Conference in Brussels
6th Conference of The Union Europe Region for the International Union Against Tuberculosis and Lung Disease, London
6th Portuguese Congress of Palliative Care, Porto
7th Cachexia Conference, Boston
7th World congress for the EAPC, Trondheim
7th Research Congress for the EAPC, Trondheim
8th Flemish-Dutch Research Forum on Palliative Care, Rotterdam
8th National Cancer Research Institute, Liverpool
8th World Research Congress of the EAPC Trondheim
9th Palliative Care Congress for the Palliative Care Research Society and the Association of Palliative Medicine, Newcastle
9th World Congress on Brain Injury, Edinburgh
10th Interdisciplinary Conference on Communication, Medicine & Ethics Trondheim (COMET), Trondheim
56th Annual Scientific Meeting of The Society for Social Medicine, London
All-Ireland Institute of Hospice & Palliative Care Launch of the Structured Research Network to Improve Quality of Patient Care Conference. Dublin, Ireland
British Thoracic Society Winter Meeting, London
European Association for Communication in Healthcare Conference, St Andrews
Homecare Conference, London

Barb Daveson
Help the Hospices National Conference. Bournemouth, UK, 2011. Outcome measures – showing the difference we make.

Dr Diana Jackson
Rehabilitation Conference, Nelson, New Zealand 2013 Have respite – be happy?

Dr Stephen Ashford
Anglia Heart and Stroke Network 2011 Measurement in spasticity management.
Anglia Heart and Stroke Network 2012 Goal Attainment Scaling in rehabilitation.

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8th National Cancer Research Institute, Liverpool
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9th Palliative Care Congress for the Palliative Care Research Society and the Association of Palliative Medicine, Newcastle
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All-Ireland Institute of Hospice & Palliative Care Launch of the Structured Research Network to Improve Quality of Patient Care Conference. Dublin, Ireland
British Thoracic Society Winter Meeting, London
European Association for Communication in Healthcare Conference, St Andrews
Homecare Conference, London
International Vaccine Institute Conference, Seoul
International Society of Quality of Life Conference, Budapest
Marie Curie Annual Palliative Care Research Conference, London
Society for Research in Rehabilitation, Ely
South West and East Kidney Society Conference, Kingston-upon-Thames
Spiritual Care and Health: Improving Outcome and Enhancing Wellbeing, International Conference, Glasgow
UK National Cancer Research Institute Conference, Liverpool

2013

4th International Conference on Cancer Nutrition Therapy, Zagreb
11th International AIDS Impact Conference, Barcelona

13th World Congress for the EAPC, Prague
64th Annual Conference of the American Association for the Study of Liver Diseases, Washington
African Palliative Care Association Conference, Johannesburg
AIDS Impact Conference, Barcelona
American Society of Clinical Oncology Annual Meeting, Chicago
American Society of Nephrology Kidney Week Conference, Atlanta
Annual Assembly of the American Academy of Hospice and Palliative Medicine & Hospice and Palliative Nurses Association, New Orleans
Association of Chartered Physiotherapists with an Interest in Neurology Conference, Northampton
British Association for the Study of the Liver Annual Meeting, London
British Renal Society, Renal Association – Joint Conference, Birmingham
British Thoracic Oncology Group Conference, Dublin
European Respiratory Society Annual Congress, Barcelona
London School of Hygiene and Tropical Medicine Conference on Snow’s Legacy: Epidemiology Today and Tomorrow, London
New Zealand Rehabilitation Conference, Nelson
Symposium on Yoga Research, Boston
The International Consensus Conference on Improving the Spiritual Dimension of Whole Person Care (ICC), Geneva
The King’s Fund Conference on Patient Reported Outcome Measures, London
## Publications

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**Publications in peer review journals 2012**


Harding R, Clucas C, Lampe FC, Date HL, Fisher M, Johnson M, Edwards S, Anderson J, Sherr L (2012b). What factors are associated with patient...


validation of the King’s Brief Interstitial Lung Disease (K-BILD) health status questionnaire. *Thorax* 67(9): 804–10.


**Publications in peer review journals 2013**


### Publications in peer review journals 2014


Selman L, Young T, Vermandere M, Stirling I, Leget C, on behalf of the EAPC Spiritual Care Taskforce (2014b). Research priorities in spiritual care: an international survey of palliative care researchers and clinicians. J Pain Symptom Manage [Epub ahead of print]

Sigurdardottir K R, Kaasa S, Rosland J H, Bausewein C, Radbruch L, Haugen D F, on behalf of PRISMA (2014). The European Association for Palliative Care basic dataset to describe a palliative care cancer population: Results from an international Delphi process. Palliat Med [epub ahead of print]


Information about books, book chapters, published abstracts and letters can be found at our website: www.csi.kcl.ac.uk
Academic and Independent Researchers

Professor Irene J Higginson
Professor of Palliative Care & Policy, Director
Cicely Saunders Institute, and Consultant in
Palliative Medicine

Professor Irene Higginson qualified in medicine from Nottingham University and has worked in wide ranging medical and university positions, including radiotherapy and oncology, in-patient and home hospice care, the Department of Health (England) and various universities. She has been at King’s as Professor and Head of Department since October 1996. While at King’s from 2002 to 2005 she was Dean of Postgraduate Studies in the School of Medicine. In 2002 she was appointed Scientific Director of Cicely Saunders International, a new charity seeking to develop a centre of research in palliative care to improve care for patients and families.

Professor Higginson has research interests and publications in the following areas: quality of life and outcome measurements, development, modelling and evaluation of palliative care especially of new services and interventions, epidemiology, clinical audit, effectiveness, psychosocial factors and care, symptom assessment, breathlessness, and elderly care.

Her day to day work comprises research, teaching, management and clinical care, including an equal participation with the other consultants in on call in palliative care.

Professor Lynne Turner-Stokes
Director of Regional Rehabilitation Unit, Herbert Dunhill Chair of Rehabilitation, and Consultant in Rehabilitation Medicine

Professor Lynne Turner-Stokes was educated at Bedales School (1966–1973), Oxford University (1973–6) and University College Hospital (1976–9). She qualified in Medicine in 1979 and after accrediting in Rheumatology and Rehabilitation in 1992, she was appointed as consultant to set up a new Regional Rehabilitation Unit (RRU) at Northwick Park Hospital in Harrow. The Regional Rehabilitation Unit provides a tertiary specialist rehabilitation service for younger adult patients with severe complex disabilities, mainly resulting from acquired brain injury. The RRU 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.

Lynne was appointed to the Herbert Dunhill Chair of Rehabilitation at KCL in 2001, with a view to developing a two-site academic department of rehabilitation between KCL and Northwick Park. Academic Rehabilitation joined forces with the Department of Palliative Care and Policy in 2003. Lynne has over 150 published articles in peer-reviewed journals. She has a special interest in outcomes measurement in rehabilitation and in developing evidence-based standards and guidelines to improve the quality of rehabilitation medicine in the UK. She is Director of the UK Rehabilitation Outcomes Collaborative – a national database which gathers data on needs inputs and outcomes for all inpatient specialist rehabilitation units in England.
Dr Richard Harding
Reader in Palliative Care

Dr Richard Harding did his first degree in Social Anthropology and Sociology (including an EC ERASMUS scholarship), followed by a Masters degree in Social Policy and Social Work studies with a Diploma in Social Work (UK Home Office Award), and a PhD in Public Health (competitive studentship awarded). He worked as an HIV/palliative care Care Manager before taking up his PhD studentship.

Dr Jonathan Koffman
Senior Lecturer, Director
MSc in Palliative Care

Dr Jonathan Koffman has a BSc in Social Administration and an MSc in Sociology with Special Reference to Medicine from Royal Holloway and Bedford New College. His PhD from King’s College London explored the experience of living with, and dying from, advanced cancer among black Caribbean and white patients living in south east London. He is Senior Lecturer in Palliative Care and Course Co-ordinator for the inter-professional Postgraduate Certificate, Diploma and MSc in Palliative Care. Jonathan was Sub Dean of Taught Postgraduate Studies in the School of Medicine from 2008 until 2013. His research interests include end-of-life experiences of black and minority ethnic groups; disadvantaged dying, mixed methods research and the development and evaluation of complex interventions.

