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Highlights

A significant highlight in the last three years was the completion of building and opening of the Cicely Saunders Institute. This had been a major project. The Institute was planned on hospice principles and involved patients and families as an integral part of its development. A key goal of the Institute is to enable the closer integration of research, education, care for patients and families, and support and information in order to more quickly bring the results from research to patients and families and to ensure that research is led by the needs of patients and families. This integration seeks to improve care quickly. While there are many purpose built institutes for other areas of healthcare, for example into ageing, child health or psychiatry, the Cicely Saunders Institute represents the first such purpose built institute for palliative care. The integration in the Institute between palliative care and rehabilitation medicine brings an additional strength and allows synergy between the teams.

After a long period of planning, fundraising and watching the Institute being built we were delighted to be able to move in and become operational in 2010. We were honoured that HRH Princess Anne formally opened the Institute in May 2010, spending time with staff, patients, families and supporters. The development of the Institute was a partnership between Cicely Saunders International, King’s College London and the partner Trusts in King’s Health Partners. I would like to express my thanks to all those organisations and those individuals who made the Cicely Saunders Institute possible. Particular thanks are due to the funders who supported the Institute, the patients and families who helped in the design, the King’s College London development office staff and the many staff and external colleagues involved in planning, designing and building the Institute. Dame Cicely Saunders was central to the early planning and development right before her death in 2005. She was a great inspiration to us all, and we were honoured that she wanted to lend her name to the Institute.

The last three years have seen the completion of some important research. Of note we have made substantial progress in our work examining place of care and place of death. This is now having an impact on UK health policy and international policy. Our study on the future projections in the number of deaths found that we are facing a 17% increase up to 2030 in the annual number of deaths. If action is not taken and current trends in place of death continue by 2030 only one in 10 people will die at home. We also examined the nature of people being admitted to and dying in emergency departments and factors affecting the quality of homecare. A major project for the World Health Organization producing guidance on better care for older people was completed and we have made substantial strides in understanding the needs of caregivers. In our theme on evaluating and improving care we have now fully published the findings of our trial of palliative care in Multiple Sclerosis preparing the ground for national and international care developments for patients and families. In addition research and service development has moved forward on end stage liver disease, intensive care units, dignity therapy, a structured prompt list for families and the development and evaluation of palliative care in Africa.

Our symptom led research has seen considerable progress in the area of three symptoms—breathlessness, depression and spasticity. In all these conditions we have published highly cited Cochrane Reviews demonstrating the effectiveness of treatments, for depression we have published European guidelines and for breathlessness and spasticity we have been trialling new treatments to help patients with these debilitating conditions.

Our work on patient reported outcome measures has been driven forward particularly through the European wide PRISMA project, a collaborative bringing together 11 specialist partners in nine European countries plus the African Palliative Care Association. As a result the...
Palliative care Outcome Scale has been refined and improved with validation and availability in 12 languages and new downloadable and accessible tools which can be accessed from our website. We have also worked on testing short measures for palliative care and rehabilitation medicine including a short version of the Zarit Burden Inventory, comprising only six questions, measures for rehabilitation, dependency, goal attainment scaling and arm activity. The brief rehabilitation measures are used across the globe in practice and research. Our findings have continued to affect policy in particular with new guidance on spiritual care and extensive numbers of systematic literature reviews and clinical reviews.

A new theme of investigation has been our studies in methodological innovation. We have demonstrated information on the willingness of patients to take part in research in palliative care and rehabilitation and have developed and tested a new variation of randomised controlled trial – the fast track design which is outlined in this report. We have also researched the longitudinal trajectories of illness and have shown flaws in existing work on trajectories. Until now most patient trajectories have been built from grouped data. However if individual trajectories are considered the patterns shown by grouped data are not seen. Instead four patterns emerge, and many patients are seen to be in one new pattern we have identified of fluctuating. This is seen in patients with cancer, renal disease and chronic obstructive pulmonary disease. Our work has benefited from many collaborations and in particular our international work in Africa is helping us learn about the ways to improve care in different contexts and settings. Our work has also benefited by a great extension of our consumer and public collaboration. Now across most projects in the department we have consumer collaboration and we are grateful to the many individuals who have taken part in this.

The clinical services within the Cicely Saunders Institute continued to provide excellent support for the patients and families in our partner Trusts at King’s College Hospital and Guy’s and St Thomas’ Hospital and the local community. Together these services see around 3,000 new patients every year. Clinicians and academics work closely together in service innovations and their potential evaluation.

I would like to congratulate the four individuals who completed and were awarded their PhDs and the many MSc, Diploma and Certificate students who have graduated in recent years. Our undergraduate teaching is spearheaded by the clinical staff in the Institute with an innovative and integrated programme which includes seminars, symposiums, bedside teaching, hospice visits and student selected components. In addition the clinical team provide education to staff within the acute hospital trusts. We are grateful to the many external speakers who have been able to assist us with our external programme of education.

A particular highlight of moving to the Cicely Saunders Institute was the opening of the Macmillan Information & Support Centre in 2010, timed to coincide with the ‘World’s Biggest Coffee Morning’. Led by Chiara de Biase the centre has already extended its reach to patients within the hospital and has begun to play a role in supporting patients and families providing a welcoming and relaxing open access drop in centre for anyone in the hospital and focusing particularly on people affected by long term and progressive conditions. Several support groups are now also being supported within the Cicely Saunders Institute and research projects and new services are being offered from our therapy rooms.

There have also been several new awards for grants building on our programmes. These include grants from the Medical Research Council to develop guidance on methods in palliative care, undertaken in collaboration with individuals at the universities of Manchester, Edinburgh and Aberdeen; the BuildCARE programme supported by Cicely Saunders International and The Atlantic Philanthropies, to develop capacity and international empowerment and access in palliative care, a major trial of palliative care in Africa; and a National Institute of Health Research programme grant in rehabilitation medicine with wide collaboration across...
the UK and with Australia. We have been able to provide through the Cicely Saunders Institute considerably enhanced teaching facilities. Thus our MSc programme has slowly expanded and we have been able to offer more external seminars and lectures.

We were delighted that in May 2011 Professor David Currow gave our inaugural Cicely Saunders Institute lecture – “Palliative Care Research – what is the return on investment?”. David Currow is Professor of Palliative and Supportive Services, Flinders University, Adelaide, Australia and is Chief Cancer Officer and Chief Executive Officer of the Cancer Institute, New South Wales. We were delighted that we were able to offer the lecture in videoconference link to our colleagues in Cardiff and hope to extend in the future the possibility to give videoconferenced lectures and to webcast our lectures. Individually several staff have received awards, including Farida Malik, Barbara Gomes and Lucy Selman. We have expanded the team of staff within the Institute and have seen a number of staff promoted, with particular congratulations to Richard Harding and Richard Siegert who were promoted to Readership and Sue Hall and Jonathan Koffman who were promoted to Senior Lecturer.

We very much hope that you find the information that you find in the report accessible and interesting and please do feel free to seek further information from individuals and via our website at http://www.csi.kcl.ac.uk/

2 Research

Research in the Cicely Saunders Institute seeks to discover, develop and test ways to improve the care for people with progressive, long term or end of life conditions. This is often a neglected area in health and social care research. Yet as people live longer, in all parts of the globe, and more and more live with and eventually die from chronic diseases, cancers, or in old age, palliative care and rehabilitation medicine are increasingly vital for care.

Palliative care is the active holistic care of patients with advanced or progressive illness. Its focus is on improving the quality of life – adding life and health to remaining years – rather than only extending life. Rehabilitation medicine focuses on the diagnosis, treatment and management of people with disabling medical conditions. Thus there is an important interplay between these two fields, which reflects the synergistic nature of research in the Institute. Despite their importance clinically and in society - most people will experience a chronic or progressive illness at some point, all will at some time be affected by caring for or losing someone from illness and everyone will eventually die – these are ‘Cinderella’ fields in health research. For example, in the UK less than 0.2% of all healthcare research spending has been on palliative or end of life care (EoLC), although this is beginning to increase now.

To mirror the multiple and complex needs of people affected by progressive, chronic or disabling conditions research in the Cicely Saunders Institute is multiprofessional and uses different methods depending on the studies aims. Research is grouped into four broad themes:

- Living and dying in society – concerned with the needs of people and their priorities in a changing society, with ageing, carers needs, cultural differences
- Evaluating and improving care – concerned with innovating and testing new treatments, models of care and services, and evaluating existing ones, to improve the way care is offered for patients, wherever they are cared for
- Focussed symptom led research – focussed on the many symptoms that people with progressive or chronic disease experience
- Patient-Reported Outcome and Experience Measurement – to refine the measurements made to assess the concerns of patients and their families, and where appropriate develop new measures for use in day to day clinical care as well as in research.

Much of our work is cross-national – involving collaborations with other centres including across Europe and in Africa, North America, Australia and New Zealand. Even when we develop and test services locally these draw from and contribute to the best in international knowledge, so that local patients benefit from the best knowledge we have. We strive always to ensure our methods are the most robust possible, collaborating with centres of excellence in palliative care, rehabilitation and health services research. We innovate new methods to improve the trials and measurement in palliative care and rehabilitation medicine. We follow the high ethical and research governance standards and audit our own practice to ensure we keep up standards. We work closely with policy makers and practitioners in many countries, and locally, to help keep our work relevant to their needs.

Patient and public participation are central to all our research, collaborating from planning to dissemination stages, with those affected by illness, with bereaved families and with patient and carer led organisations and charities. We gain greatly from this participation, as it helps to ensure our questions, methods, results and reporting meet the needs of those who are affected by the illness, suffering and problems we seek to help to alleviate.
2.1 Living and Dying in Society

Preferences and priorities for care towards the end of life

Death is a certainty for all, and as chronic conditions are increasingly leading causes of death, most of us should expect a period of illness preceding death. In addition, many may also be involved in caring for those close to them. The shape of future care towards the end of life (in society and individually) is a public health matter and concerns all - young and old, men and women, rich and poor, sick and healthy - in all parts of the world. Many of the studies carried out by the department therefore include an assessment of patients and families’ preferences and priorities for EoLC.

A major European Commission FP7 funded project entitled - Reflecting the positive diversities of European priorities for research and measurement in end of life care (PRISMA) began in 2008. This pan-European coordinating action brought together nine specialist research institutions from across Europe led by King’s College London, with the aim of driving forward the delivery of optimal end of life cancer care for European

In Focus

The PRISMA survey of public priorities for end of life care across Europe

The PRISMA survey was carried out to identify and compare people’s preferences and priorities for EoLC across countries in Europe and Africa. We also wanted to investigate if people’s experiences of illness, death and dying and facilitating conditions (such as age, others living in the house, and religion) affected these preferences and priorities.

Following testing of the questions through cognitive interviewing with 30 volunteers (Daveson, et al., 2011), 9,340 people aged 16 years or older were surveyed over the telephone in England, Italy, Portugal, Spain, the Netherlands, Belgium and Germany (66% women and 33% men). Similar surveys took place in Kenya and Namibia, though conducted in the streets rather than by telephone.

We explored the preferences and priorities of members of the general public as if they were confronted with a serious disease, with cancer as an example, and had less than one year to live.

Most of the people interviewed had a close friend or relative diagnosed with a serious illness like cancer in the last five years (65%) and/or experienced the death of a relative or friend (70%). About half of all people had experience supporting and caring for a close relative or friend in their last few months of life. 10% of participants had been diagnosed with a serious illness in the last five years.

The results showed most people in all countries would prefer to die at home if circumstances allowed them to choose (83% in the Netherlands to 50% in Portugal), followed by in a hospice/palliative care unit (except for Belgium, where hospital was the second most preferred place). There was a trend towards those diagnosed with a serious illness wanting more often to die at home. People’s three top concerns were feeling pain and discomfort, being a burden to others and being breathless. What would matter most to them was to have pain and discomfort relieved, and to remain positive. Over 75% of people in all countries would always like to be informed about the care options available, the symptoms they were likely to experience and whether they had limited time left to live.

These and other results from the survey will help coordinate initiatives across Europe and Africa to ensure EoLC and research respond to people’s preferences, concerns, goals and priorities. Findings are being reported at meetings, conferences, in scientific journals, and by distribution to national palliative care associations, international non-governmental organisations and key EoLC research groups.

“The most important thing is to die with dignity; people should not die feeling pain. Palliative care should be improved to benefit patients at the end of life”

Comment from a participant in the PRISMA survey in Portugal

6 Living and Dying in Society
citizens by sharing, comparing and exchanging measurement approaches and experiences, and identifying and coordinating the key research priorities for EoLC throughout Europe. Though focussed initially on end of life cancer care, the work has relevance for other non-cancer diseases with similar trajectories and symptoms. The work of PRISMA is divided into eight integrated work packages, some of which can be found in different parts of this report. As part of the programme, Barbara Gomes and Professor Irene Higginson led a work package that carried out the first cross-national survey of public preferences and priorities for EoLC; see In Focus.