Dr Gao Wei
Lecturer in Statistics and Epidemiology

Dr Wei Gao (Gao Wei) received her first degree in medicine (MBBS equivalent), a Master of Medicine in Environmental Hygiene from Tongji Medical University, and a PhD in Epidemiology and Health Statistics from Huazhong University of Science & Technology. She has research experience in a wide range of areas including large scale epidemiologic studies, ecological and clinical trials, molecular epidemiology, laboratory-based studies, environmental health, and applied statistical epidemiology. She had postdoctoral research experience with five Top Higher Education Institutions in three countries before joining the department in 2007. She was the only statistician working full time for COMPASS Collaborative – an initiative and collaboration between 11 UK Universities to improve complex interventions in palliative care populations, primarily working on Strand I outcome assessment. Gao Wei became a Lecturer in 2012. She has been co-leading with Professor Higginson developing and implementing palliative care and end of life care research using large scale routine data sources, such as death registry database for place of death research (funded by NIHR HS & DR, Marie Curie Cancer Care), electronic database from primary care for analgesic prescribing in cancer patients (supported by MRC and NIHR COMPASS Collaborative).

Dr Fliss Murtagh
HEFCE Academy Clinical Senior Lecturer and Consultant in Palliative Care (NIHR Faculty)

Dr Fliss Murtagh qualified in medicine in the UK in 1986. She initially trained in General Practice, and worked as a General Practitioner from 1992 – 2000, then undertook specialist training in palliative medicine between 2000 and 2004. She went on to undertake a PhD at King’s College London, on ‘Improving the quality of care of patients with Stage 5 Chronic Kidney Disease’ in the Department of Palliative Care, Policy & Rehabilitation at King’s College London. She has now gained a HEFCE Clinical Senior Lectureship – one of the first nationally in Palliative Care. She is based at King’s College London and King’s College Hospital. Fliss has recently been named a Fellow of the Royal College of Physicians in London.

She has published on the palliative and end-of-life care needs of renal patients, including on symptoms, withdrawal from dialysis, survival, and use of opioids. Fliss has a keen interest in longitudinal study, including methodological development, and symptom and functional trajectories in the last year of life. She led analytical modelling work commissioned for the Palliative Care Funding Review, and is currently working on evaluating complexity in palliative care, and mapping needs, service provision, and outcomes. She is co-leading a 5 year national research project (the NIHR-funded C-CHANGE project) to take forward recommendations from the Funding Review, and in particular, to validate a casemix classification for palliative care, and test the effectiveness and cost-effectiveness of different models of palliative care.
Dr Katherine Sleeman
NIHR Clinical Lecturer in Palliative Medicine

Dr Katherine Sleeman graduated from University College London Medical School in 1999 with a degree in Developmental biology (top 1st – 1996) and distinctions in clinical pharmacology and pathology. After training in general medicine at Guys and St Thomas’ Hospitals, she did a PhD at the Institute of Cancer Research (London) on breast cancer stem cells, graduating in 2007. Dr Sleeman started specialist training palliative medicine in 2007, and was appointed to an NIHR Clinical Lectureship in palliative medicine at KCL in 2010. In this post she combines clinical training on the London Deanery rotation, with academic work based at the Cicely Saunders Institute.

Dr Roxana Alexandrescu
Lecturer in Health Services Research in Rehabilitation

Dr Roxana Alexandrescu joined the Department in April 2013 as a Lecturer in Health Services Research in Rehabilitation. Her work currently focuses on psychometric evaluation of the UK specialist Rehabilitation Outcomes Collaborative (UK-ROC) scales, outcome measurement and evaluation of complex interventions in rehabilitation. Before coming to Cicely Saunders Institute, she worked for four years at the Dr Foster Unit at Imperial College London. Roxana qualified in medicine at the University of Târgu Mureș and specialised in public health medicine, following which she worked for several years at the Public Health Institute in Romania. She completed a MPH at The Netherlands School of Public & Occupational Health Utrecht in 2001, writing her thesis in adolescent unwanted pregnancy. In 2012 she completed her PhD on trauma epidemiology at the University of Manchester. She became a Fellow of the Faculty of Public Health the same year.

Dr Catherine Evans
NIHR Clinical Lecturer, Honorary Clinical Nurse Specialist Sussex Community NHS Trust

Dr Catherine Evans is an NIHR Clinical Lecturer in palliative care. This is a joint clinical academic post between Sussex Community NHS and the Cicely Saunders Institute, King’s College London. Catherine joined the Cicely Saunders Institute in 2010 as a senior research fellow managing a research project ‘Methods of Evaluating End of Life Care’ (MORECare) funded by the NIHR/MRC.

Catherine has continued this work undertaking a study on capacity and consent in end of life care (MORECare Capacity) funded by Marie Curie Cancer Care. Catherine commenced her NIHR clinical lecturership post in 2011. Catherine’s research focuses on developing research methods in palliative care and optimising palliative care for frail older people in community settings leading the research study OptCare Elderly. Catherine’s research has concerned primary health care and community nursing, notably developing and evaluating services for older people in care homes. She is a qualified district nurse and health visitor, and works clinically as a community clinical nurse specialist in palliative care.

Dr Barbara Gomes
Research Fellow

Dr Barbara Gomes did her first degree in Psychology and Health at the University of Porto (2001), including a one-year internship in the Palliative Care Unit of Porto’s Cancer Institute. She completed the King’s MSc in Palliative Care and has a PhD from Kings. Her other training covers Epidemiology, Statistics and Health Economics. Barbara joined King’s to work with Professor Higginson in a research programme aiming to enable patients with advanced illness to die where they wish, with quality care. Together, they have conducted studies on preferences, factors and outcomes associated with death at home, projections for place of death, and a Cochrane review on the effectiveness and cost-effectiveness of home palliative care services. In 2013 Barbara was awarded a five-year grant by the Calouste Gulbenkian Foundation to train early researchers and develop an optimised model of home palliative care in Portugal (DINAMO project). She is working at King’s both in London and remotely in Portugal, with an honorary visiting fellowship at the Institute of Public Health of the University of Porto.
Dr Matthew Maddocks
Lecturer in Health Services Research in Palliative Care

Dr Matthew Maddocks qualified from the University of Nottingham in 2005 with first class honours in Physiotherapy. He undertook his doctorate in the School of Molecular Medical Sciences, University of Nottingham, under the supervision of Dr Andrew Wilcock. The thesis examined the role of therapeutic exercise in cancer cachexia and the use of physical activity level as an outcome measure. His post-doctoral experience includes a lead physio role in a National Cancer Research Institute funded study of neuromuscular electrical stimulation (NMES) for people with lung cancer receiving palliative chemotherapy, with qualitative and translational sub-studies. In 2011 Matthew became an NIHR Post-Doctoral Research Fellow. He is/was the principal investigator in a study into the use of NMES in people with severe chronic obstructive pulmonary disease, with mentorship from Professors Higginson and Moxham across the Departments of Palliative Care, Policy and Rehabilitation, and Asthma, Allergy and Lung Biology. He obtained his current Lecturer post in 2014.

Dr Lucy Selman
Cicely Saunders International Faculty Scholar

Dr Lucy Selman did her first degree in Philosophy at the University of Nottingham (1st; 2000), followed by an MPhil specialising in epistemology and the philosophy of science at Birkbeck College, University of London (2003). Lucy joined King’s as a Research Associate in 2005, completed the King’s Post-graduate Certificate in Palliative Care with distinction in 2006) and was awarded a PhD in Palliative Care in 2012.

Most recently, Lucy was appointed Cicely Saunders International Faculty Scholar, a prestigious post-doctoral post for future leaders in palliative care. From 2013–14 Lucy is a Visiting Scholar at the University of California, San Francisco, where she is contributing to a pilot study of a yoga intervention for patients with heart failure and COPD as well as leading the San Franciscan arm of the International Access, Rights and Empowerment (IARE) study. The IARE study, funded by Atlantic Philanthropies and Cicely Saunders International and coordinated by Dr Daveson and Prof Higginson, is examining models of hospital-based palliative care in the UK, USA and Ireland. Lucy also continues to collaborate with Dr Harding on the IMPAQT study evaluating and improving quality of palliative care in South Africa (funded by the European Commission).

Before joining the Cicely Saunders Institute in 2009 to work on the cross-national European Commission funded project called PRISMA, she held a variety of academic positions including a conjoint academic-clinical post with the University of Queensland (Australia).

Dr Barbara Daveson
Cicely Saunders International Lecturer in Health Services Research in Palliative Care

Dr Barbara Daveson is a Principal Investigator on the International Access, Rights and Empowerment (IARE) study that forms part of BuildCARE. The IARE study involves research in Ireland, the US and the UK and aims to generate information regarding access to improve the rights of palliative care patients and their families. Barbara also coordinates project BuildCARE with Irene, and she supervises three of the BuildCARE PhD candidates.