A good death at home: time to get it right
Our research has shown that home is where the majority of people prefer to die and where patients spend more than 50% of their time in their last months of life. However, it is important that the quality of care at home is high to ensure a good death at home. Promoting optimal home care at the end of life is therefore at the heart of future EoLC. This goal has guided recent developments in our 15 year research programme on place of death, funded since 2002 by the charity Cicely Saunders International and led by Barbara Gomes and Professor Irene Higginson. Three major developments are highlighted:

UK projections of home and institutional deaths
In 2008 Barbara Gomes and Professor Irene Higginson published the results of a pioneering set of projections - the first forecasts in the world - to project the influence of socio-demographic trends onto palliative care needs by setting. The authors projected the numbers of deaths by place of death for England and Wales until 2030. Published in Palliative Medicine, one of the top two international palliative care journals, the paper discussed the implications for care of rising numbers of deaths (Gomes and Higginson, 2008) (see Figure 1).

Palliative care needs among older people in emergency departments
In many countries older people are less likely to die at home than younger patients, and often their last hospital admission occurs close to death, as a result of an emergency. Funded by the charities of Guy’s & St Thomas’ and King’s College Hospitals, research by Teresa Beynon, Barbara Gomes, Professor Irene Higginson and colleagues from the emergency and palliative care departments determined the prevalence of palliative care needs among people aged 65 years who died in the emergency departments of these two major general hospitals in London analysing all hospital records and patient notes.

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**Figure 1. Projections of numbers of deaths for England and Wales (Gomes and Higginson, 2008)**
**Living and Dying in Society**

**All deaths**

N=102

### Narrow palliative care criteria

Presence of symptoms or/and complex psychosocial issues  

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Count (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathlessness</td>
<td>n=23</td>
</tr>
<tr>
<td>Pain</td>
<td>n=9</td>
</tr>
<tr>
<td>Confusion</td>
<td>n=9</td>
</tr>
<tr>
<td>Weight loss</td>
<td>n=5</td>
</tr>
<tr>
<td>Nausea</td>
<td>n=4</td>
</tr>
<tr>
<td>Anxiety</td>
<td>n=2</td>
</tr>
</tbody>
</table>

Complex psychosocial issues  

n=28  

* some patients had more than one symptom and/or complex social issue

### Broad palliative care criteria

At least one major diagnosis  

n=58*  

Neurological (Dementia (8), Parkinson’s (5), MS, MND) n=18  

<table>
<thead>
<tr>
<th>Condition</th>
<th>Count (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>COPD</td>
<td>n=18</td>
</tr>
<tr>
<td>Cancer</td>
<td>n=14</td>
</tr>
<tr>
<td>Heart failure</td>
<td>n=14</td>
</tr>
<tr>
<td>Renal failure</td>
<td>n=9</td>
</tr>
<tr>
<td>Liver failure</td>
<td>n=1</td>
</tr>
</tbody>
</table>

≥ on Charlson index n=5  

* some patients had more than one condition

Figure 2. Flowchart showing patients likely to have palliative care needs in the emergency department (Beynon, et al., 2010)

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**Going beyond ‘neural pathways’: culture and pain**

Four themes emerged from the data in relation to the meanings patients attributed to their cancer pain: a “challenge” that needed to be mastered by the individual, not necessarily by drugs; an “enemy” which represented an unfair attack. A number of Black Caribbean spoke of pain as a “test of their faith” which referred to confirmation and strengthening of religious belief, and pain as a “punishment” strongly associated with moral wrongdoing.

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**Beyond kith and kin**

Patients from both ethnic groups reported that they valued social support from family and friends as their disease progressed. Many spoke of the presence of spouse or partner who was considered to be an indispensable feature. However, more Black Caribbean than White British participants referred to the presence of social networks made through their church communities as being a source of practical and emotional support. Many referred to this support as being akin to family who accompanied them during the course of their illness.

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**Religion, prayer and community**

Patients from both ethnic groups discussed the meanings of religious faith and belief in God in their lives. Religious faith was a more frequent and central feature among Black Caribbean patients and along with their belief in God assisted them to comprehend the inexplicable diagnosis of their cancer and helped them live with the physical and psychological effects of their illness. Several Black Caribbean patients referred to the cancer experience as a means of helping them find greater religious meaning and connection with God.

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Figure 3. Themes from comparative studies of black Caribbean and white British cancer patients (Koffman, et al., 2008a; Koffman, et al., 2008b; Koffman, et al., 2011)
The study found considerable palliative care need among the 102 older people who died in the emergency departments over a one year period (nearly 60% admitted from home), (see Figure 2). Over half presented with diagnoses that signalled palliative care need, and half had attended the same emergency department or been admitted to the same hospital in the previous 12 months. Crucially, only a minority was known to palliative care services. These findings, published in the Emergency Medicine Journal (Beynon, et al., 2010) and shared with the directors and staff of both hospital emergency departments, identified a need to identify, and manage earlier, older people with palliative care needs in order to avoid undesired admissions and deaths in hospital.

QUALYCARE study – better care at the end of life
In 2010, we embarked on a population-based survey of end of life care with nearly 600 bereaved relatives of cancer patients in London. We refined the methods following in-depth work, including interviews with 20 bereaved relatives of people who died from cancer.

QUALYCARE aims to find out whether a death at home met patients’ and families preferences, was associated with better care and outcomes, and at what cost to patients, caregivers and to the NHS and social care services.

Results from our study, published in Palliative Medicine (Gomes and Higginson, 2008) showed that few patients achieved a ‘good death’ at home but most wanted this. In addition, we examined changes in relatives’ preferences for place of death and found that most families shared the patient preference for place of death and that, in retrospect, only a quarter said they had changed their mind in the three months before death. This challenged current thinking (based on studies from the early 1990s) that preferences for place of death commonly change towards the end of life. With family preferences being stable and in tune with patient preference, there is a need to offer and provide the care needed for patients to die peacefully where they wish to be. Whilst our main analysis continues, findings have already informed the Government’s End of Life Care Strategy and local care provision, through local presentations to healthcare commissioners and services.

Ethnicity and culture
Over the last 12 years, we have been actively researching and raising awareness to the importance of cultural issues at the end of life. Recent examples, of our research in this area include work by Jonathan Koffman and colleagues, who conducted qualitative in-depth interviews with 26 black Caribbean and 19 white British people living with, and dying from, advanced cancer to explore the interface between culture and the impact of cancer on their lives, and how they managed their illness as it progressed. The three main issues identified through this study were: (i) pain attributions (Koffman, et al., 2008a); (ii) the place of social support (Koffman, et al., 2011); and (iii) the meaning and roles of religion and spirituality during advanced disease (Koffman, et al., 2008b) (see Figure 3).

Culture and ethnicity also featured in the PRISMA project, with one work package – culture - bringing together European experts to examine and debate topics related to culture at the end of life including minority groups, setting of care and death, and end of life decisions, in order to develop culturally relevant approaches to EoLC that translate into practice, policy and research. This network of experts in culture and EoLC will provide the basis for future collaboration in this area (Gysels, Pell, Strauss and Pool, 2011). We have analysed data from Spain, Italy and Portugal, to identify common themes. Similarities included higher proportions of people who wished to die at home than actually died at home, a persistent trend for partial disclosure in Italy and Spain, low use of advance directives, and low incidence of all medical end of life decisions (with the exception of terminal sedation) compared to northern European countries. The role of religion and the importance of family ties were the two main cultural factors used to explain the similarities (Menaca, et al., 2011).

Caring for older people in society
Populations around the world are ageing, and more older people are living with the effects of serious chronic illness towards the end of life. Meeting their needs is a public health priority and presents a complex challenge to palliative care. A specific programme of research dedicated to improving palliative care for older people, led by Sue Hall and Professor Irene Higginson, is now in its fifth year and is at the heart of the work we do as the World Health Organization Collaborating Centre for Palliative Care and Older People. The programme has been jointly supported by four charities - Dunhill Medical Trust (who pioneered support of Sue Hall), Cicely Saunders International, Guy’s & St Thomas’ charity, and the Maruzza Lefebvre D’Ovidio Foundation. Recent highlights include:

New World Health Organization (WHO) guidance on palliative care for older people
As part of the WHO Solid Facts Series (we previously published two general booklets on palliative care
Palliative care for older people: better practices provides examples of better ways to aid those involved in planning and supporting services for older people in the most appropriate and effective ways. Examples show how to improve aspects broadly within the whole health system; and how to improve specific services, for instance, for those in nursing homes, or for people with dementia and their families. The recommendations will have an impact on how older people are cared for towards the end of life in Europe and beyond.

**Palliative care interventions for older people in nursing homes**

We conducted a Cochrane Review to identify ways to improve palliative care for older people in nursing homes (Hall, et al., 2011a). These reported promising findings, such as increased referral to hospice services and family members' satisfaction with residents' EoLC, and highlighted the need for trials in Europe and for measurement of standard outcomes for older residents. As a result, we tested different instruments to measure quality of life with nursing home residents using cognitive interviewing techniques (Hall, et al., 2011b). Two simple, easy to use rating scales were identified - one asking people to rate their current quality of life, the other asking about their satisfaction with their quality of life. The results from these scales remain strongly associated with scores on well-established quality of life measures, which are more comprehensive but more difficult for residents to use.

The Gold Standards Framework (GSF) is a care system developed by Professor Keri Thomas at the Gold Standards Framework Centre, University of Birmingham in the UK, to improve the EoLC provided in the context of primary care; the tool has been championed nationally through the Department of Health’s End of Life Care programme and applied in care homes. We conducted 121 qualitative interviews with care home staff, residents and members of their families in 34 care homes in London exploring the benefits of and barriers to providing EoLC and implementing the GSF in care homes. Benefits found included symptom control, communication, staff confidence, care home reputation, whilst barriers identified were increased paperwork, lack of financial resources and GP cooperation. Secondary analyses on advance care planning and the meaning of EoLC in care homes revealed the need for staff training and early initiation of discussions around planning for the end of life, and difficulties that care home staff experienced in identifying when residents had reached the dying phase (Stewart, Goddard, Schiff and Hall, 2011; Goddard, Stewart, Thompson and Hall, 2011).

**Long Term Neurological Conditions**

Over the past seven years Diana Jackson, Professor Lynne Turner-Stokes and colleagues have worked on a programme of research examining the experiences and needs of over 680 family carers of working aged adults with long term neurological conditions (LTNCs).

Research in this context has been patchy to date and our three mixed methods studies, commissioned by the Department of Health’s Policy Research Programme and now complete, will significantly increase knowledge of carers’ support needs and inform cost effective ways of meeting them (see www.ltnc.org.uk).

**Carers’ experiences in general and their unmet needs for support**

In one recent study 282 carers recruited via national voluntary organisations and hospital neuroscience centres completed postal/on-line questionnaires and participated in telephone interviews. The adults they cared for had a range of progressive conditions: Multiple Sclerosis (MS), Huntington’s disease, motor neurone disease (MND), Parkinson’s disease (PD); sudden onset conditions: head injury, stroke, brain infections, hypoxia; and stable/intermittent conditions: epilepsy, others.

While some derived satisfaction from caring in difficult circumstances, other carers reported high levels of burden, with fatigue, worry, stress, loss and social isolation being contributing factors. Significant numbers needed help with various issues (see Figure 4) (Jackson, et al., 2011. Support for carers, particularly those with multiple caring roles: an investigation of support needs and the cost of provision. London: King’s College London).

**Recommended support services by condition type**

We found that some carers found it hard to reconcile their new or evolving role as a carer with their previous role of solely being a spouse/partner/parent. This was distressing for different reasons according to the type of LTNC. Carers of adults with progressive conditions, such as MS, faced the inevitable decline and death of a loved one; sometimes rapid and sometimes long drawn out. Palliative care and support was poor and we recommended that carers should have access to palliative care services that can offer counselling both before and after bereavement.

Different problems faced carers of adults with sudden onset conditions, such as head injuries. Many were
adjusting to a long term future with a ‘different person’ from the one they knew before and grieved for the loss. For this group we recommended the development of services offering long-term psychosocial support from a trained befriender or family therapist for carers who have difficulty adjusting in cases where the adult cared for has ‘hidden’ problems, for example memory loss, depression or anger.

The need for respite/replacement care and its future provision

One critical unmet need identified by us entailed access to respite/replacement care (day care, home-based or residential care) for people who could not be left while the carer was otherwise occupied. This was a particular concern for those who wished to work alongside their caring role. We followed this issue up in a questionnaire survey of 142 white British carers and through own language focus groups and interviews with 22 South Asian and 14 African Caribbean carers.

The white British sample revealed a clear unmet need for respite/replacement care services, with twice as many wanting to access them as were receiving them. A total of 45% would need services so they could work, 84% would want day care or home-based services so that they could take a short break for rest/relaxation, with 59% wanting residential services so they could take a longer break.

Findings from the black and minority ethnic groups highlighted religious and cultural issues that providers of respite/replacement care services should know about to avoid causing offence. In particular, gender matching when providing personal care is important to South Asians, who may also feel uncomfortable about receiving care from strangers.

Across all these groups, barriers to service use included concerns about staff competence in dealing with adults with complex physical or psychosocial problems. In addition, both carers and the adults they cared for were disinclined to attend day or residential services where young people would be placed in elderly care settings with a lack of age appropriate companionship and activities. Our recommendations included developing training schemes for care staff so that some could obtain advanced qualifications in managing LTNC; especially rare ones.

This body of work will contribute towards a synthesis of findings from a larger series of studies carried out under a national programme of research dedicated to providing an evidence base for policy-making in the Department of Health. Next steps will include developing screening tools to assist health and social care professionals in identifying those carers at risk of health breakdown and examining the cost implications of developing training packages for health and social care professionals.
# 2.2 Evaluating and Improving Care

The ultimate goal of research in the Cicely Saunders Institute is to improve the care and treatments that patients and families receive. Research evaluating and improving care and testing new and existing treatments and services for patients and their families, are described in this section.

## Improving care for patients with end-stage kidney disease

Little attention has been given to the needs of kidney patients at the end of life, despite the little known fact that kidney disease has a worse mortality than many cancers. What are the palliative and EoLC needs of this largely elderly group of patients? What symptoms do they experience and how can these be assessed and improved? Does the ‘cancer model’ of specialist palliative care apply, or is something different needed?

We have undertaken innovative work to describe the symptoms and other concerns of patients with advanced kidney disease to identify ways to improve their quality of care. Recent findings include:

- Our longitudinal study of symptoms and quality of life found that symptoms such as fatigue, itch, pain and dyspnoea are both highly prevalent and disproportionately distressing, with a marked increase in symptoms in the weeks before death. This may prove a more useful clinical indicator to trigger increased care and advance planning than deteriorating biochemical markers. (Murtagh, et al., 2007; Murtagh, et al., 2010)

- We identified distinct trajectories of symptoms and functional change in end-stage renal disease, which require different patterns and timing of care (Murtagh, Addington-Hall and Higginson, 2011)

- We developed a renal modification of the Palliative care Outcome Scale-Symptoms (POS-S), one of the first validated clinical tools to assess symptoms (Murphy, et al., 2009).

Understanding and interpreting the patient experience of illness was an important component of this work; these patients see kidney disease as a ‘hidden’ illness, are unsure how to attribute symptoms and are often hesitant in seeking symptom relief, despite the high levels of symptom distress.

This understanding has helped inform the training of kidney professionals in recognising and managing symptoms, and further clinical research will result in development of a complex palliative care intervention to be implemented in renal units to improve patient outcomes.

The Cicely Saunders Institute is a leader in renal palliative and EoLC research nationally and internationally, with members invited to present findings in Europe, USA, Australia and New Zealand. We have also contributed to UK policy documents including the Department of Health’s ‘End of Life Care in Advanced Kidney Disease: A Framework for Implementation’, and the renal guidelines for the Liverpool Care Pathway (LCP), which are transforming management of EoLC among nephrology professionals (NHS Kidney Care and the National End of Life Programme. End of Life Care in Advanced Kidney Disease: A Framework for Implementation. London, UK: Department of Health, 2009; Douglas, et al., 2009).

## Palliative Care in Neurology

The King’s Centre for Palliative Care and Neurology, co-led by Professors Nigel Leigh and Irene Higginson with Rachel Burman, Professor Lynne Turner Stokes and Fiona Norwood, continues to act as a virtual centre to foster and further research to improve the palliative care and rehabilitation outcomes of patients with neurological conditions. Amongst the conditions studied are Multiple Sclerosis, Parkinson’s disease and motor neurone disease.

Our work developing and then evaluating a new model of care for people severely affected by MS has reached a critical stage. We have completed all the phase 0 to II work, including a significant phase II trial, which both used a new trial method and innovated a new short term model of palliative care. See In Focus. Now we are planning a phase III multicentre study.
In Focus

A trial of a new model of short term palliative care for people severely affected by Multiple Sclerosis

Patients with considerable disability as a result of MS - either primary or secondary progressive, are a group whose needs were little understood. Although some patients with MS have little disability, 15% present with a primary progressive course, and half of those with relapsing-remitting disease develop secondary progression after 10-15 years. These patients may have both marked physical and psychological impairments and may develop severe symptoms including: pain, spasticity, fatigue, depression, bedsores and incontinence. Supported by the UK MS Society, our research in this programme found that these symptoms were as prevalent as among cancer patients receiving palliative care (Higginson, et al., 2006). Our qualitative studies also found problems with care co-ordination, with relatives describing how they were often fighting for everything (Edmonds, et al., 2007). and emotional and social isolation with multiple losses for patients (Edmonds, et al., 2007).

After consultation with staff, other experts and patient groups (including working closely with the MS Society UK, who funded the programme) we innovated a short term palliative care service for people severely affected by MS. The service was multiprofessional – with a doctor, nurse, psychosocial worker and co-ordinator – and was designed to quickly sort out symptoms, care co-ordination and help with future planning, including end of life planning if appropriate. After around 3 visits the service would hand over to other local services (Higginson, et al., 2006; Higginson, et al., 2008).

We evaluated this new service in a RCT, and achieved our recruitment targets as planned (which is unusual in palliative care trials). We believe we achieved these targets because of our careful planning, our patient participation in the planning, and the innovative trial design – a fast track trial (see methods innovation section) (Higginson, et al., 2006; Higginson, et al., 2008).

We found that the group receiving earlier short term palliative care, at 12 weeks had:

a) Improvement in 5 key symptoms, (Mean change -1.0), compared with a deterioration in the control group (mean change 1.1, F=4.75, p=0.035)

b) An improvement in caregiver burden as assessed with the ZBI, and a deterioration in the control group (F=7.6, p=0.013)

c) Lower total costs (£1,789, bootstrapped 95% CI was -£5,224 to £1,902) compared to the control group. The main cost savings were in hospital costs, the caregiver costs were unchanged by the service.

Importantly the service appeared to produce better outcomes for patients and families at lower costs (see Figure 5).

Figure 5. Cost effectiveness plane, plotting difference in costs against difference in caregiver burden as assessed by the Zarit Burden Inventory (ZBI). Points in the UPPER LEFT quadrant would indicate higher costs and worse outcomes, points in the LOWER RIGHT quadrant indicate lower costs and better outcomes. These data show better outcomes and usually lower costs. (Higginson, et al., 2009)
Defining the palliative care needs of people with late stage Parkinson’s disease, Multiple System Atrophy and Progressive Supranuclear Palsy

PD and associated Parkinson’s Plus conditions are becoming more common with the ageing of society. To better understand the needs of those affected, supported by the UK Department of Health we have completed a research project aiming to provide robust longitudinal data on symptom prevalence and severity, health costs, and care needs in the advanced stages of PD and the related ‘Parkinson plus’ disorders.

Implementation of an end of life care pathway in intensive care units: does it make a difference?

This mixed method study is being led by Professor Irene Higginson with a team including Caroline Rumble, Cathy Shipman, Jonathan Koffman, and colleagues from both the King’s College Hospital Palliative Care Team (PCT) and Adult Intensive Care Units (ICUs). The aim is to develop, implement and evaluate an intervention to improve EoLC in adult ICUs, based on research into the experience of families and patients and the views of ICU and palliative care professionals and referring clinicians.

The study team gathered data on experiences, views and preferences about EoLC from relatives and staff, and disseminated results to ICUs and palliative care staff through an EoLC group forum. This group facilitated the development of a complex intervention comprising an amended EoLC guidance document, a psychosocial assessment document, a GP fax proforma, education and awareness-raising of the importance of EoLC, input and support from the hospital PCT and increased psychosocial support. Formal evaluation of this complex intervention will observe the effect of the care pathway on the process and quality of care, changes to practice, and provide guidance for future implementation.

Dignity Therapy: a novel therapy at the end of life

Loss of dignity for people reaching the end of life is associated with high levels of psychological and spiritual distress and the loss of will to live. Dignity Therapy is an intervention developed by Professor Harvey Chochinov, at the University of Manitoba, Canada, for cancer patients in Canada, which was previously untested in other parts of the world and with other patient populations.

The implications of these findings could be considerable – around 85,000 people of the 57 million UK population have MS, of whom about 11% i.e. 9,350, are severely affected according to a disability score (note this cut off may underestimate the number of people who would benefit). Even if the palliative care service produced only three months of cost savings, rolling it out across the UK could result in total cost savings of almost £17 million per year.

The work was published in the top palliative care journal (Higginson, et al., 2009) and the top MS journal (Edmonds, et al., 2010). The data also allowed us to estimate sample size and methods for a multicentre trial.

Interestingly we also found that, if one takes a societal approach to costs, the main costs are those of informal care (for which caregivers were not reimbursed), followed by hospital costs in the NHS (Higginson, et al., 2009).

In a follow-up study, the effects of the service appeared to wane after the service is withdrawn. The service is withdrawn after 4-6 weeks and sometime (12 – 24 weeks) later its effects wane. This suggests that attention is needed to the educational work of the service and/or some kind of pulsed support is needed (Higginson, et al., 2011).

All these findings are relevant to other long term conditions for which palliative care is considered, as MS is good model for many of these.
Dignity Therapy is a brief psychotherapy intervention. It comprises a recorded interview in which the participant talks about the things they would most want to be known or remembered regarding their life, identity or loved ones, which is then transcribed, edited and returned to the patient for bequeathing to people of their choosing. Sue Hall and Professor Irene Higginson, in collaboration with Canadian colleagues, led two phase II clinical trials of Dignity Therapy, one with 45 advanced cancer patients, and one with 60 older people in care homes in London (Hall, Longhurst and Higginson, 2009a; Hall, Longhurst and Higginson, 2009b). Both quantitative and qualitative results showed that Dignity Therapy is feasible and acceptable for advanced cancer patients and older residents in care homes, and resulted in potential improvements in hopefulness, sense of purpose and will to live.

Improving information giving: The Question Prompt List
The Question Prompt List (QPL) - a structured list of topics and questions for patients and carers to raise with their health professionals - was pioneered in Australia, and showed effectiveness under trial conditions. In a recent study in our Institute, changes were suggested to tailor the QPL more to the needs of UK patients, by inclusion of questions relating to diet, lifestyle, benefits etc. Following a wide clinical consultation, the original intervention has been adapted to take into account the changes, and a pilot randomised controlled trial (RCT) has been started to determine the most feasible evaluation methods.

A public health evaluation of PEPFAR Care and Support in Kenya and Uganda
The President’s Emergency Plan for AIDS Relief (PEPFAR), funded by the US government, is the biggest programme ever launched against a single disease. Its three objectives are:
• Prevention of new infections
• Treatment with antiretroviral therapy
• Palliative care (care and support)

Richard Harding, Professor Irene Higginson and Vicky Simms carried out a mixed-methods public health evaluation of PEPFAR-funded HIV palliative care provision in Kenya and Uganda in 2007-2008, in collaboration with the African Palliative Care Association (APCA). A survey of 120 care facilities in Kenya and Uganda found that over 90% of facilities provided some level of clinical, psychological, and preventive care, but pain control was very limited with paracetamol often the only analgesic. In focus group discussions, patients appreciated free care and positive attitudes from staff, but said that services would be improved by more staff, shorter queues, and reliable drug supplies (Harding, R., et al., 2009. PEPFAR Public Health Evaluation Care and Support. Phase 1: Uganda. University of North Carolina. Available at: http://www.cpc.unc.edu/measure/publications; Harding, R., et al., 2009. PEPFAR Public Health Evaluation Care and Support. Phase 1: Kenya. University of North Carolina. Available at: http://www.cpc.unc.edu/measure/publications).

Phase 2 consisted of a longitudinal cohort study to measure patient-reported outcomes of care and support, a costing survey, and qualitative interviews to understand patient and carer experiences. The results showed that over time and with care, physical and mental health improved, and multidimensional problems were reduced. Patients taking antiretroviral (ART) therapy had the same level of self-reported health as those not taking ART. Almost all participants received preventive care but social and spiritual care was more limited, and challenges included staff burnout and overwhelming need (Harding, R., et al., 2010. PEPFAR Public Health Evaluation Care and Support. Phase 2: Uganda. University of North Carolina. Available at: http://www.cpc.unc.edu/measure/publications; Harding, R., et al., 2010. PEPFAR Public Health Evaluation Care and Support. Phase 2: Kenya. University of North Carolina. Available at: http://www.cpc.unc.edu/measure/publications).

“This has given me an outlet, an outlet for talking about my life and, again, brought a purpose. It’s not just ended with nothing... it made me feel that it wasn’t just, I wasn’t just a number, it’s... a part of something that’s going to be carried on for the future.”

Comment from a cancer patient receiving Dignity Therapy
Symptom-led Research

Our research into symptoms focuses on the better understanding of individual symptoms but also, importantly, on improving management and treatments for symptoms found in palliative care and rehabilitation. Symptoms being studied include breathlessness, depression and spasticity.

Breathlessness

Understanding and improving breathlessness in advanced disease

Building on the work featured in the previous report, the Improving Breathlessness programme investigates the effects of breathlessness on patients suffering from advanced conditions, and the effectiveness of treatments to alleviate symptoms encountered.

The experience of breathlessness

To better understand the experience of breathlessness and its effects on patients and caregivers across different conditions - lung cancer, chronic obstructive pulmonary disease (COPD), cardiac failure and MND - Marjolein Gysels and Professor Irene Higginson conducted qualitative interviews with 76 patients and 27 carers, which showed that distress and disability were experienced as a result of breathlessness regardless of disease state (Gysels and Higginson, 2011).

Interviews with COPD patients revealed that contact with healthcare was postponed to crisis point, once the symptom had acquired meaning in a person’s life, and that a lack of clear prognostic information contributed to the lack of reference to the future seen in patient narratives. The results show that good communication practices are fundamental in the care for COPD patients and that diagnosis and prognosis in particular need to be rethought to suit the condition.