Barbara’s first degree was in music therapy (University of Queensland, Australia). This was followed a PhD from University of Melbourne (Australia) that resulted in theory from grounded theory research and by health service management studies (University of Manchester). Barbara has worked clinically as a music therapist in acute care, oncology, palliative care (in hospice, specialist inpatient, day hospice and home-based environments) and neuro-rehabilitation in Australia and the UK, and she has led a therapy department for people with complex neuro-disability and neuro-degenerative disease in the UK. She holds a special interest in grounded theory methodology and qualitative synthesis, and is experienced in cross-national research.
Hamid Benalia  
Research Associate  

Hamid Benalia joined the department in 2009 to work on the PRISMA project, a major European-wide project funded by the European Commission under the 7th Framework Programme.

Since 2010 Hamid has been playing an active role in the Palliative care Outcome Scale (POS) new developments (www.pos-pal.org)

From 2011, he was involved in the MORECare project which looks at the methods for evaluating service delivery models for end of life care (EoLC).

Anna Bone  
Research Assistant  

Anna Bone completed a BA in Human Sciences at the University of Oxford in 2011 and went on to study for a Masters in Public Health at Imperial College London. In the MPH thesis Anna explored inequalities in cancer patient experience from national survey data using quantitative methods. Anna joined the department in 2013 and is working on the OPTCare Elderly project led by Dr Catherine Evans and Professor Irene Higginson. This project involves developing an intervention to improve palliative care services for the frail elderly with non-malignant conditions in the community and testing its feasibility in a single NHS Community Trust.

Dr Katherine Bristowe  
Research Associate  

Dr Katherine Bristowe graduated with a BA (Hons) in English Language and Linguistics, from the University of Wales, Bangor (2000). She then went on to complete an MA in Linguistic Studies (2004), and a PhD in Linguistics (2010), both at the University of Essex. Her PhD thesis was a linguistic analysis of outpatient plastic surgery consultations in a teaching hospital, with a particular focus on consultations with multiple health professionals present.

In 2009 Katherine moved to the University of the West of England where she worked on a study exploring teamwork, team communication and leadership in obstetric emergencies. She joined the Cicely Saunders Institute in 2010 to work on a project looking to improve the care for renal patients approaching the end of life (The Advanced Renal Care Project). In 2012, she moved to the AMBER care bundle evaluation project which is a feasibility study to explore the best methods to evaluate a new care bundle, developed to improve care for patients who are deteriorating, clinically unstable, with limited reversibility and at risk of dying in the next 1–2 months.
Joanna Davies received an MSc in Social Research Methods from the University of Bristol in 2009 and a BA(Hons) in Criminology and Sociology from the University of Liverpool in 2006. She joined the Cicely Saunders Institute in August 2012. Previously Joanna worked in the Department of Social Policy and Intervention at the University of Oxford on a number of projects including the Index of Multiple Deprivation for England 2010 (IMD 2010). She is currently working with Dr Gao Wei and Professor Irene Higginson on research looking at changing patterns of place of cancer death in children and young adults – the project is funded by Marie Curie Cancer Care.

Dr Mendwas Dzingina
Cicely Saunders
International PhD Training Fellow

Dr Mendwas Dzingina joined the Cicely Saunders Institute in August 2012 and will mainly be working in the area of health economics. Mendy qualified in medicine from the Ahmadu Bello University in Zaria, followed by a master’s degree in public health (health economics stream) at the London School of Hygiene and Tropical Medicine in 2010.

Before joining the department, Mendy worked as a Technical Analyst in health-economics in the Internal Clinical Guidelines team of the Centre for Clinical Practice at the National Institute for Health and Clinical Excellence (NICE). While at NICE, Mendy was involved in the development of National Clinical Guidelines for several diseases such as sickle cell anaemia and chronic renal failure.

Clare Ellis-Smith
Cicely Saunders
International PhD Training Fellow

Clare Ellis-Smith joined the Cicely Saunders Institute in July 2012. Her project involves developing a palliative care intervention for people with dementia living in residential care homes. Prior to this post, Clare worked as an occupational therapy clinical specialist in a memory service for South London and Maudsley NHS Foundation Trust.

Clare qualified as an occupational therapist at the University of Cape Town. She then moved to London and worked in a variety of clinical posts, predominantly in older adult mental health and dementia. Clare completed a part-time MSc in mental health services research at the Institute of Psychiatry, King’s College London in 2011.

Iris Groeneveld
Research Assistant

Iris Groeneveld completed a BSc (Hons) in Liberal Arts & Sciences (Utrecht University), an MSc in International Public Health (VU University Amsterdam) and an MSc in Health Policy, Planning and Financing (London School of Hygiene and Tropical Medicine and the London School of Economics and Political Science). Prior to joining the department, she conducted a study looking at psychosocial services for people living with HIV in the Johannesburg area (South Africa) and undertook an internship with the World Health Organization’s Health Workforce Migration and Retention team.

Iris joined the Cicely Saunders Institute in 2010 to work on the C-CHANGE project with Dr Fliss Murtagh, laying out the groundwork for a palliative care casemix classification to inform palliative care funding models. Her work at the institute has focused on outcome measurement, international funding mechanisms, and patterns of health resource use in palliative and end of life care. Iris is also a member of the Palliative care Outcome Scale (POS) development team.
Dr Lesley Henson
Cicely Saunders International PhD Clinical Training Fellow

Dr Lesley Henson qualified in medicine from Guy’s, King’s and St Thomas’ School of Medicine and Biomedical Sciences in 2005. Following her graduation Lesley worked in hospital based general medicine for four years across London and the south east during which time she completed her membership to the Royal College of Physicians. She chose to specialise in Palliative Care in 2009 and worked for two years in the UK as a specialist registrar before moving to Kampala, Uganda as a Clinical Fellow in the Makerere University and Mulago Hospital Palliative Care Team. Lesley joined the Cicely Saunders Institute in September 2012.

Dr Pauline Kane
Cicely Saunders International PhD Clinical Training Fellow

Dr Pauline Kane studied Medicine at the Royal College of Surgeons in Ireland and following this, undertook training in general internal medicine, achieving Membership of the Royal College of Physicians in Ireland (MRCPI) in 2006. She was awarded an MSc in Healthcare Ethics and Law from the Royal College of Surgeons in Ireland in 2011, attaining first class honours. She worked as a Registrar in Palliative Medicine in Blackrock Hospice, Dublin and Beaumont Hospital, Dublin prior to her appointment as Specialist Registrar in Palliative Medicine with the London Deanery in 2010. Since coming to London, Pauline has worked in hospitals and hospices in North and North East London.

Pauline joined the Cicely Saunders Institute in October 2012. Her project involves the introduction of a palliative care patient-reported outcome measure into the heart failure service in selected tertiary referral hospitals in Dublin, Ireland. This measure will be coupled with a healthcare professional educational module on palliative care.

Dr Stephen Kriese
NIHR Doctoral Research Fellow/PhD Student

Dr Stephen Kriese studied at University College London, graduating in 2002 with bachelors degrees in immunology and medicine. Following this he undertook training in general internal medicine, achieving Membership of the Royal College of Physicians (UK) in 2005. He then commenced specialist training in gastroenterology and hepatology and has worked in hospitals across London, Surrey and Sussex.

Stephen joined King’s College Hospital as a Specialist Registrar in Hepatology in 2009 and the following year was appointed as a Clinical Research Fellow at the Institute of Liver Studies, King’s College London. During this time, he supported the research programme of Dr Michael Heneghan into autoimmune liver disease and predictors of mortality in liver transplant candidates.

Stephen joined the Cicely Saunders Institute as a PhD student in 2012 having won an NIHR Doctoral Research Fellowship to carry out a longitudinal mixed-methods study into end of life care needs for people living with advanced liver disease and their carers.

Dr Diana Jackson
Senior Research Fellow

Dr Diana Jackson trained as a physiotherapist at King’s College Hospital and specialised in neurological rehabilitation, working across in-patient, out-patient and community settings. Following an MSc in Rehabilitation Studies, she joined the Regional Rehabilitation Unit at Northwick Park Hospital as a researcher in 1996. Work to develop a multi-disciplinary integrated care pathway for managing post-stroke shoulder pain, with a focus on pain assessment in patients with communication and cognitive deficits, subsequently led to a PhD on the assessment of post-stroke shoulder pain from the University of Southampton.