The carer interviews revealed that breathlessness was particularly challenging - carers did not have strategies to relieve the symptom and were ill prepared for acute exacerbations. There is a need for carers to be included in opportunities for support provision in advanced illness.

Patients who had undergone the pulmonary rehabilitation appeared to have the best coping strategies, providing further support for this intervention (Gysels and Higginson, 2010)

Symptom burden and breathlessness trajectories

Little is known about the trajectories of breathlessness over time and towards death. To address this gap in the knowledge, the symptom burden of patients with advanced cancer or severe COPD and the course of breathlessness over time was examined in a longitudinal study conducted by Claudia Bausewein. Patients were followed until death or over six months, and results showed that for COPD patients, breathlessness increased over time, whereas in cancer patients breathlessness increased towards death. Twenty-one cancer and 43 COPD patients provided data for individual breathlessness trajectories, which revealed wide individual variations with four different patterns: fluctuation, increasing, stable and decreasing breathlessness. Symptom trajectories on the population level representing the whole group mask individual variation, reflected in distinct symptom trajectories with different patterns (Bausewein, et al., 2010a).

What treatments are effective at relieving breathlessness?

We conducted two Cochrane Reviews looking at the effectiveness of treatments for the relief of breathlessness. In the first, the effectiveness of non-pharmacological interventions to relieve breathlessness in advanced disease was evaluated, with twelve different types of intervention identified in 47 studies – mostly conducted with COPD patients. The results showed that breathing training, walking aids, neuro-electrical muscle stimulation and chest wall vibration appear to be effective non-pharmacological interventions for relieving breathlessness in advanced stages of disease. The evidence for acupuncture/acupressure was low and there was no evidence for the use of music. There was not enough data to judge the evidence for relaxation, fan, counselling and support, counselling and support with breathing-relaxation training, case management and psychotherapy (Bausewein, et al., 2008).

As benzodiazepines are widely used in clinical practice to relieve breathlessness, we undertook a second Cochrane Review to assess their effectiveness. This review identified seven studies, including 200 analysed participants with advanced cancer and COPD. Analysis of all studies, including a meta-analysis of six out of seven studies, did not show a beneficial effect of benzodiazepines for the relief of breathlessness in these patients. The results support the use of benzodiazepines only if other first-line treatments, such as opioids and non-drug treatments, have failed to control breathlessness (Simon, et al., 2010).
Antidepressants have been shown to ease depression in physically healthy people, but there are doubts about whether they are appropriate in people with a physical illness. To inform the treatment section of the European Palliative Care Research Collaborative (EPCRC) guidelines, Lauren Rayner and Professors Matthew Hotopf and Irene Higginson conducted, with other leading experts in the field, a Cochrane Review of antidepressants for depression in physical illness (Rayner, et al., 2010). Fifty-one studies including 3603 patients were included in the review, which compared antidepressants and placebo at 4-5, 6-8, 9-18 and >18 weeks. Meta-analysis showed that antidepressants were more effective than placebo at every time-point. The effect size was greatest at 6-8 weeks, and this analysis included the largest number of trials and patients (see Figure 6).

Overall, the findings suggest that antidepressants are effective in treating depression in people with a physical illness and should be considered for this patient group.

In addition, a subgroup analysis of trials in patients with a life-threatening illness was conducted to explore whether antidepressants may be appropriate in a palliative care setting. Twenty-five studies were included in this meta-analysis which again showed antidepressants to be more effective than placebo at every time-point. It is probable that the effect sizes yielded in these reviews overestimate the efficacy of antidepressants due to biases such as selective reporting and publication. However, the magnitude and consistency of the effect does suggest genuine benefit.

Development of a clinical practice guideline on the management of depression in palliative care

Depression is common among patients with advanced disease and is associated with many adverse outcomes such as poorer prognosis, poorer quality of life, and increased disability. A four year project, undertaken on behalf of the EPCRC and led by Professor Irene Higginson, Lauren Rayner and Professor Matthew Hotopf, commenced in November 2007 to develop a clinical practice guideline on the management of depression in palliative care. The aim was to provide evidence-based recommendations on managing depression in palliative care to inform clinical practice, establish policy, promote European consensus and ultimately improve patient outcomes.

The guideline was developed in accordance with the methods of the National Institute for Health and Clinical Excellence (NICE), and an expert group was constituted to help identify clinical priorities, provide expert opinion and critically discuss and develop the guideline recommendations. Recommendations were devised using the best available evidence, and where evidence was absent or equivocal, Delphi consensus methods were implemented to elicit and refine expert opinion.

The resulting guideline has three main sections: 1) prevention; 2) detection, diagnosis and assessment; 3) treatment. The prevention section outlines strategies such as optimal palliative care and support, effective communication and information-giving. The detection section provides recommendations on symptoms, screening, diagnosis and severity assessment. The treatment section gives guidance on treatment decisions including choice of psychological therapy and antidepressant medication.

This is the first comprehensive, evidence-based guideline on managing depression in palliative care, putting together the most current and important evidence in the field, enabling clinicians to access and implement evidence-based knowledge quickly and easily. In addition, the group produced a patient-friendly leaflet on depression in advanced disease which has been translated into five European languages (Rayner, et al., 2010; Rayner, et al., 2011b).

Figure 6: Forest plot of response to treatment at 6-8 weeks: antidepressants versus placebo. (Rayner, et al., 2010)
The effectiveness of a hand-held fan
Claudia Bausewein embedded into her longitudinal study an RCT of 70 patients to test the feasibility of using a hand-held fan (HHF) compared to a wristband over time to relieve breathlessness. After two months, about half of the patients used the fan but only 20% the wristband without a statistical difference, and 9/16 patients judged the fan as helpful versus 4/5 patients the wristband. There was no difference in mean breathlessness change scores between the HHF and the wristband at this time point. The study found that the preliminary evidence of effectiveness of the HHF could not be proved, and also highlighted the challenges associated with finding a suitable control for a visible intervention. Further work is underway to identify those who might benefit from the fan (Bausewein, et al., 2010b).

Depression
Improving the management of depression in palliative care
One of the most neglected areas of healthcare research is the effects of physical illness on an individual’s mental health. Work in the Cicely Saunders Institute aims to improve the understanding and treatment of depression in palliative care setting and rehabilitation. This work is carried out in collaboration with Professor Matthew Hotopf from the Institute of Psychiatry at King’s College London, who is a world leading expert in this field and a key collaborator in the Cicely Saunders Institute. See in focus for examples of evidence review and guidelines.

Cross-sectional survey of depression in palliative care
Estimates of the prevalence of depression in palliative care vary widely due to methodological problems, such as small sample size, and there is a dearth of data on the course of depression in this patient group. In an observational study, Lauren Rayner, Professors Matthew Hotopf and Irene Higginson, and colleagues determined the prevalence and remission of depression in a sample of 300 consecutive patients, who were interviewed at the point of registration with a palliative care service and followed up one month later. Nineteen per cent met criteria for major depression at the first interview, and of those 58 depressed patients, 69% no longer met criteria for major depression when followed up. This study indicated an increased risk of depression in palliative care, but refuted the notion that depression is inevitable or integral to the dying process. The high remission rate suggests that good palliative care has a positive impact on patients’ mood (Rayner, et al., 2011a).
**Spasticity**
Management of spasticity in patients with hemiparesis. Spasticity is a common symptom in patients 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 focal spasticity are to improve passive function (to make it easier to care for the limb) or to restore active function when possible, with the main treatment options being physical therapy and Botulinum toxin type A (BoNT-A).

Dr Stephen Ashford and Professor Lynne Turner-Stokes explored the role of BoNT-A in the management of the spastic hemiplegic shoulder and identified common achievable goals for treatment. They also identified that BoNT-A injection of the proximal upper limb, with combined therapy, produced a reduction in spasticity, and an improvement in passive function and pain. Management of upper limb spasticity should therefore include evaluation and, if necessary, treatment of the shoulder girdle and proximal musculature (Ashford et al, 2009).

The researchers further tested the combination of physical therapy and Botulinum toxin (BoNT) in an open label prospective cohort study with 58 patients conducted in a two-centre specialist spasticity management setting in London. This showed that passive function was improved following BoNT administration and physical therapy intervention by 8 weeks and that this was maintained at 16 weeks despite the physiological effects of the BoNT gradually reducing over this time period (see Figures 7 and 8) (Ashford, S., Turner-Stokes, L., and Slade, M., 2010. Physical therapy and botulinum toxin-A (BoNT-A) – the temporal relationship between spasticity reduction and functional gain. American Academy of Physical Medicine and Rehabilitation, Seattle USA, November 5; Ashford, S., Turner-Stokes, L., and Slade, M., 2011. The temporal relationship between spasticity reduction and functional gain following focal spasticity interventions. World Confederation of Physical therapy, Amsterdam, Netherlands, June 21.). The role of individual physical therapy interventions in generating and maintaining passive function gains following spasticity management with BoNT warrants further exploration.

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**Figure 7**: ArmA passive function change from baseline to 8 and 16 weeks (n=38) (Ashford, S., Turner Stokes, L., and Slade, M., 2010)

**Figure 8**: Composite Modified Ashworth change from baseline to 8 and 16 weeks (n=44) (Ashford, S., Turner Stokes, L., and Slade, M., 2010)

Additional work evaluating spasticity intervention undertaken in collaboration with other centres and the British Society of Rehabilitation Medicine focused on systematic recording of multicentre intervention data (Upper Limb Intervention Study-1; ULIS-1) and outcomes data from multiple centres internationally (Upper Limb Intervention Study-2; ULIS-2).

The ULIS-1 study, a UK pilot for a large international prospective cohort analysis of the use of BoNT-A in upper limb spasticity, examined routine clinical practice in the use of BoNT for upper limb spasticity in the UK, identified commonly used methods for clinic-based documentation, follow-up and outcome evaluation, and piloted a preliminary case report proforma for future use in a large international prospective cohort study. The study showed that although there was wide diversity with respect to normal clinical practice and documentation, the recording of goals and their achievement was readily undertaken by most clinicians. Further training is required, however, to develop consistency in methods of recording goal attainment.

ULIS-2 is currently ongoing to explore outcomes data in routine clinical practice, having implemented further training in goal recording and setting using the Goal Attainment Scaling (GAS) method (see section 2.3: Patient-reported Outcome Measures for more on GAS). (Ashford, S., Turner-Stokes, L., and Slade, M., 2010)
2.4 Patient-reported Outcome Measures

Palliative care and rehabilitation are both relatively new fields in healthcare and deal with conditions where quality of life is a primary focus, and assessing individual patient needs and the quality and cost effectiveness of service delivery are central concerns. Much of the work in the Institute is spearheading the development of scientifically rigorous outcome measures that measure the outcomes that matter most to patients and their families. 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, led by Richard Siegert.

Patient-centred palliative care outcome scales
The Institute has been a leader in the development of patient-reported outcomes measures (PROMs) for palliative care since its inception in 1996. In particular, Professor Higginson and colleagues have been at the forefront of the need for short outcome measures, and have validated and refined two measures; the Support Team Assessment Schedule and the Palliative care Outcome Scale, as well as testing short form measures.

Support Team Assessment Schedule
The Support Team Assessment Schedule (STAS) was developed by Professor Irene Higginson and is a unique tool that assesses the clinical intermediate outcomes of palliative care. Before STAS was developed there was no standard reliable, valid and responsive measure to assess palliative care - most existing measures had floor effects and did not reflect palliative care goals. STAS can be used in studies to compare palliative care services or in clinical audit and 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., 2011).

Palliative care Outcome Scale
The Palliative care Outcome Scale (POS) is an outcome measure questionnaire specifically developed for use in palliative care settings, which was devised after a systematic review of palliative care outcome measures found a paucity of clinical questionnaires that adequately reflected the holistic nature of palliative care (Hearn and Higginson, 1997). The POS evolved from a literature review of measures, work by a multi-professional project group with individuals who worked in different palliative care settings, and a patient representative, and was piloted in hospice, home, hospital and other community settings. The questionnaire covers physical and psychological symptoms, spiritual considerations, practical and emotional concerns and psychosocial needs, and the two versions of the questionnaire - one for patients to complete, the other for staff - bring together two complementary perspectives allowing patient’s problems to be identified and enabling staff to provide individualised care. The POS showed acceptable validity when used in a variety of settings such as home care, hospice inpatient and day care, and hospital inpatient care, as well as outpatient and community services, and was shown to be a credible, clinical, research and audit tool acceptable to both patients and staff (Hearn and Higginson, 1999). The POS can be used routinely to guide clinical practice and monitor service interventions, and is a valuable audit tool that can help meet the current statutory requirements on clinical governance.

A user’s guide to the POS, developed in collaboration with the Palliative care Outcome Scale Action Partnership and with the financial support of Help the Hospices, was published (Aspinal, et al., 2002) to enable both health professionals and researchers to achieve the maximum potential from the measure. It provides further details on the origins of the POS, and suggestions for its implementation in clinical practice, and analysis of data.

Further development (see Figure 9) validated POS in a German palliative care context (Bausewein, 2006), and compared it with two other quality of life scales (Higginson and Donaldson, 2004). In addition to German the POS has been translated into Italian, Spanish, Portuguese, Urdu, Punjabi, Chinese, Dutch, French, Khmer and Malayalam (Bausewein, et al., 2011). POS has subsequently been further developed in Africa, and as part of the PRISMA project, with a new symptom card for assessment, see below.