Since joining the CSI in 2003, Diana has led research on three successive Department of Health funded studies into experiences of caring for adults with diverse Long Term Neurological Conditions (LTNCs). This work has generated quantitative and qualitative data from 650 family carers throughout the UK, providing a rich source of knowledge on everyday experiences of living with progressive and sudden onset neurological impairments, the impacts of caring, ways in which carers want to be supported and the formal and informal costs of care and rehabilitation for adults with LTNCs. More recently she has collaborated with colleagues on an evaluation of community rehabilitation service delivery in adults with LTNCs newly discharged from in-patient care. Evidence from this body of work will inform the way health and social services are delivered to people with LTNCs and their carers in the future, and determine the costs of providing rehabilitation and aftercare to this group.
**Katrien Moens**
Marie Curie Early Stage Research Training Fellow

Katrien Moens completed with honors her degree in Nursing in 2004–2005 at the EHSAL in Brussels, Belgium. In the last year of her bachelor training she did a seven weeks voluntary internship on a palliative care unit in Belgium. In 2006–2007 she obtained her Master in Nursing Sciences with distinction doing a master thesis on ‘The complementary care giving by nurses in all Flemish palliative care units.’ In 2007–2008 she started working at the Federatie Palliatieve Zorg Vlaanderen (FPZV) as a staff member general policy-education and training. This function was combined with the work as a lecturer within the bachelor Nursing at the Hogeschool Universiteit Brussel (HUB), Belgium.

In 2008–2010 she worked 50% as a lecturer within the HUB and 50% as a researcher within the research centre PRAGODI of the HUB. Under the supervision of Prof. Dr Mieke Grypdonck she obtained funding for her own developed research project called ‘The image of palliative care among the general population. Development, testing and application of a scientific measurement instrument.’ In 2010–2011 she worked as a fulltime lecturer within the HUB and this was until the first of March because on the 7th of March she was offered a research training fellowship at the Cicely Saunders Institute being part of an EC funded project called EURO IMPACT. This fellowship ends on the 6th of March 2014.

**Christina Ramsenthaler**
Research Assistant and PhD Student

Christina Ramsenthaler qualified in clinical psychology and clinical neuropsychology at Bremen University, Germany, in 2009. Christina also completed the MSc course in the Department of Palliative Care, Policy and Rehabilitation at King’s College London. She won the Cicely Saunders Prize and the second prize in the Royal Society of Medicine’s Palliative Care Grand Round for her MSc dissertation on the use of factor analysis in palliative care research.

Christina joined the department in 2010 as a research assistant, working on a study investigating quality of life in myeloma. She also worked part-time on a project on episodic breathlessness in advanced disease. She is now working towards a PhD supervised by Professors Irene Higginson, Dr Gao Wei and Dr Richard Siegert. Her research interests include psychometrics, research methodology, quality of life and psychosocial care and palliative care in non-malignant disease.

**Dr Vera Sarmento**
Clinical PhD Research Training Fellow (Calouste Gulbenkian Foundation)

Vera Sarmento graduated as a doctor in 2009 at the Spanish Universidad de Extremadura Medicine School. Her interest in palliative care developed during these undergraduate years, driven by professional and personal experience of palliative care needs in Portugal and services development in Spain. She completed her general medical training and the first year of internal medicine training in Hospital do Espirito Santo de Evora, in the southeast region of Portugal. She then interrupted this programme to integrate the DINAMO project on home palliative care, funded by the Calouste Gulbenkian Foundation.

With this purpose, Vera joined the Cicely Saunders Institute at King’s College London in 2012. Since then she is undertaking advanced research training in palliative care in the department. She has also been studying Portuguese preferences for place of death and palliative care services development in this country, examining trends and developing projections for place of death in Portugal, and exploring the experiences of patients and family caregivers with home palliative care services, in order to inform the next steps of the DINAMO project.

**Melinda Smith**
Research Assistant

Melinda Smith joined the Department in May 2012 as Research Assistant for The International Access, Rights and Empowerment Study (IARE). Her work focuses on all aspects of the study implementation including coordination of the three sites involved in the study (London, Dublin, San Francisco and New York); recruiting and interviewing patients and carers; coordinating a bereaved carer survey; and analysing data. Before coming to Cicely Saunders Institute she worked as a Research Assistant on the NICE mental health guidelines at University College London.

Melinda graduated with a Masters of Science in Health Psychology from The University of Auckland, New Zealand, in 2008, writing her thesis on the impact of genetic testing on changing health behaviour.
Dr Liesbeth van Vliet  
Marie Curie Experienced Research Training Fellow

Dr Liesbeth van Vliet obtained a bachelor and masters in Clinical Psychology from the Erasmus University Rotterdam (the Netherlands, 2008). Before enrolling into a PhD Liesbeth conducted a study into bereaved parents’ experiences of paediatric palliative care at the Sophia Children Hospital Rotterdam and worked as a scientific teacher in Clinical Psychology at the Erasmus University. In 2013 she completed her PhD on communication at the transition from curative to palliative breast cancer care at the NIVEL (Netherlands Institute for Health Services Research) and Utrecht University (the Netherlands). This project investigated the patient perspective on how oncologists can balance explicit with general information and realism with hope.

In January 2013 Liesbeth joined the Cicely Saunders Institute as a Marie Curie Senior Research Fellow on the EU-funded EUROIMPACT project. Together with Professor Irene Higginson she is developing more clinical guidance for the use of patient reported outcome measures, with a focus on the Palliative care Outcome Scale (POS). She is a member of the POS development group and the Postgraduate Coordination Team.

Dr Jana Witt  
Research Associate and Project Manager, OACC

Dr Jana Witt joined the Department of Palliative Care, Policy and Rehabilitation in 2013 to work on the Outcome Assessment and Complexity Collaborative (OACC) project, which aims to implement outcome measurement in routine palliative care. Prior to joining the department, she conducted research towards a PhD at the University of Cardiff within the Healthcare Quality team, developing a decision support intervention for women at increased familial risk of ovarian cancer. Jana also has a BSc (Hons) in Virology and Immunology (University of Bristol) and an MSc in Science Communication (University of the West of England).

Dr Deokhee Yi  
Health Economist

Dr Deokhee Yi graduated with a BS in Pharmacy and an MPH in Public Health (emphasis on Health Economics) from Seoul National University in Korea. After three years of research at the Institute for Population and Health, Seoul National University and teaching at Wonkwang University, she went to the US to pursue the PhD study at the University of North Carolina at Chapel Hill. She taught master level microeconomics and PhD level methodology preparatory course. She used data from the skilled nursing facilities in the US to find the effects of the prospective payment system on quality. She also helped translate the long term care minimum data set instruments into Korean language and data collection. Her dissertation investigated the effects of health on the labour market performance in China during the economic and social changes. Before joining the CSI in November 2013 Dr Yi worked at Health Economics Research Unit, University of Aberdeen as a research fellow.
Dr Stephen Ashford
NIHR Clinical Lecturer and Consultant Physiotherapist

Dr Stephen Ashford trained in Physiotherapy at Salford University and qualified in 1993. He completed an MSc in Neurorehabilitation at Brunel University in 1998. Then undertook a Post Graduate Certificate in Education through the University of Greenwich while working at the Royal Hospital for Neurodisability, Putney. He subsequently became part-time lecturer and course director for the MSc Neurorehabilitation at Brunel University from 2001 until 2003, while working clinically at the Regional Rehabilitation Unit (RRU), Northwick Park Hospital.

In 2003 Dr Ashford became clinical specialist and research physiotherapist at the RRU and Honorary Research Fellow, Department of Palliative Care, Policy and Rehabilitation, King’s College London. Dr Ashford completed a PhD at King’s College London investigating the measurement of arm function following focal interventions for spasticity. In 2012 he became consultant physiotherapist and in 2013 NIHR Clinical Lecturer and is undertaking further investigations into focal spasticity and measurement of outcome. Dr Ashford completed a Post Graduate Certificate in non-medical prescribing in 2013 at London Southbank University. Dr Ashford has published a number of peer-reviewed papers in the rehabilitation literature as well as book chapters and clinical guideline contributions.

Dr Teresa Beynon
Consultant in Palliative Medicine and Honorary Senior Lecturer

Dr Teresa Beynon is multidisciplinary lead for the hospital palliative care team at St. Thomas’ Hospital. She is audit lead for the Oncology and Haematology directorate. She also coordinates the undergraduate palliative care teaching and examining of medical students at Guy’s and St. ‘Thomas’ hospital, is clinical advisor to undergraduate clinical students and arranges special study modules and elective visits for students and other visitors to the hospital trust. Teresa, Richard Harding, Lucy Selman, Eloise Radcliffe and the dermato-oncology team at St. John’s Institute have completed an 18 month study funded by Dimbleby Cancer Care exploring the needs of patients with Cutaneous T cell lymphoma and their caregivers (formal and informal). Some of the work has been published and some still needs to be written up. Further work is expected to explore the management of specific symptoms and quality of life tools.