Gao Wei and Professor Irene Higginson and colleagues tested the validity of a family completed version of POS. This is important because patients cannot often complete assessments when they become ill, but the accuracy of family assessments is not known. The research found that for many aspects agreement between caregivers and patients was substantial or good. But compared with patients self-ratings, caregivers described more problems with information given and sharing feelings and were less likely to assess the patient felt their life was worthwhile or felt good about themselves. However, caregiver burden and positivity affect their assessments, especially of psychological patient domains and whether patients assess their life as worthwhile. Disagreement for three POS item ratings was significantly associated with higher caregiver burden: “feeling anxious” (OR: 4.5; 95%CI: 1.3 to 15.6), “life worthwhile” (OR: 12.4; 95%CI: 2.9 to 54.3) and “felt good” (OR: 7.7; 95%CI: 2.0 to 29.6) (Gao, et al., 2008).

Richard Siegert led a factor analysis of POS data. We began with a confirmatory factor analysis (CFA), which indicated that the POS is not a unidimensional scale. This was followed by an exploratory factor analysis that
suggested two factors—one reflecting a psychological well-being dimension and the other consisting of three items relating to the standard of professional care. A similar two-factor structure also was identified in the second sample using CFA. Thus POS appears to capture two factors, psychological status and quality of care, and to have three items that function independently (family anxiety, symptoms, and pain control). These findings suggest that future evaluations of palliative care services should include assessment not only of symptoms and well-being or quality of life, but also of quality of care, and that unidimensional measures will not capture all relevant aspects in palliative care (Siegrist, 2010).

**African Palliative Care Association African Palliative care Outcome Scale**

In response to our systematic review of palliative care outcomes in Sub-Saharan Africa (Harding, et al., 2010), Richard Harding led a collaboration of the Universities of Cape Town, KwaZulu Natal and the Witwatersrand with the African Palliative Care Association to develop and fully validate the APCA African POS. The work was carried out with local partners and a wide range of pan-African clinical sites to ensure that the tool was tested across conditions and countries; local researchers piloted the tool in 11 sites across eight countries, and it was subsequently validated in 682 patients and 473 carers in five care centres.

**Palliative care Outcome Scale - Symptoms**

A further development of the Palliative care Outcome Scale is the addition of a symptom list - POS-S, with ten symptoms and two open questions about which symptom affected the patient the most and which symptom has improved the most (Bausewein, et al., 2011c). The standard POS-S has been developed for cancer, the POS-S Renal for end stage kidney disease (Murphy, Murtagh, Carey and Sheerin, 2008), the POS-S PD for patients with Parkinson’s disease and the POS-S MS for advanced Multiple Sclerosis patients.

More recently a POS and POS-S booklet have been developed as part of the PRISMA project, in collaboration with Centro de Estudos e Investigação em Saúde da Universidade de Coimbra and Hospital Santa Maria, Portugal. The format and content of this booklet, a pocket version, have been designed for everyday use by clinicians and researchers, and it can be used to complement the POS user guide. Initially produced in English and Portuguese it has been translated into Dutch, Italian, Spanish and German and will be further translated into French.

**PRISMA Measurement tools: POS and STAS**

As reported, the Cicely Saunders Institute led the important European Commission funded project, PRISMA, which organised 11 partners across nine countries into a series of work packages to coordinate the key research priorities for EoLC throughout Europe. Claudia Bausewein led a PRISMA work package on best practice and resources in EoLC, focusing on:

- Identifying and describing the ways in which the Palliative care Outcome Scale (POS) and the Support Team Assessment Scale (STAS) and other tools are used as measurement tools in European countries and Africa. A survey into tool use in EoLC saw two thousand invitations sent to potential respondents in Europe, plus hundreds sent within Africa; the findings are awaiting publication.

- Coordinating the exchange of experiences of those who use the POS and STAS and other tools in EoLC

- Developing resources and support for those who use the tools. A guidance booklet on the use of outcome measures in EoLC is produced.

A notable output from project PRISMA in 2011 was our Palliative care Outcome Scale website http://pos-pal.org. PRISMA’s research showed that clinicians and researchers needed resources to aid their work, and their work could be aided through the provision of outcome measurement training and guidance. E-learning will feature on our new website and guidance regarding good outcome measurement practice. A POS development team has also been established to help advance the work of POS users situated around the world.

**Short measures for use in palliative care and rehabilitation**

When patients are very ill short measures are needed. Therefore as part of the work in the National Cancer Research Institute (NCRI) collaborative COMPASS, Professor Irene Higginson and Gao Wei developed a collaborative programme to test measures that might be shorter, with as few questions as possible.

We found that in palliative care a six question version of the ZBI was as good as the 22 or 12 item version, and even a four item version might work in some screening situations (Higginson, et al., 2010), (see Figure 10).

**Measures for rehabilitation in the UK**

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 with which to assess the effectiveness of rehabilitation intervention, and exploration of the relationship between different measures in current use in the UK. Evidence has been presented that clearly demonstrates that rehabilitation is not only effective, but also highly cost-effective in patients with severe complex disabilities following acquired brain injury.

A set of tools to measure complexity of patient rehabilitation need, service inputs and service outcomes for neurological rehabilitation services has been developed by this department. These are undergoing continued testing and refinement, and form part of the national dataset for specialist rehabilitation services.

**Rehabilitation Complexity Scale**
The Rehabilitation Complexity Scale (RCS) 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 RCS is designed to provide a crude 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 specialist Rehabilitation Outcomes Collaborative dataset (UKROC), led by Professor Lynne Turner-Stokes and based at Northwick Park Hospital, London was set up in September 2008 to develop a national database for collating case episodes for inpatient rehabilitation. The first five years focus on neurorehabilitation and it will ultimately include data from all specialist neurorehabilitation services (levels 1 and 2) across the UK. The database will be developed

**Figure 10. Receiver Operating Characteristic (ROC) curves for various short-form versions of ZBI and areas under the curve (AUC, 95% confidence interval), a total score of 46 on the full scale ZBI as the cut-off value between low and high burden. (Higginson, et al., 2010)**
in collaboration with the British Society of Rehabilitation Medicine (BSRM) and the Australasian Rehabilitation Outcome Centre (AROC), which is now 10 years into a similar programme. The UKROC database will provide: Casemix and costing data to inform development of complexity-weighted tariffs by 2012; Benchmarking of service quality and outcomes.

It will also serve to ‘open the black box of rehabilitation’ by providing information on rehabilitation requirements, the inputs provided to meet them, outcomes and cost-benefits of rehabilitation for patients with different levels of need.

The full UKROC 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 together with measures of:

1. Rehabilitation needs – documenting the individual requirements for rehabilitation measured by the Rehabilitation Complexity Scale (RCS)
2. Input – documenting the services actually provided to meet those needs, so unmet needs can be identified and reasons for variance can be recorded; medical, nursing and therapy inputs are recorded by the Northwick Park Dependency Scales (NPDS and NPTDA)
3. Outcomes – the gains that are made during rehabilitation; these are recorded using an agreed set of measures which include the UK FIM + FAM (Full dataset), Barthel index (Minimum dataset) and Goal Attainment Scaling (GAS) (see below) as a person centred outcome

The hierarchical dataset structure (illustrated in Figure 11 above) 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 casemix 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 (Turner-Stokes, 2009). 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.
In Focus

The Arm Activity measure – a measure of active and passive function in the hemiparetic arm

Background
The complex nature of upper limb function presents a challenge for rehabilitation following neurological injury. Some patients with relatively mild injury have potential to recover useful function, such as the ability to use the hand to hold and manipulate objects (active function). Others with more severe injury will continue to have a non-functional upper limb, and may require assistance from another person (or their own non-affected arm) to care for the affected limb (passive function). The aim of this work was to develop and evaluate a self-report upper limb measure of active and passive function – the Arm Activity measure (ArmA) (see Figures 12 and 13). Goals for hemiparetic upper limb may be:

a) To restore active function if motor control is possible, or
b) To improve passive function making it easier to care for the limb

A systematic review demonstrated that no suitable measure was available, but provided possible items for inclusion in the ArmA. Patient-selected items were also included from goal setting for spasticity intervention. A modified Delphi consultation was undertaken to reduce the number of items, followed by item confirmation with a larger group of clinicians and pilot testing with patients and carers. The resulting twenty-item measure has two sub-scales of ‘active’ and ‘passive’ function (Ashford, Slade, Malaparade and Turner-Stokes, 2008).

Results
No ceiling or floor effects were identified in the Time 1 ratings on the passive function sub-scale. However a ceiling effect occurred with 37% of scores for active function at the maximum point on the scale.

Conclusion
Following preliminary psychometric evaluation, the ArmA passive function scale fulfils a number of psychometric requirements for use in measurement for research and clinical practice. Further evaluation will be valuable and is ongoing for both sub-scales, but particularly the active function sub-scale in a more able patient group.

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>0 = no difficulty</th>
<th>1 = mild</th>
<th>2 = moderate</th>
<th>3 = severe difficulty</th>
<th>4 = unable to do activity</th>
</tr>
</thead>
</table>

In each column, please CIRCLE the amount of difficulty that you or your carer have experienced in doing the activity, over the last 7 days

### Activities
(affected arm)

<table>
<thead>
<tr>
<th>Activities</th>
<th>Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Cleaning the palm of the hand</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>2 Cutting finger nails</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>3 Cleaning the arm pit</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>4 Positioning arm on a cushion or support in sitting (if never done circle 0)</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>5 Putting arm through a garment sleeve</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>6 Putting on a glove (if never done circle 0)</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>7 Putting on a splint (if never done circle 0)</td>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>

### Section A Caring for your affected arm (not using it in tasks or activities)

1. Cleaning the palm of the hand
2. Cutting finger nails
3. Cleaning the arm pit
4. Positioning arm on a cushion or support in sitting (if never done circle 0)
5. Putting arm through a garment sleeve
6. Putting on a glove (if never done circle 0)
7. Putting on a splint (if never done circle 0)

### Section B Independently completing tasks or activities

Please indicate by circling yes (Y) or no (N) if this item involves use of your affected arm or both (B) for both arms used

<table>
<thead>
<tr>
<th>Activities</th>
<th>Y / N / B</th>
<th>Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 Difficulty with balance when walking due to your arm</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>9 Hold an object still while using unaffected hand</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>10 Open (affected hand) a previously opened jar</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>11 Pick up a glass, bottle, or can</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>12 Drink from a cup or mug</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>13 Brush your teeth</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>14 Tuck in your shirt</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>15 Write on paper</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>16 Eat with a knife and fork</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>17 Dial a number on a home phone</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>18 Do up buttons on clothing</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>19 Comb or brush your hair</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>20 Use a key to unlock the door</td>
<td>Y / N / B</td>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>

Figure 12: The ArmA was developed for evaluation of active and passive function in the paretic upper limb. (Ashford, et al., 2008)
2.5 Impact on Policy

Much of our work is quoted in policy documents such as the UK End of Life Care Strategy and the National Service Frameworks for many conditions, such as long term conditions, heart failure, renal disease.

A further major area of work is the demonstration of effectiveness and measurement of rehabilitation and palliative care through systematic review of the literature and the development of evidence-based standards and guidelines. These guidelines play a significant role in influencing policy regarding the provision and quality of rehabilitation services and palliative care services in the UK, building on work for the NICE outlined in our last triennial report.

For example, since 2007 we have published eight Cochrane Reviews (five in rehabilitation and three in palliative care), along with over 37 other reviews and meta-analyses.

Our work as a World Health Organization Collaborating Centre means that we produce policy guidance for the World Health Organization.

In collaboration with an expert African spiritual care group, we produced guidelines on spiritual assessment for patients and families in African palliative care populations, with a foreword by Desmond Tutu. (Selman, et al., 2010. Spiritual care recommendations for people receiving palliative care in Sub-Saharan Africa. Available at: http://www.csi.kcl.ac.uk/spiritualcare.html)
2.6 Methodological Innovation

As illustrated throughout this report, palliative care and rehabilitation pose particular challenges in research. Patients who use these services are often very ill, the outcomes to be measured are very individual and clinical trials suffer from difficulties of recruitment and attrition. The patients, their families and the services required to meet their needs are all complex.

The Institute is responding to these challenges by innovating and improving research methods for this group of patients, and developing an understanding of whether and why patients and families wish to participate in research. Areas of development cross the main research programmes, and have included: refinement of trial designs, both randomised and non-randomised; carrying out research with vulnerable groups; refining longitudinal study designs with non-cancer and cancer groups; outcome measurements; identifying a pan-European consensus on best practice; informing quality assurance and measuring spirituality. The programmes encompass both national and international work to aid developments in policy, clinical practice, teaching and research. Some highlights of our work are below.

Are patients and bereaved families willing to participate in research?

The Institute has led studies on how to enable patients’ participation in research and has incorporated this understanding in designs to build the evidence base on the effectiveness of interventions. Innovation has enabled patient/carer participation, particularly for those with the severest symptoms who may benefit most from a palliative care intervention.

Willingness to take part in research

Research into palliative care is often hampered by poor recruitment and retention of participants. To develop the evidence base in this area requires a greater understanding of patients and families’ attitudes to participation and any motivational factors (Gysels, 2008a; Gysels, 2008b).

Marjolein Gysels and colleagues’ study on patients’ and families’ participation in palliative care research challenges views on this group’s desire and ability to participate in research studies, variance by disease group, and the potential benefits from participation (Gysels M, 2008a; Gysels, 2008b). The processes of recruiting and interviewing patients and families bestowed a greater understanding of the organisational, methodological and ethical issues inherent when undertaking research in palliative care. Differences in individuals’ motivation to participate reflected the heterogeneity in this population group, and motivation to participate also varied by disease group and reflected patterns of decline; the steeper the trajectory of decline, the less likely patients were to participate. Patients’ motivation to participate is influenced by a sense of altruism, the opportunity to discuss experiences, and the services received - an awareness of these motivational factors, and their variance by disease group, helps inform how to tailor recruitment strategies to different patients groups, such as timing in mapping participation requirements with disease stage, and by emphasising the benefits of participation.

Cathy Shipman and colleagues iterated these findings (Shipman, et al., 2008) in their study of advanced cancer patients’ participation in longitudinal research. This demonstrated the willingness of patients to participate, with involvement often viewed as being a positive and supportive experience as it allowed participants the opportunity to talk about their experiences. Research recruitment and data collection strategies need to show sensitivity to patients fluctuating symptoms, and take into account the preference for participation to be in the comfort of their own home, and to involve face-to-face interviews.

Testing new interventions

Trials of new palliative care services are uncommon, particularly for non-cancer conditions, and are beset with methodological challenges that may precipitate trial failure. A fast track randomised phase II trial of a palliative care service for people severely affected by MS demonstrated the feasibility of this trial design for very ill patients (Higginson, et al., 2008; Edmonds, et al., 2010); the cost effectiveness of short term palliative care for this group that supports application of a phase III trial (Edmonds, et al., 2010; Higginson, et al., 2009); and addressed an area where palliative care is considered applicable, but evidence on effectiveness and cost-effectiveness is weak.

The project is the first report of a fast track randomised design in palliative care, and the study design built on earlier work on developing a model of short-term palliative care (Edmonds, et al., 2007; Edmonds, et al., 2007) reported in our 2004/5-2006/7 report. Fast track uses a ‘wait list’ control or delayed intervention group, giving all patients the possibility of receiving the service - some immediately, and others following a wait equivalent to normal NHS services (see Figure 14). The research project developed the term ‘fast track’ as opposed to ‘wait list’, to more accurately convey promptness of service receipt compared to standard care (Higginson, et al., 2008). The project randomised 52 patients severely affected by MS to fast track or control, and the results demonstrated the intervention lowered caregiver burden and cost-effectiveness compared to the control (Higginson, et al., 2009).
The project demonstrated that fast track randomisation was feasible and suitable for patients with advanced illness and severe symptom burden, maintained good recruitment and compliance rates, and scored highly in terms of patient acceptance and preference (Higginson, et al., 2008; Edmonds, et al., 2010; Higginson, et al., 2009). Missing data in the trial was minimal (mean 1–5 items out of 56 items per interview) with the majority of patients (95%) completing the outcome measurement questionnaires over the time points (Higginson, et al., 2008). This was an achievement in itself given the high levels of fatigue and symptom burden experienced by these patients.

Other research groups have worked with the Institute to adopt this trial design for palliative care patients, including colleagues at University of Cambridge who are using a fast track design to evaluate the effectiveness of a Breathless Intervention Service (BIS) for patients with COPD or cancer (Farquhar, Higginson, Fagan and Booth, 2010). Professor Irene Higginson has worked with the group to develop the fast track methodology, testing the feasibility of single-blinding in a fast track pragmatic randomisation of BIS verses standard care (Farquhar, Higginson, Fagan and Booth, 2009; Farquhar, Higginson and Booth, 2009; Farquhar, 2010). The trials demonstrated the feasibility of this methodology for both cancer and non-cancer patient groups, attainment of recruitment and sample size, and relatively minimal missing data. The feasibility of single-blinding is, however, inconclusive with a relatively high un-blinding rate (6/25 early un-blinding) (Farquhar, Higginson, Fagan and Booth, 2010).

**Building research methods**

Testing new interventions to improve palliative care is complex. The Medical Research Council (MRC) has developed a ‘Guidance on the Development and Evaluation of Complex Interventions’ (Campbell, et al., 2000; Campbell, et al., 2007). Our research projects are at the forefront of developing and applying this framework to evaluations on complex interventions in palliative care.
Sue Hall and colleagues’ (Hall, et al., 2009a; Hall, et al., 2009b) evaluation of dignity therapy for older people in care homes is an important and rare UK example of a successful RCT in this care setting and aimed to assess the feasibility, acceptability, and effectiveness of this intervention. Although older people living in a care home generally die there, there is a dearth of robust evaluations on interventions to improve EoLC. The trial was informed by the MRC framework with emphasis on: understanding the context; who dignity therapy works for; if it fails; why; unexpected consequences. The study demonstrated the feasibility and acceptability of undertaking an RCT in care homes with frail older people, and processes of randomisation and consent in this care setting.

Our work using observational trial designs has developed strategies to improve non-RCT designs, weakened frequently by the likelihood of bias. Observational studies are important in understanding the effectiveness of palliative care services, particularly when an RCT is unfeasible (e.g. evaluating an existing service). Our work on observational designs has contributed to developing research methods to minimise recruitment bias in observational designs (Higginson, Gao, Amesbury and Normand, 2010; Simon and Higginson, 2009). Professor Irene Higginson and colleagues (Higginson, Gao, Amesbury and Normand, 2010) evaluated HDC using a quasi-experimental prospective comparative trial, which used two main strategies to lessen the weakness of non random allocation to HDC. First, the use of two control groups, a ‘before’ group with data collection prior to the HDC opening, and a ‘standard care’ group receiving home palliative care, but not attending the HDC. Second, calculation of a propensity score to test for selection bias between patients in the HDC and standard care groups by fitting a logistic regression of the conditional probability of being in the day care given age, gender, baseline overall health status and baseline total score. The score showed no statistical evidence for selection bias between the two groups (day care, 0.38 (SD, 0.08; 95%CI, 0.35 to 0.42; standard, 0.35 (SD, 0.11; 95% CI, 0.31 to 0.38; t test, tdf=60=-1.45, P=0.15).

The development of quasi-experimental designs requires debate on methodological issues to reduce bias and confounders. We have identified some specific strategies to strengthen validity in these types of studies by controlling and minimising secular trends and recruitment bias (e.g. using a control group, propensity score, time series, and valid outcome measures (Simon and Higginson, 2009).

**MOREcare**

Our work developing research methods is nationally and internationally recognised, and this is evident in a successful grant application to develop methods guidance on developing and evaluating palliative and EoLC awarded by the Medical Research Council Methodology Research Programme/National Institute of Health Research (the MORECare study: http://www.csi.kcl.ac.uk/morecare.html). We are leading a collaboration between King’s College London, the University of Manchester, Edinburgh and Aberdeen.

MORECare (Methods for evaluating service delivery models for EoLC; development of best practice guidance) will identify, appraise and synthesise ‘best practice’ methods for the evaluation of EoLC, particularly focusing on complex service-delivery interventions and reconfigurations. Research methods are being used in parallel to build the evidence base that informs the recommendations in the methods guidance on developing and evaluating palliative and EoLC. Systematic reviews have been undertaken on methodological strengths and weaknesses of effectiveness evaluations on palliative care services, recruitment of practitioners, and patients’ and families’ attitudes to participation in palliative care research. Think-tank workshops with experts on the use of mixed methods in effectiveness research, outcome and economic measurement, ethical considerations, and statistical analyses are also being undertaken, along with a web-based consultation to establish a consensus on the priority of the recommendations made, and face-to-face consultations of the presentation of data to stakeholders and the format of the methods guidance.

The final data synthesis informs the methods guidance. The MORECare study recruited a breadth of experts to its project advisory group (PAG) to inform the development of the methods guidance and the next steps for the project. The PAG has representations from across the disciplines that draw on diverse expertise with representations from health and social care, the voluntary sector (Age UK, Macmillan Cancer Support and Marie Curie Cancer Care) and lay user representatives. The group has provided lively and stimulating debates on such areas as economic evaluation and the implementation of research into practice.
Longitudinal disease trajectories

Understanding how symptom distress and quality of life changes over a disease trajectory is essential to understanding the points at which people require palliative care, and to develop services effectively. This area is, however, little researched because of difficulties in undertaking longitudinal studies with both cancer (Gao, et al., 2010) and non-cancer groups (Murtagh, et al., 2010; Bausewein, et al., 2010).

Our longitudinal work with non-cancer groups has shown the feasibility of undertaking these studies, strategies to improve methodological rigour, and the importance of this type of work in demonstrating how chronic disease trajectories differ to cancer trajectories. This work is vital to the development of optimal palliative care services for non-cancer groups. Fliss Murtagh and colleagues undertook a ground-breaking longitudinal study with conservatively managed patients with advanced chronic kidney disease patients (stage 5 CKD) to describe for the first time a distinctive renal trajectory (Murtagh, Sheerin, Addington-Hall and Higginson, 2011), with detailed analysis on symptom prevalence and severity in the last month of life, and comparison with advanced cancer patients (Murtagh, et al., 2010). The study illuminated methods to examine end of life trajectories. The two year longitudinal design observed a relatively high proportion of deaths (n=49, 66%), demonstrating that prospective methods can derive sufficient data to provide meaningful evidence on patterns of death, and demonstrated the feasibility of a 2 year longitudinal study (with monthly data collection) with patients over the last year of life; few previous studies have achieved this. The study re-emphasised the importance and advantage of data analysis backwards from point of death to provide detailed analysis on patterns in relation to the outcome measured (functional status) and death.

Longitudinal designs are often weakened by bias through participant selection and missing data. Fliss Murtagh’s study demonstrated 3 methodological approaches to control and reduce bias, and enhance validity in longitudinal studies:

1) The use of detailed clinical databases at the respective renal units to enable comparisons of the participants included and the population they are drawn from to ascertain degrees of selection bias; ethnicity was the only variable to differ significantly across the groups.

2) Detailed individual follow-up of included participants with regular telephone contact and place-of-care tracking to minimise missing data and bias through attrition. The strategies were effective with complete datasets obtained on all but 6 of the participants (12%).

3) Use of a generic outcome measurement validated in both cancer and non-cancer populations to enable comparisons with study populations studied using the same instrument MSAS-SF (Chang, et al., 2000). The study demonstrated that stage 5 CKD patients experienced a rapid decline toward death with high levels of symptom burden similar or greater than those with advanced cancer, and a considerable need for proactive assessment and management of symptoms at the end of life.

Breathlessness is a common and distressing symptom in advanced disease for cancer and non-cancer groups. Claudia Bausewein’s longitudinal study on the trajectories of breathlessness over time and towards death reported for the first time individual breathlessness trajectories for patients with cancer or COPD, and the feasibility of prospective longitudinal work with these groups (Bausewein, et al., 2010). The study was pioneering in that it used a prospective design with patients with advanced disease, examined symptom change over time, moved beyond functional status, and included forwards and backwards data analysis to provide detailed examination of population and individual symptom trajectories (Bausewein, et al., 2010). The detailed data analysis revealed individual variations in breathlessness, and was summarised as four trajectories; symptom analysis at the population level masks this finer detail on individual experiences. This highly detailed analysis is imperative for practice to inform understanding on changes in breathlessness over time with greater symptom distress associated with fluctuating trajectories than more stable trajectories.

Understanding how the level of psychological distress in patients changes from point of cancer diagnosis through to survivorship or death is essential to effectively time interventions and provide optimal care. Gao Wei and colleagues (Gao, et al., 2010) used an innovative approach to longitudinal study design that incorporated data from three study settings that included patients from early to late stages of the cancer journey. The study incorporated study data from cancer outpatients and palliative care patients, and analysis of national data from the Health Survey for England on community patients with cancer. The study used pioneering analysis methods across these data sets to control heterogeneities in the psychological measure and across the three care settings, using the same assessment instrument and analytic approaches across the three samples - this is the first study to achieve this. Cancer groups demonstrated a prevalence of psychological distress in cancer from survivorship to the end of life; assessment of psychological distress is essential to allow targeted psychological support.

Overall, the Institute has undertaken ground breaking work pushing and innovating research methodologies to enable patients with advanced disease to participate in research, and the execution of high quality robust studies with high confidence in their findings and recommendations for practice.
Global Collaboration

Our commitment to global health
The Cicely Saunders Institute has been building on its strategic commitment to the delivery of palliative care to all, wherever they live in the globe and whatever their life limiting or life threatening condition. King’s Health Partners, our Academic Health Sciences Centre, has positioned itself as a leading player in global health, and the palliative care programme strongly supports this activity. Our global palliative care programme has been built on partnerships with leading clinical, academic and advocacy partners in low and middle income countries, particularly in Sub-Saharan Africa, and with leading academic centres on a number of collaborative studies with high income countries, principally across Europe with PRISMA and the ECPRC; North America with the Dignity Study, renal research, MORECare and BuildCARE; and with Australasian rehabilitation academic and clinical centres to advance the science of measurement and goal attainment.

Our programme of work in Sub-Saharan Africa (see below) is built on a strategy of integrating education, policy enhancement, primary research studies, and a focus on improved care through clinical/academic partnerships. Through establishing partnerships with experts in diverse settings we are able to use our scientific skills to learn from, and identify effective responses to, local challenges in delivering appropriate and effective palliative care.