Dr Rachel Burman
Consultant in Palliative Care and Honorary Senior Lecturer

Rachel has been a consultant in palliative care since 1997. She is working part time with the palliative care team at King’s College Hospital Foundation Trust where she leads on the development of palliative care for people with neurodegenerative disorders and is a member of the multiprofessional MND Centre. She worked in cardiology and neurology before entering a career in palliative care. This has left a commitment to the palliative care needs of patients with a non-malignant diagnosis. She has just finished as the lead consultant on a research project funded by the MS Society looking at the needs of people severely affected by MS and their carers. A Masters in Medical Law and Ethics informs her interest in planning and decision making in advanced disease and also the relevance of the Human Rights Act to healthcare provision. She is a collaborator on an ongoing research project funded by the Department of Health Defining the Palliative Care Needs of People with late stage Parkinsonism. She is a member of the Management and Scientific Board of the King’s Centre for Palliative Care in Neurology.
Dr Irene Carey
Consultant in Palliative Medicine and Clinical Lead

Dr Irene Carey has been Consultant in Palliative Medicine and Clinical Lead at Guy’s & St Thomas’ NHS Foundation Trust since 2004. Her interests include renal palliative care and the needs of patients with lung cancer. She has jointly led the development of the AMBER care bundle which aims to improve patient centred care and decision making for patients with an uncertain potential for recovery.

Dr Polly Edmonds
Consultant in Palliative Care and Honorary Senior Lecturer

Dr Polly Edmond’s background is in General Medicine and Medical Oncology before Senior Registrar appointments in Palliative Medicine at the Royal Marsden Hospital, St George’s Hospital and Trinity Hospice. Her special interest is in medical postgraduate training, where she has held appointments locally and nationally. Since 2010 she has developed her managerial experience as an assistant medical director at King’s College Hospital NHS Foundation Trust.

Professor Rob George
Consultant in Palliative Medicine and Professor of Palliative Care

Rob trained in Chest & General Medicine, but developed a passion for the young dying during his doctorate research in chronic respiratory failure and adult cystic fibrosis. Triggered by the HIV epidemic in the '80s, he established & led the Palliative Care Centre at UCL Hospitals and its community from 1987–2003, which pioneered needs-based palliative care beyond diagnosis.

He was Clinical Lead for Palliative and End of Life Care for London from 2009–13; led on cardiopulmonary resuscitation for the National End of Life Care Programme, advises Government on ethical and practical aspects of End of Life Care, the latest of which is as independent clinical advisor to the “More Care, Less Pathway” Review led by Lady Neuberger, and sits on various ethics committees. He is Vice-President of the Association for Palliative Medicine in 2013 and anticipates a busy Presidency with the media as over the next 4 years.

He is a clinical academic, rather than researcher and before gaining his professorship at the CSI he was Senior Lecturer in Ethics at UCL.

His overarching academic interests are to understand the nature of suffering across different cultures and the complexities that this introduces to care and service delivery. He has something over a hundred publications ranging across medical ethics, Law and care modelling. Whilst he has an international reputation as a clinical innovator and thinker, he remains a full-time clinician working between Guy’s and St Thomas’ Hospitals and its integrated local community palliative care service in Lambeth Southwark and Lewisham.

Dr Wendy Prentice
Consultant and Honorary Senior Lecturer in Palliative Medicine

Dr Wendy Prentice qualified in 1992 and has a background in general medicine and a broad experience of palliative medicine in a variety of settings. She commenced her first consultant post in the North East in 2002. Within this post she led a multi-professional palliative care team working in primary and secondary care and also developed the undergraduate palliative medicine curriculum for Newcastle University. Wendy joined the palliative care team at King’s College Hospital towards the end of 2006 and became the Clinical Lead for the service in 2010.

Throughout her career Wendy has been interested in the better integration of specialist palliative care services within non-specialist settings. At Kings she established the Trust’s End of Life Strategy Group, she was involved in the NIHR funded project evaluating end of life care in the intensive care setting, alongside developing the palliative care service for people with liver diseases.

Wendy is also interested in the development and delivery of education, and is a member of the Faculty of Education of the Royal College of Physicians, London.
Dr Shaheen Khan  
Consultant in Palliative Medicine

Shaheen Khan is a Consultant in Palliative Medicine at Guy’s and St Thomas’. His roles include lead for the GSTFT community palliative care team, Training Programme Director for the Palliative Medicine StR training scheme, Deputy chair of the CSI Executive Education Committee, Postgraduate medical education lead for the GSTFT palliative care team, membership of the RCP Standards Setting Group for the Palliative Medicine SCE, co-chair of the London Opioid Safety and Improvement Group (LOSIG) and tutor and lecturer on the MSc in Palliative Care.

Paramjote Kaler  
Research Nurse

Param qualified as a nurse in 2008. Initially she worked at Lings Bar Hospital in Nottingham before moving to Kings College Hospital and working in acute medicine. She has recently been working as a research nurse in elderly care working on a study looking to prevent falls in care homes and one examining the effects of Vitamin E in the elderly population. She joined the Cicely Saunders Institute in April 2014 to help on NIHR portfolio studies including IPOS validation, IARE and MyCare.

Caty Pannell  
Senior Research Nurse

Caty Pannell has worked for many years as a clinical nurse specialist in palliative care in hospital and community settings. In March 2010 Caty joined the Cicely Saunders Institute as Senior Research Nurse for NIHR badged studies. She is presently helping on a number of studies including IARE, NMES in COPD, QoL in Myeloma and The IPOS validation. Her role also involves working with local palliative care CNS’s, encouraging their interest in research.

Vicky Robinson  
Consultant Nurse in Palliative

Vicky Robinson, Consultant Nurse in Palliative and End of Life Care, Guy’s and St. Thomas’ NHS Foundation Trust. Vicky has worked in palliative care since 1988. From 2003–2007 she was Nurse Consultant at St. Christopher’s Hospice in Sydenham. In 2008 she returned to the NHS to lead palliative and end of life care nursing developments at Guy’s & St. Thomas’. She is particularly driven by the unique position held by nurses in end of life care, teamwork and spiritual care.
Susanne De Wolf-Linder
Quality Improvement Facilitator for the OACC project

Susanne De Wolf-Linder trained as a nurse in Switzerland and worked in a variety of clinical settings in Oncology before specialising in palliative care. She has a BSc in general nursing and is currently pursuing an MSc in palliative care at King’s College London, which she will finish in 2015. The goal of her thesis is to understand why patients/carers want to be involved in shaping palliative research and what a meaningful outcome would be for them.

Susanne has coordinated clinical and non-clinical trials in palliative care in Switzerland and the UK. She worked as an NIHR funded research nurse in palliative care at the Cicely Saunders Institute for two years and moved just recently to her new role as Quality Improvement Facilitator for the Outcome Assessment Complexity Collaborative (OACC) project lead by Dr Fliss Murtagh, and Dr Barbara Daveson at the Cicely Saunders Institute. Susanne’s focus is on teaching and support for clinical teams, evaluating the implementation of outcome measures in order to change routine practice and improve the quality of services provided in the field of palliative care together with the clinical teams.

Dr Simon Noah Etkind
NIHR Academic Clinical Fellow in Palliative Medicine

Simon Noah Etkind qualified from the University of Cambridge School of Clinical Medicine with a distinction in 2009. He completed an intercalated BA in Neuroscience in 2006. Since 2009 he has been working clinically and has been undertaking Foundation and Core Medical Training at hospitals in Sussex and South London and is a Member of the Royal College of Physicians. He studied at the London School of Hygiene and Tropical Medicine in 2012 and gained a Diploma in Hygiene and Tropical Medicine with distinction. In late 2012 he was appointed as an Academic Clinical Fellow in palliative medicine and is currently combining 75% clinical commitments with 25% protected research time at the Cicely Saunders Institute. As part of this he will complete PGCert in Applied Research Methods for Integrated Academic Trainees. Current work includes: Understanding patterns of place of death in patients with CKD 4–5, Advanced Renal Care Project, and development of PhD proposal looking at palliative care needs in young adults with chronic disease.