The local and the global
While our research programme recruits strongly within our Academic Health Sciences Centre and local community; the rigour of our science brings direct applicability to the global delivery of better palliative care. For example Professor Irene Higginson’s randomised controlled trial of palliative care in MS and Fliss Murtagh’s programme in renal palliative care have identified palliative care needs and effective interventions in non-cancer diagnostic groups, with direct relevance to patient populations around the world. While our local population directly benefit from the development and testing of new interventions, our studies have direct relevance to translation into settings elsewhere. This global reach is underpinned by our belief that better science can achieve better care.

UK, European and international collaboratives
We are collaborating with centres of excellence on a number of collaboratives - these bring significant scientific advantage through the synergy of shared expertise and discovery of new knowledge.

COMPASS
COMPASS (COMplex Interventions: Assessment, trials and implementation of Services) is one of two UK supportive and palliative cancer care research collaboratives funded since 2006 for a five year period by the National Cancer Research Institute partners (Department of Health (England), Marie Curie Cancer Care, Macmillan Cancer Support, Cancer Research UK, Medical Research Council, Economic & Social Research Council), to advance research into the development, evaluation and implementation of complex interventions to improve the supportive and palliative care (SuPaC) of people living with cancer and other serious illnesses.

The collaborative model was proposed with the aim of joining together the fragmented workforce in this field to drive up the quality and impact of work being done. Centred around research groups at the University of Edinburgh, King’s College London and the University of Leeds, the collaborative brings together researchers from these and other UK institutions including the Universities of Cambridge, Oxford, Sheffield, Stirling, Surrey and Warwick, with a range of backgrounds including clinical trial methodology, palliative care, psychiatry, primary care, nursing and oncology. Professor Irene Higginson has co-led the Board with Dr Dan Stark, University of Leeds, since 2009.

As well as funding post-doctoral fellow and statistician posts to build research capacity in the field, the collaborative has developed an active user involvement group who have helped COMPASS members increase engagement of consumers in their research. COMPASS has staged annual scientific meetings throughout its lifespan, including one organised by Professor Irene Higginson in 2009, attracting leading UK and international speakers as well as providing an important opportunity for networking and for both established and less senior researchers to present their work.

Research by the collaborative has studied psychological distress over time and refined its assessment. In a collaborative study, Gao, et al. found that the prevalence of psychological distress was 24.5% (95% CI: 18.5-30.5%) in cancer outpatients during or soon after treatment, 16.5% (95%CI: 12.7-20.3%) in the general community. But it rose to 59.3% (95%CI: 51.4-67.2%) in specialist palliative care. Cancer type was the best predictor for psychological distress in both specialist palliative care (PR(prostate cancer versus other cancers)=5.61; 95%CI: 1.21-26.04; p=0.008) and general community samples (PR(lung cancer versus other cancers)=3.64; 95%CI: 1.08-12.35; p=0.003). Higher scores on GHQ-12 items predicted shorter survival in palliative care patients and showed weak protective or no association with survival in cancer outpatients. Patients undergoing oncological treatment and then again as they approach death have increased levels of psychological distress. We suggested that assessing psychological distress through survivorship and especially during treatment and at the end of life may identify unmet psychological needs and allow targeted psychological support (Gao, et al., 2010)

EPRC
The European Palliative Care Research Collaborative was funded by the European Commission to improve the management of pain, depression and cachexia in cancer
patients through translation research, and to develop a long lasting European collaborative in palliative care cancer research. Eight participating centres in the UK, Italy, Switzerland, Germany, Austria and Norway headed the various work packages, with Professor Irene Higginson leading the work on depression which looked at the applicability of antidepressants for people with a physical illness, and developed clinical practice guidelines for the management of depression in palliative care (see Section 2.3: Symptom-led research). The guidelines are now available for download from the EPCRC website in five European languages.

**PRISMA**

This pan-European EC FP7 funded coordinating action, led by Richard Harding (Principal investigator) and Professor Irene Higginson (Scientific Director) consisted of a consortium of 11 specialist partners in nine European countries representing the leading academic and clinical centres of excellence, plus the APCA (see Figure 15) (www.prismafp7.eu).

The aim of PRISMA (reflecting the Positive diveRsities of European priorities for reSearch and Measurement in end of life cAre) was to drive forward the delivery of optimal end of life cancer care for European citizens through an integrated programme of work packages, which harmonised measurement of the cancer experience in the last year of life. This was achieved through a multidisciplinary set of discrete projects that came together to ensure that measurement is patient-centred (established through the pan-European population-based survey on end of life preferences and priorities led by Barbara Gomes at King's College London - see Section 2.1: In Focus); that it reflects cultural diversity (through an expert group of anthropologists ensuring measurement on culture, led by Marjolein Gysels at the University of Barcelona); and addresses clinical challenges (established through a pan-European survey of palliative care medical priorities, led by Professor Stein Kaasa at the Norwegian University of Science and Technology).

Further work led by Claudia Bausewein with the German Palliative Medicine Association informed best practice in the selection and utilisation of tools at the end of life, based on a pan-European survey of tool use (see Section 2.4: Patient-reported Outcome Measures), and Professor Pedro Lopes Ferreira at the University of Coimbra led the production of a simple-to-use POS score card for routine clinical practice. Work on expansion of measurement into the ageing European populations was headed by Professor Luc Deliens at the Vrije University of Brussels and Vrije University of Amsterdam, who convened a series of expert groups and a systematic review on data collection and measurement in long term care settings.

The full list of PRISMA work packages is:

- Culture
- Public priorities and preferences
- Clinical research priorities
- Measurement tools (POS and STAS)
- Symptom measurement and POS-S
- Nursing homes and measurement
- Management work package
- Final conference

![Figure 15: PRISMA: Reflecting the positive diversities of European priorities for research and measurement in end of life care](www.prismafp7.eu)
EUROImpact
At the end of 2010 two new early-stage researchers were recruited to the department who are entering a new multisectoral PhD learning programme led by Vrije University Brussels with ourselves, Lancaster University, Vrije University Amsterdam, the National Cancer Research Institute Italy, and the Norwegian University of Science and Technology. These leading universities have established an international programme of study that enables the 12 post-holders to move between institutions and to access national and international datasets and learning.

BuildCARE
Funded by a philanthropic donation Project BuildCARE (Building Capacity, Access, Rights and Empowerment) will identify, recruit and develop future academic and clinical stars in the field of palliative care, thereby building capacity for the future and has an integral rolling programme of research. The latest technologies will be used to disseminate expertise and research developed by staff at the Institute across the globe, and strategies will be pioneered to engage our communities in the work as well as identifying variations in access to care. As part of the programme we will engage in an international study comparing palliative care experiences in London, Dublin and New York through collaborations with Mount Sinai Medical Centre and Dublin hospital.

International rehabilitation collaborations
Professor Lynne Turner-Stokes has held an Adjunct Professorship at Auckland University of Technology (AUT) since 2005 to assist in the development of a National Institute for Rehabilitation Research for New Zealand, with Professor Kath McPherson, AUT, holding a corresponding Visiting Professorship in our department. Current work is focused on the development of a new measure for vocational rehabilitation the Work ability Support Scale which was presented at the Australasian Faculty of Rehabilitation annual conference in Queenstown New Zealand, July 2008.

Collaborations in Australia include partnerships with Associate Professor Fary Khan, University of Melbourne and Dr Ian Baguley, Department of Rehabilitation Medicine, University of Sydney, with whom Professor Lynne Turner-Stokes has published five Cochrane Reviews examining the effectiveness of multidisciplinary rehabilitation in MS and other neurological conditions.

With Drs Kevin and Barby Singer, University of Western Australia, Professor Lynne Turner-Stokes has worked with local rehabilitation services to apply the casemix tools that we have developed in the UK for identifying rehabilitation needs, interventions and outcomes in patients with complex disabilities.

The AROC houses the national dataset for rehabilitation case episode data for rehabilitation in Australia. A collaborative partnership with Professor Kathy Edgar, University of Wollongong, is focussed on the development of casemix and funding models for NHS rehabilitation services. The UK-ROC is the UK equivalent database development, led by Professor Lynne Turner-Stokes, which collates case episode data for inpatient neurorehabilitation services across the UK. The dataset is developed in collaboration with the BSRM and AROC, and is funded by a Department of Health National Institute of Health Research Programme Grant - £2m over 5 years which is based at our clinical base Northwick Park Hospital.

Further global partnerships
In service organisation and policy, Jonathan Koffman has been working with the government of Montenegro to advise on the development of palliative care services. In non-cancer palliative care, Fliss Murtagh is leading a programme with the University of Alberta to drive forward the renal palliative care field, and Richard Harding and Richard Siegert are working with the Canadian UK Rehabilitation Research Collaborative Collaboration to establish cross-national research in disability and neurocognitive rehabilitation in HIV disease. In the field of health economics, Dr Murtagh is leading a group made up of members of our department and the University of Wollongong to develop casemix classification for adults and children in palliative care. In complementary therapies Barbara Daveson is collaborating with the University of Queensland in the evaluation of music therapy. Dr Massimo Costantini from the National Cancer Institute, Italy and Dr Karl Lorenz, Director of Palliative Care for the VA Center for the Study of Healthcare Provider Behavior, USA are collaborating on the MRC-funded MORECare project previously described.

Our programme in Sub-Saharan Africa
Our Sub-Saharan Africa programme exemplifies an integrated series of research, education, policy, capacity and improved care. This has been achieved through close collaboration with local expert groups such as the Universities of Cape Town and Nairobi, AIDSRelief and the University of Maryland, APCA and Hospice Palliative Care Association (HPCA), and a wide range of clinical services across East and South Africa.
Richard Harding led an observational study of the effect of palliative care training and drug availability in two regions of Tanzania, and the study showed (using the APCA African POS developed and validated under the PRISMA project) that patient outcomes improve at the site where palliative care is provided (even when controlling for demographics, CD4 count and ART use). The main findings from the study conducted in collaboration with the Tanzanian Palliative Care Association and AIDS Relief at the University of Maryland, can be seen in Figures 16, 17 and 18 below. Site 1 offers standard HIV care, Site 2 offers standard care plus integrated palliative care.

Figure 16: Improved outcomes over time on the APCA AfricanPOS for HIV patients receiving integrated palliative care (site 2) compared to standard HIV outpatient care (site 1) n=128 (Harding, et al., 2010)*

Figure 17: Improved outcomes over time on the MOS-HIV physical health subscale for HIV patients receiving integrated palliative care (site 2) compared to standard HIV outpatient care (site 1) n=128 (Harding, et al., 2010)*

Figure 18: Improved outcomes over time on the MOS-HIV mental health subscale for HIV patients receiving integrated palliative care (site 2) compared to standard HIV outpatient care (site 1) n=128 (Harding, et al., 2010)*

*All 3 graphs show mean score with 95% CI over a 10 week period from study entry
We have been able to offer two full scholarships to Africans to study our part-time MSc. Eve Namisango (African Palliative Care Association) and Dr Jacinto Amandua (Ugandan Ministry of Health) have been able to attend the course whilst retaining their employment at home, and therefore have the opportunity to continually implement their new knowledge. Their MSc studies have led to innovative African research in the fields of HIV symptom clusters and hospital-based palliative care. At the end of 2010 Richard Harding secured a new grant that includes support for King’s College London to deliver guest-lectures in palliative care at the University of Nairobi and the University of Cape Town. Richard Harding also co-supervised the first African PhD candidate in palliative care to successfully reach thesis submission (with the University of Nottingham).

Improved care
Led by Richard Harding in collaboration with APCA and the University of North Carolina, the PEPFAR evaluation was the largest centrally funded US Government-supported evaluation of its African care and support programme (see Section 2.1: Evaluating and Improving Care). Involving 120 sites across two countries, this mixed methods study followed up 1300 patients over time and discovered that while physical and mental health problems improved over a period of 4 months, this was not related to the use of ARTs. This study was also the first to determine the palliative care needs of newly diagnosed HIV-infected persons, and demonstrated a high prevalence of psychosocial need in the two weeks following diagnosis.

Catalysing change through partnership
The PRISMA project led by Richard Harding included partnerships with the Universities of Cape Town, Kwazulu Natal and Witwatersrand, and 5 clinical sites in South Africa. PRISMA developed and validated the first outcome measure for African palliative care (the APCA African POS), conducted the first full clinical audit of patient outcomes, and reported on the importance of spirituality in quality of life and the prevalence of symptoms in palliative care patient populations.

This programme pioneered a raft of change through its strategic approach to partnership and the central role of best science measurement in improving care. Since the PRISMA data was collected, The APCA African POS has been rolled out as a standard tool in South African hospice provision, and is the primary outcome measure in an RCT launched in 2010 by Harding to test the effectiveness of palliative care for HIV-infected persons on ART therapy.