Dr Natasha Lovell
NIHR Academic Clinical Fellow in Palliative Medicine

Dr Natasha Lovell graduated from the University of Leeds with BSc. Hons First Class (1st) Intercalated Degree in International Health (2007) and MBChB Bachelor of Medicine and Surgery (2009). Went on to complete PGCert Health Research at the University of Leeds as part of the West Yorkshire Foundation School Academic Programme. Currently an Academic Clinical Fellow at Kings College Hospital completing a nine month research block at the Cicely Saunders Institute. As part of this she will complete PGCert in Applied Research Methods for Integrated Academic Trainees. Current work includes: Understanding patterns of place of death in patients with CKD 4–5, Advanced Renal Care Project, and development of PhD proposal looking at palliative care needs in young adults with chronic disease.

Dr Anton Pick
Academic Clinical Fellow in Rehabilitation Medicine

Anton graduated with Honours from Medical School at the University of Bristol in 2007. During his medical training he completed an intercalated degree in Neurophysiology during which he researched the neural correlates of visual awareness and attention using electroencephalograms. After medical school he has rotated through clinical training in hospitals scattered across London and achieved Membership of the Royal College of Physicians before choosing to specialize in Rehabilitation Medicine in 2012. Alongside his clinical training he is developing his academic interests around the complex interplay between psychosocial and physical factors, as they contribute to recovery in rehabilitation. At the CSI his focus has been on the use of outcome measurements to inform medical resource allocation for Rehabilitation.
Dr Meenakshi Nayar
Academic Clinical Fellow in Rehabilitation Medicine

Dr Meenakshi Nayar (Meena) qualified with a degree in Medicine (BMBS) and Biomedical sciences (BMedScs) from the University of Nottingham in 2009. She finished her foundation training in Kent, Surrey and Sussex and moved to London where she completed core medical training. During this period, she worked at King’s, The Royal Marsden and Croydon and achieved membership of the Royal College of Physicians (MRCP). She has an interest in chronic disease and disability management and attained the London NIHR academic clinical fellowship ST3 post in rehabilitation medicine. Her academic interests include neurological recovery in patients after stroke, service provision and outcome measures in stroke rehabilitation.

Dr Sabrina Bajwah
Locum Consultant in Palliative Medicine and PhD Student

Dr Sabrina Bajwah qualified in medicine at the University of Manchester, and came from a background of general practice into specialist medical training for Palliative Medicine. She has completed the MSc in palliative care at King’s College London and an MA in the ethics of cancer and palliative care at Keele University. Sabrina is a part-time Palliative Medicine Consultant with clinical sessions at the Royal Brompton Hospital and the Royal Marsden Hospital. She is also completing a PhD in developing and evaluating a complex intervention at the end of life for patients with progressive idiopathic fibrotic lung disease. Sabrina is also active in a number of research committees related to interstitial lung disease. These include the British Lung Foundation Idiopathic Pulmonary Fibrosis Research Committee.

Keira Lowther
PhD Student

Keira Lowther qualified as a paediatric nurse following a first degree in Nursing Sciences at the University of Hull in 2002. She then worked as a paediatric nurse in various clinical contexts in four north London hospitals during which Keira completed a Diploma in Tropical Nursing at the London School of Hygiene and Tropical Medicine. She continued her studies at LSHTM in 2006–2007 completing a Masters Public Health Nutrition including a thesis on the use of complimentary feeding in Zambia. Following this Keira worked for Action Against Hunger in Chad, China, and Swaziland conducting exploratory assessments and nutrition surveys. Following a year of working as a paediatric nurse in the NHS again, she then returned to Swaziland with Action against Hunger to manage an HIV and nutrition project in rural Swaziland for a year. Her thesis on palliative care in HIV began in 2011.

Emma Murphy
PhD Student

Emma Murphy has worked in the field of Nephrology nursing for 15 years. She completed her MSc at Kings College London, Florence Nightingale School of Nursing and Midwifery. Emma has been awarded a PhD training fellowship from the Biomedical Research Centre, Guy’s and St Thomas’ NHS Foundation Trust. Her research interests include symptom prevalence in Chronic Kidney Disease and end of life experiences of patients withdrawing from dialysis. She completed a qualitative study to explore the healthcare needs of patients withdrawing from dialysis which identified the priorities for further research in an area where there is little prior evidence. Her PhD aims to describe the trajectory of illness and care received during the last year of life for those people with ESRD who die following withdrawal of dialysis.
Dr Thomas Osborne
PhD Student

Dr Thomas Osborne completed a BA in Experimental Psychology at Cambridge University in 2001. He went on to complete his clinical training at Guy’s, King’s and St. Thomas’ Medical School and graduated with MBBS in 2004. Since 2004 he has trained within the NHS in a range of medical specialities, and began specialist training in Palliative Medicine in 2008. He became a Member of the Royal College of Physicians (UK) in July 2008. He joined the academic department at the Cicely Saunders’s Institute as a Clinical Research Fellow in 2010. He is currently working towards a PhD supervised by Professor Irene Higginson on a programme of research investigating quality of life of people with multiple myeloma. He is particularly interested in outcome measurement, the supportive care of patients with haematological cancer, and tools to aid with prognosis predication in palliative populations.

Administration

Emma Bennett
Research and Dissemination Facilitator

Emma Bennett joined the Cicely Saunders Institute in 2010 to assist with the final report and a symposium for PRISMA (a large European Commission funded project that aimed to coordinate research and practice in end-of-life care across Europe and Africa). She subsequently developed a three-year Dissemination, Engagement and Empowerment (DEE) programme for ‘BuildCARE’ (building capacity, access, rights and empowerment). The DEE programme is comprised of online activities, an events programme, networking and resource development, and press and public relations work.

Emma worked for the Academy of Medical Sciences from 2002 to 2009 where, as Senior Officer of Grants and Policy, she managed a National Mentoring Scheme and was lead Secretariat to the Academy’s Academic Careers Committee. She graduated from Central Saint Martin’s in 1996 and has an MA in Fine Art from Chelsea College of Art and Design.

Sian Best
Institute Business Manager

Sian Best has a BA Hons from the University of Warwick and studied for a PGCE in English, also at Warwick. She worked as a picture researcher for national and international newspapers and magazines for 15 years before joining King’s College London in 2005. Her administrative responsibilities include education, research grants, website and finance.
Francesca Cooper
Research Administrator to OACC and BuildCARE

Francesca Cooper joined King’s College London in December 2013 as the Administrator for OACC and BuildCARE. She was previously employed by Ashford and St Peter’s NHS Foundation Trust as their Colposcopy Administrator and was responsible for the DoH database entry of patients and management plans. Francesca holds a BSc (Hons) in Medical Biochemistry from Royal Holloway, University of London and also has a PGCert in Intellectual Property Law from Brunel University.

Maria Heldakova
PA to Professor Irene Higginson

Maria has an educational background in Psychology and has worked in varying positions in other multi-professional organisations. She worked at London Bridge Hospital from 2006 to 2008, then as an Appointments and Information Officer at The London Clinic, and later as Department Secretary in Intensive Care Unit in The Wellington Hospital. Maria joined King’s College London in September 2013 as Administrator / PA to Professor Irene Higginson.

Hetty Kaye
PA to Dr Richard Harding

Hetty Kaye joined the Cicely Saunders Institute as an Executive Assistant to Dr Richard Harding (Reader in Palliative Care) in July 2013. She was previously completing her PhD at the University of East Anglia, where she also taught in the School of Arts and Humanities and worked as a conference organiser. Hetty holds BA (Hons) from the University of East Anglia in History, and an MA from King’s College London in Medieval History.

Michaela Eccles
MSc Administrator

Michaela has a BA Hons in Religion, Philosophy and Ethics from King’s College London. Since graduating she has worked in a diverse range of administration and customer service roles including working for the NHS and a private training company. In 2014 she joined the Institute as MSc Administrator, supporting the MSc programme, short courses, e-learning and other educational activities of the Cicely Saunders Institute.
Rowena Vohora  
BuildCARE Administrator  
Rowena Vohora graduated with a BA Hons in Psychology from the University of Aberdeen in 2009. She has a background in Human Resources administration and most recently worked at Macmillan Cancer Support. Rowena joined the department in May 2012 as an administrator for the BuildCARE and MORECare projects.

Katie Witcombe  
PA to Dr Fliss Murtagh  
Katie Witcombe joined the department as the PA and Administrator to Dr Fliss Murtagh in October 2013. She has a background in administration and most recently worked as the PA to the Director of a charitable arts organisation. Katie moved to London after graduating with a BA in English Literature and an MA in Modern and Contemporary Cultures from Newcastle University.

Fiona Wong  
EA to Professor Higginson/Department Manager  
Fiona Wong joined King’s College London in March 2012, and transferred from the Institute of Psychiatry to Cicely Saunders Institute in September 2013. She has extensive administration experience in the Higher Education sector, having worked at London South Bank University as Programme Administrator for 7 years, then as Project Administrator at Imperial College London before joining the Institute of Psychiatry, King’s College London. Fiona holds a BCom from the University of Melbourne, Australia.

Michelle Goode  
Macmillan support centre  
Michelle has an educational background in Science and Health & Social Care and has worked in different positions in several multi-professional organisations. She worked at Metropolitan Police and Whitbread Leisure Company, then as a Project Manager at Dignity Mental Health Advocacy Service, and later as Macmillan Information & Support Co-ordinator and Cancer Information Lead for South Bedfordshire based at Luton & Dunstable Hospital. Michelle has joined Macmillan Cancer Information and Support Service, Kings College Hospital, London in July 2013 as the Support Centre Manager. At the Macmillan Cancer Information and Support Service, we are a source of support, helping with all the things that people affected by cancer want and need. It’s not only patients who live with cancer, we also help carers, families and communities. Michelle has had articles published on the subject of Adoption and has appeared on television and radio discussing the subject; she is also an Independent Member Buckinghamshire’s Adoption & Permanency Panel.
**Bárbara Antunes**  
Marie Curie Early Stage Research Training Fellow

Bárbara Antunes qualified as clinical psychologist in 2003 in Instituto Superior de Ciências da Saúde – Norte, Portugal where she also completed her MSc in “Psychology of Pain” in 2006. She has always integrated clinical work with research posts. In 2008 she joined the Portuguese research centre Centro de Estudos e Investigação em Saúde da Universidade de Coimbra (CEISUC). In 2009 she joined the PRISMA project led by King’s College London, Cicely Saunders Institute. She temporarily joined the Department in 2010 and in 2011 she got a 3 year fellowship through the EU funded EUROIMPACT project as a Marie Curie Early Stage Research Training Fellow based at the Cicely Saunders Institute.

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**Professor Claudia Bausewein**  
Professor of Palliative Medicine

Dr Claudia Bausewein qualified in medicine at Munich University in 1992. Her medical background is internal medicine although she has been involved in palliative care in Germany for more than 20 years. From 2001 to 2007 she worked as a Consultant in Palliative Medicine at the Interdisciplinary Centre for Palliative Medicine at Munich University. Since 2004, Claudia has been vice-president of the German Association for Palliative Medicine and was co-editor of the German Journal of Palliative Medicine from 2000 to 2009. After completing the MSc course in the Department of Palliative Care, Policy and Rehabilitation at King’s College London, Claudia joined the department in 2005 as research training fellow to undertake a PhD on breathlessness in advanced disease funded by Cicely Saunders International. She completed her PhD in 2009 in which she described the high symptom burden of COPD and cancer patients suffering from breathlessness. Also, for the first time, she described individual breathlessness trajectories over time and towards death. In 2011, Claudia was appointed Professor of Palliative Medicine at the University of Munich.

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**Dr Sara Booth**  
Honorary Research Fellow

Dr Sara Booth became interested in palliative care before she went to medical school after working as an auxiliary nurse at St Christopher’s Hospice. After training in anaesthetics to registrar level she then spent 6 months in psychiatry before taking up a post as Registrar at St Christopher’s Hospice and then Senior Registrar at St Michaels Sobell House, Oxford. She then started an R&D Training Fellowship for 11 months during which she validated the “Shuttle Walking Test” for patients with cancer.

Dr Booth then went to Cambridge to take up an NHS Consultant post setting up a hospital team. Since being in post she has been active in trying to maintain a research programme and is now collaborating with Professor Irene Higginson, King’s College, London on symptom control in breathlessness. The developing service uses a rehabilitative model looking at integrating wellbeing interventions into the management of symptoms.
Professor Julia Downing
Professor Downing is an experienced palliative care nurse, educationalist and researcher, with a PhD that evaluated palliative care training in rural Uganda. She has been working within palliative care for 24 years, with fourteen of those working internationally in Uganda, Africa and Eastern Europe. She is an Honorary Professor at Makerere University, Kampala and an International Palliative Care Consultant working with the International Children’s Palliative Care Network (ICPCN) and an EU funded project to develop palliative care in Serbia. She has extensive experience in research, presenting at conferences and writing for publication, and is on the editorial board of the International Journal of Palliative Nursing (IJPN). She has been involved in a number of local, national and international research studies, and regularly teaches research skills.

Professor Downing serves on the Boards of several international NGOs including the International Association of Hospice and Palliative Care, is on the Board of Hospice in the Weald, and APCA UK, and is Vice Chair of the Scientific Committee of the International Children’s Palliative Care Network. She is also an Honorary Research Fellow with the Department of Palliative Care, Policy and Rehabilitation, at King’s College London, England. She was the recipient of the IJPN’s Development Award in 2006.

Dr Marjolein Gysels
Dr Marjolein Gysels completed an MA at the University of Ghent in Belgium and received a PhD in anthropology at the University of Amsterdam in 1996. She has carried out research in D.R. Congo on Swahili and oral literature. She worked for the TANESA project on AIDS in Tanzania on female infertility, and for the Medical Research Council (UK) Programme on AIDS in Uganda on commercial sex work. At King’s College London, she collaborated on the Project to Improve Management of Terminal Illness (PROMOTE), and she wrote the systematic reviews for the Research Evidence Manual which has been published as part of the NICE Guidance for supportive and palliative care for those affected by cancer. As a senior research fellow she conducted a programme of research on breathlessness funded by The Cicely Saunders Foundation. This encompasses research projects on the experience of breathlessness in patients with different conditions, at different phases in their illness and in different settings.

Professor Richard Siegert
Professor Richard Siegert trained in New Zealand as a clinical psychologist and then completed a PhD which examined psychiatric symptoms and social support in unemployed people. He lectured in psychology for 12 years specialising in clinical neuropsychology. Before joining King’s he headed an interprofessional rehabilitation research and distance teaching unit. His research interests include psychometrics and measurement, cognition in neurological disorders, and rehabilitation and palliative care in complex neurological conditions. He has published over 55 papers in peer-review journals and four book chapters.

Rev. Dr Peter Speck
Dr Peter Speck graduated with a first degree in biochemistry and zoology before studying for an MA in theology. His thesis focused on the theological aspects of visiting in times of illness.

Following a position in a Parish Ministry in North Wales and chaplain position in Sheffield, Peter became a Chaplain and Honorary Senior Lecturer (medical ethics) at the Royal Free Hospital in London. He was Trust Chaplaincy Team Leader for Southampton University NHS Trust until 2002. Currently Visiting Fellow (Faculty of Medicine) at Southampton University and Hon. Senior Research Fellow, King’s College London (Palliative Care, Policy & Rehabilitation), Peter is author of several books on pastoral care, chapters on aspects of palliative care, and spiritual care and bereavement. He was a member of the Editorial Board of Palliative Medicine and served on the Editorial Board of NICE producing “Supportive Care in Palliative Care” Guidance. He is a Fellow and Member of the Council of Palliative Care section of the Royal Society of Medicine. His research interests include belief systems and whether they influence outcomes in illness, with several peer reviewed papers published.
Dr Sue Hall
Dr Sue Hall studied Psychology at the Polytechnic of East London (now the University of East London) where she was awarded a first class degree and received a PhD in Health Psychology at King’s College London. Her first academic appointment was on a study exploring quality of life for patients with high grade brain tumours. For most of the next 11 years, she worked with the Psychology & Genetics Research Group, King’s College London, running national and international studies focusing on adjustment to serious negative life events, behaviour change, and facilitating informed choice. During this time she spent a year at the Centre for Health Care Research, at the University of Brighton as Research Fellow and NHS R&D Consultant. In March 2006, she joined the Department of Palliative Care, Policy and Rehabilitation as Herbert Dunhill Lecturer in Care, Policy and Rehabilitation, at King’s College London. In 2007, she was appointed visiting “G.Ghirotti” Hospice of Genoa. Since 1992, when he was appointed as full time consultant epidemiologist at the Clinical Epidemiology Unit (IST Genoa), his research interests were focused in the areas of palliative care and quality of life. From 2002 to 2004 he has been Medical Director of the “G.Ghirotti” Hospice of Genoa. In 2008, he joined the Department as full-time Visiting Research Fellow and worked on the breathlessness programme. Steffen conducted a systematic review on the effectiveness of benzodiazepines in the relief of breathlessness for his Masters dissertation, set up a qualitative interview study about episodic breathlessness and worked for the EU funded project PRISMA (Work Package 4, outcome measurements in palliative care). After moving back to Germany in October 2010 Steffen is now working as a Consultant at the Department of Palliative Medicine of the University of Cologne, Germany with clinical work, teaching and research in palliative care. He is the Lead of the Clinical Trials Unit in Palliative Medicine by initiating clinical trials in the area of symptom control, mainly in the area of breathlessness. Steffen’s research interests are palliative care for noncancer patients and core attitudes of professionals in palliative care.
Visitors

Dr Farida Malik

Dr Farida Malik qualified in medicine at UMDS, University of London. She went on to train in general medicine before joining the South Thames specialist registrar rotation in palliative medicine. Farida has previously undertaken an intercalated BSc in Psychology and an MSc in Palliative Care (King’s College London). Her interests are breathlessness and sleep disturbance in patients with advanced disease, steroids in brain tumours and symptom assessment. Farida was awarded her PhD from King’s College London, looking at the dying processes and patient and carers’ opinions of care received by people with cancer at the end of life.

Visitors

Dr David Blum

Dr David Blum obtained his medical degree from the University of Zürich (2002) and received the Swiss board certification of Internal Medicine (2009) and Medical Oncology (2011). He was working as resident doctor at Oncology DIM KSSG St. Gallen and research fellow in the European Palliative Care Research Collaborative (EPCRCC). He is a EURO IMPACT – Marie Curie PhD training fellow at European Palliative Care Research Center NTNU, Trondheim, Norway. David’s main research interests include symptom assessment and the role of computer assistance, cancer cachexia, physical activity and integration of oncology and palliative care.

Lara Pivodic

Lara Pivodic is a PhD Training Fellow in the Marie Curie Initial Training Network EURO IMPACT (European Intersectorial and Multidisciplinary Palliative Care Research Training). Lara holds an MSc in psychology from the University of Vienna, Austria, and her home institution is Vrije Universiteit Brussels, Belgium. As part of EURO IMPACT, she was a Visiting Research Associate to the Institute. Lara’s PhD focuses on the use and evaluation of palliative care for cancer patients in different European countries. Her research includes cross-national comparisons of the number of people accessing palliative care, places of care and places of death as well as family carers’ opinions of care received by people with cancer at the end of life.

Dr Despina Anagnostou

Despina completed her first degree in nursing in Athens, Greece and was awarded an MSc in advanced nursing with a focus on cancer and palliative care from the University of Edinburgh. She recently completed her PhD at King’s College London, looking at the dying processes and patient and family experience over the last months of life of patients with advanced cancer in Greece. Despina’s ambition is to further help advance the care of patients with a life threatening illness and help with the establishment of palliative care services in Greece. She is involved in the development of the Greek palliative care policy and a home palliative care team in Greece. Despina held a scholarship from the State Scholarship from the Foundation of Greece and an award by the Schilizzi Foundation.

Dr Brian Cassel

Visiting Senior Lecturer, King’s College London Fullbright Scholar 2011–2012 (Home institution / role: Cancer Informatics and Palliative Care Research Director, Virginia Commonwealth University, Massey Cancer Center, Richmond, Virginia, USA) As the Fulbright – King’s College London Scholar, Brian Cassel is working at the Institute on comparisons of the role that financial and economic issues play in the development and sustainability of palliative care in the US and the UK. Brian received his BS and PhD in Psychology, and has worked in healthcare outcomes evaluation for 20+ years in a variety of healthcare settings in the US. His research focuses on the clinical and financial outcomes of cancer services and palliative care programs. He is a member of the Palliative Care Leadership Center at Virginia Commonwealth, training more than 150 specialist teams from hospitals across the US in establishing and sustaining palliative care programs.

Professor Harvey Chochinov

Professor of Psychiatry, Community Health Sciences, and Family Medicine (Division of Palliative Care), University of Manitoba, Canada. Director of the Manitoba Palliative Care Research Unit, Cancer Care Manitoba. One of Professor Chochinov’s innovative areas of work has been the development of dignity therapy. This is a short intervention and seeks to address the existential and psychological distress of people near the end of life. It aims to improve their sense of worth, attain a sense of peace and promote death with dignity. Professor Harvey Chochinov visited Institute to carry out training in dignity therapy with researchers working on studies in the UK.

Dr Scott Moreland

Dr Scott Moreland works with Measure Evaluation at the University of North Carolina and is part of the team evaluating PEPFAR-funded HIV services in Kenya and Uganda; a study that is being headed by Dr Richard Harding. As well as his role in facilitating the dissemination and utilisation of study results through Measure, Scott is a health economist by training. During his visit to King’s he worked with colleagues from the department and the Institute of Psychiatry on analysis of the evaluation economics data.

Dr Steve Pantilat

Senior Fulbright Scholar Central Sydney Palliative Care Service, University of Sydney and Royal Prince Alfred Hospital Professor of Clinical Medicine, Alan M. Kates and John M. Burnard Endowed Chair in Palliative Care Director, Palliative Care Program and Palliative Care Leadership Center University of California, San Francisco Dr Steve Pantilat visited the department in May/June 2008. During that time Dr Pantilat met with members of the department and clinical teams at St Thomas’ and King’s College Hospitals.

Dr Steve Pantilat visited the department in May/June 2008. During that time Dr Pantilat met with members of the department and clinical teams at St Thomas’ and King’s College Hospitals. He also attended the EAPC conference in Trondheim. On 4th June Dr Pantilat presented the monthly Compass Collaborative Open Seminar entitled ‘Palliative Care for People with Heart Failure’.
### Previous Members of the Department (since 2011)

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<thead>
<tr>
<th>NAME</th>
<th>POSITION</th>
<th>YEAR OF DEPARTURE</th>
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<tr>
<td>Lauren Rayner</td>
<td>Research Assistant</td>
<td>2011</td>
</tr>
<tr>
<td>Rachael Dodd</td>
<td>Academic Administrator</td>
<td>2011</td>
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<tr>
<td>Susie Edwards</td>
<td>Research Support Officer, COMPASS Research Collaborative</td>
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<tr>
<td>Hannah Jones</td>
<td>Research Associate</td>
<td>2011</td>
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<tr>
<td>Bernadette Khoshaba</td>
<td>Research Associate</td>
<td>2011</td>
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<tr>
<td>Wendy Magee</td>
<td>Honorary Senior Research Fellow</td>
<td>2011</td>
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<tr>
<td>Caroline Rumble</td>
<td>Research Associate</td>
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<tr>
<td>Sasha Wade</td>
<td>Research Assistant</td>
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<tr>
<td>Lucy Bradley</td>
<td>Research Manager</td>
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<tr>
<td>Eleni Epiphaniou</td>
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<tr>
<td>Cassie Goddard</td>
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<tr>
<td>Leonie Hayes</td>
<td>Academic Administrator</td>
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<td>Susan Chandler</td>
<td>Executive Administrator</td>
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<tr>
<td>Helen Horsley</td>
<td>Academic Administrator</td>
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<tr>
<td>Yvonne Kaloki</td>
<td>Research Assistant</td>
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<td>Christine O'Connell</td>
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<td>Nancy Patel</td>
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<td>Hristina Petkova</td>
<td>Health Economics and Research Training Fellow</td>
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<tr>
<td>Tariq Saleem</td>
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<td>Yuen King Ho</td>
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<td>Natalia Monteiro Calanzani</td>
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<tr>
<td>Chiara De Biase</td>
<td>Manager Macmillan Support Centre</td>
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<td>Eloise Radcliffe</td>
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<td>Charles Reilly</td>
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<td>Cathy Shipman</td>
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<td>Katie Stone</td>
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<td>Fliss Cheek</td>
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<td>Anna Gillespie</td>
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<td>Dannii Leivers</td>
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<tr>
<td>James Milne</td>
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<td>Veronica Monte</td>
<td>PA to Fliss Murtagh</td>
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<td>Sophia Blake</td>
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<td>Natalie Campbell</td>
<td>Research PA to Professor Turner-Stokes</td>
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<tr>
<td>Andrew Steer</td>
<td>MSc Administrator</td>
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We thank the following organisations who have supported research, teaching and development in the Cicely Saunders Institute during 2011–14. Most funding is won through peer review grants.

<table>
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</table>
Staff 2013
We welcome enquiries about any aspect of our work:

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