A systematic appraisal of paediatric palliative care in Sub-Saharan Africa was launched by King’s College London and the Diana Princess of Wales Memorial Fund. This study aimed to systematically identify and appraise the evidence for paediatric palliative care in Sub-Saharan Africa, in order to identify best practice and effective models of care, and to inform the development of the discipline. It is authored by a team of clinical, academic and advocacy experts from across Sub-Saharan Africa and the UK (Harding, Sherr and Albertyn, 2010. The status of paediatric palliative care in Sub-Saharan Africa. Available at: http://www.csi.kcl.ac.uk/paediatric-palliative-care-in-africa.html).
2.8 Consumer and Public Collaboration

Consumer and Public collaboration is integral to the research projects carried out in the department. Users of services bring unique and invaluable experience, knowledge and perspectives to the research process and help ensure that the research being undertaken focuses on what is most important to the public in general, to people using the services, and those affected by the conditions. We are actively seeking ways to improve and expand our collaboration with consumers and the public. Examples of some of the ways that we involve consumers are:

Consumer collaboration in the new Institute
Consumers were centrally involved in the planning of the new Institute building, and were asked to give their views and preferences regarding the form, content and activities that would take place in the building. Input was sought regarding the Macmillan Information and Support Centre on the ground floor including access, appointment systems, the design of this area, and ways to link the Information and Support Centre to the rest of clinical services. Consumers also described how teaching, care and research functions of the Institute could be best offered, and how to ensure that patients and families are aware of the services we house, the research studies we undertake, and how to access them.

In the future, we will establish a consumer/public collaborative group, to help us drive forward the research in the Institute, keeping it focussed on consumer and public concerns.

The following people gave their time and ideas to help design and build the vision of the Institute: Cynthia Benz, Margaret Brothwood, June Casson, John and Susan Dickenson, Peter Headicar, Frederick Larkin, and we are very grateful for their help.

Collaboration on individual projects
• The MORECare project has three user representatives on the Project Advisory Group, which works on specific aspects of the project such as the guidance on mixed methods and ethical considerations. The COMPASS collaborative Consumer Research Panel supported the process of developing and reviewing the job description and flyer, and the representatives were recruited through advertising the post with Macmillan and Cancer Experiences Collaborative (CECo).

• A Project Advisory Panel of service users played a pivotal part in guiding a series of Department of Health funded research studies into experiences of Caring for adults with Long Term Neurological Conditions. The aims of the projects were to investigate the differential support needs of carers of adults with a diverse range of conditions, and to determine how these needs could be met most cost effectively. Input from members of the Panel at quarterly meetings included:
  • Developing the content of two questionnaire surveys and ensuring that questions relevant to carers themselves were included
  • Advising on how to circulate information about the research via national voluntary organisations to facilitate participant recruitment

(L – R) Lay members of the LTNC Carers Project Advisory Panel: Mary Porter, Caryl Reeves, Savita Jain, Nancy Esterson, Norman Keen, Martin McLeish.
• Contributing to the analysis of findings by coding short answer questions from returned surveys, and working in pairs to build codes into themes through discussion and consensus
• Critically reviewing and adding to the content of some sections of the final report

The feedback received from Panel members has been very positive:

‘I am proud of the achievement. I would love to be involved in future studies.’

‘I have enjoyed being part of the panel, feel a bit sad it is over so if you ever need my input again I’d be happy to help.’

• A project entitled ‘Preferences for care and knowledge among people severely affected by MS and their caregivers: does ethnicity make a difference?’ sought to explore and compare the experience and costs associated with care of people with MS among the black Caribbean, white British and Asian communities living in London. A user group comprising people with MS and carers of people with MS from the black Caribbean and Asian communities living in London were recruited to inform the research team throughout every stage of the study. User contributions included devising creative methods to recruit people with MS from ‘hard-to-reach’ communities, commenting on the wording of study documents, helping the researchers appraise the implications of the study in relation to improving health services for people with MS from diverse communities, and identifying further research questions relevant to the study.

• A Questionnaire Prompt List (QPL) is a list of specific topics and questions designed for patients and carers to raise with their clinicians to address their unmet information needs. Following successful use of a QPL in palliative care in Australia, work began to develop and pilot test a UK-specific QPL to meet the information needs of advanced cancer patients in the UK. Fifteen patients and 15 carers were consulted on the content and layout of the question prompt list, and patient and carer suggestions were used to redesign the booklet in conjunction with input from the clinical PCTs.

• ‘Development, effectiveness and cost-effectiveness of a new out-patient breathlessness support service’ is a project to develop and evaluate the effectiveness and cost-effectiveness of a multidisciplinary outpatient breathlessness support service (BSS) for the palliation of breathlessness experienced by people with advanced malignant and non-malignant disease. User involvement came by way of a patient representative who was part of the Project Advisory Group of the Randomised Controlled Trial for the Breathlessness Service, and who helped with the practicalities of setting up the service. Several patients also gave input into the original application for the project.

• The Carers Intervention developed in the department was reviewed and supported by the NCRI carer users in the Primary Palliative Care Group.

• For the rehabilitation research project entitled ‘Assessment of functional improvement in the hemiparetic arm following focal rehabilitation intervention’, which involved the development and psychometric evaluation using an upper limb function outcome measure for use following focal spasticity intervention, users were involved through commenting on and suggesting measurement items as well as pilot testing of the proposed measure, ArmA.

• As part of the work to develop European Guidelines on the Management of Depression in Palliative Care, an Expert Group was constituted to compare practice and develop proposals regarding the management of depression. The group included two patient representatives to ensure that the guidelines embrace issues important to patients as well as health professionals.

• The QUALYCARE project involved two user representatives, Nell Dunn and Kirstie Newson. One representative (who lost her partner to cancer and supported his death at home) was part of the Project Steering Group, reviewing the methods and findings and working on specific aspects, such as information materials for the study. Another user representative (who cared for her mother until she died at home from cancer), who joined the study at a later stage, became involved as a co-applicant in a grant proposal to undertake further analyses and derive maximum value from the data gathered in this large survey with bereaved relatives. Their valuable contribution and support led us to use methods and language and pursue research of analysis that were both acceptable to patients and families and of importance to them.

• For the C-CHANGE project, the COMPASS Consumer Research Panel was employed to inform and refine the bid for this work, and work is underway to establish a local Consumer Panel with the aim of having representatives from cancer, chronic heart failure, COPD, dementia, and stroke. The Consumer Panel would be consulted to help interpret findings to design the new research programme.

• As part of the Advanced Renal Disease Care, a patient and a carer are an integral part of the core team, and work on and advise on a wide range of project elements.

In addition we have worked with pan-European service-user representative organisations to enable service-user involvement in palliative and EoLC policy discussions within Europe. PRISMA, our major 3-year project funded by the European Commission and led by our department, hosted an invite-only symposium in Brussels in 2011 to enable policy developments and inform cross-national developments. PRISMA worked with the European Cancer Patient Coalition (ECPC) to ensure that the service-users’ views were represented and considered within these policy discussions.
Clinical Services

Clinical palliative care services are represented in the Institute by way of the King’s College Hospital clinical palliative care team, which is based here. This affords clinical and academic colleagues in the palliative care community the opportunity to learn from each other and to work together to develop research that can have a real impact on patient care. Clinicians and researchers also work in collaboration with other King’s Health Partners at Guy’s & St Thomas’ NHS Foundation Trust.

A number of clinical consultants have honorary academic appointments within the Institute – and vice versa in the case of Professor Irene Higginson and Fliss Murtagh - and a growing number of clinical-academic posts (including clinical lecturers and research fellows, project managers and research nurses) have helped to further integrate research and clinical activities.

A programme of monthly joint journal clubs, clinical academic division and forum meetings and clinical updates allows the exchange of information and ideas. As well as providing clinical services, the teams are involved in service development and translational research, provide trust-level education and training and contribute to the undergraduate teaching curriculum (see Education and Outreach).

Clinical palliative care services

Clinical palliative care services are provided by an established multi-professional team working in an advisory capacity at King’s College Hospital NHS Foundation Trust (one hospital PCT) and at the Guy’s & St Thomas’ Foundation Trust (two hospital PCTs and one community PCT) and provide a seven day a week visiting service, and consultant-delivered 24-hour telephone advice across both Trusts and the University Hospital Lewisham.

Since March 2009, Guy’s & St Thomas’ Foundation Trust clinical nurse specialists have also provided a 24hr home visiting service. There are no inpatient beds, all hospital patients are seen in an advisory capacity and all remain under the admitting team; in the community, patients remain under the care of the primary healthcare team.

The palliative care service at King’s College Hospital sees around 1200 referrals a year of which approximately 60% have cancer and 40% a non-cancer diagnosis; Guy’s & St Thomas’ Foundation Trust receives approximately 1800 referrals per annum, 1300-1400 to the hospital team and 400-500 to the community service.

Clinical rehabilitation services

Specialised neurorehabilitation following trauma and complex neurological illness/injury is provided across London by a network of eight (level 1) provider units, commissioned by the London Neurorehabilitation Specialised Commissioning Group.

Two of these rehabilitation services are integrated with the Department of Palliative Care, Policy and Rehabilitation:

- The Frank Cooksey Rehabilitation Unit (FCRU) based at Lewisham Hospital, led by Dr Julian Harriss is the King’s Health Partners specialist neurorehabilitation service
- The Regional Rehabilitation Unit (RRU) at Northwick Park Hospital, directed by Professor Lynne Turner-Stokes, is an affiliated unit of King’s College London, and provides inpatient and outreach neuro-rehabilitation for a catchment population of over 15 million, spanning London and the home counties.

The consultant-led rehabilitation teams in both services provide fully coordinated inter-disciplinary rehabilitation in a range of different service models including inpatient and outreach rehabilitation. They support a range of district (level 2) specialist rehabilitation services and community-based teams, as well as linking with a number of specialist nursing homes to provide life-long residential care for patients with long term conditions resulting in complex neurological disability.

Service innovation

A number of service advancements have taken place across King’s College London and Guy’s & St Thomas’ over the past three years, notable examples of which are given below:

- **Development of the liver palliative care service**
  A project funded to facilitate further development of palliative care services within the Liver Division at King’s College Hospital will improve patient care and the patient experience for those with advanced liver disease, more effectively utilise resources and further develop the clinical/academic interface
- **Coding for palliative care**
  Work has taken place with the coding teams at King’s College Hospital and Guy’s & St Thomas’ Hospitals to identify palliative care activity – both hospital and community based - and Liverpool Care Pathway deaths both to generate income for the service through a local tariff, and as part of the national reporting of mortality data. The Guy’s & St Thomas’ team is also leading on the implementation of a morbidity and mortality forum to review and learn from all inpatient haematology-oncology deaths with respect to safety, quality, decision making, preferences and place of care
- **Innovative models of care**
  The Guy’s & St Thomas’ team has tested models to shape services around the needs and preferences of patients, and to align with other patient pathways e.g. through the Emergency Institute (ED). As well as inpatient care, criteria are being refined for the differing models of medical consultation through outpatient clinics/day units, through ‘Clinic at Home’ and through a virtual emergency Institute clinic.
- **AMBER**
  The PCT links closely with the End of Life Care Modernisation Initiative for Lambeth and Southwark,
and as part of this work Irene Carey and others have led the development of a care bundle (AMBER) to improve the hospital identification and care of those patients for whom recovery is uncertain and who are at risk of dying in the next month or so. This bundle operates alongside appropriate active medical therapy and drives multidisciplinary teamwork and communication, facilitating decision making and communication with patients and carers. It was developed and piloted in Guy’s & St Thomas’ and has been tested in King’s College Hospital and three sites nationally as part of a pilot supported by the National End of Life Care team.

- **Acute oncology assessment unit**
  An acute oncology assessment team incorporating rapid response symptom control and palliative care through the chemotherapy day unit is under development in Guy’s & St Thomas’. This team will improve ambulatory care, improve safety, quality and experience and reduce unnecessary admissions.

- **Specialist palliative care pharmacy**
  A dedicated specialist pharmacist at Guy’s & St Thomas’, Steve Wanklyn, has pioneered various service innovations such as dedicated prescription charts, the Trust Opioid Safety Action Group and electronic support for junior doctors around discharge prescription of injectable medications at the end of life.

**In Focus**

**King’s College Hospital service development for palliative and end of life care in renal services**

Over the last five years, extensive collaboration between nephrology and palliative care services at King’s College Hospital has led to major advances in improving palliative and EoLc for patients with advanced kidney disease. King’s College Hospital is regarded as a national and international leader in innovation and service development in this area.

The clinical palliative care team at King’s College Hospital sees a relatively high number of patients with end-stage renal disease; 7% of all non-cancer referrals during 2009/10 were for patients with end-stage renal disease, despite the relatively low prevalence of end-stage renal disease as compared with other advanced diseases such as chronic heart failure or COPD. One of the notable achievements in developing palliative and end of life services for these patients has been the incorporation of palliative care into the nephrology team, and the up-skilling of renal professionals such that they can deliver appropriate and effective care to those with end-stage renal disease nearing end of life. For example, renal palliative care nurses are now embedded into nephrology services, and renal palliative care skills have been supported and developed by attachments, such as the part-time secondment between Autumn 2009 and Spring 2010 of the renal palliative care nurse, Kate Shepherd, to work as part of the PCT.

In terms of service development, Fliss Murtagh and Paul Donohoe have led work on understanding and improving quality of care for people with conservatively-managed end-stage kidney disease (ESKD).

There has been ongoing dissemination and implementation of the findings from this collaborative work, both locally and regionally, which has led to a number of further service development and research initiatives, including the Advanced Renal Disease Care (ARC) project. This project, funded by NHS KidneyCare for King’s College Hospital’s renal unit (in partnership with Guy’s & St Thomas’ renal unit and academics in the Institute) seeks to extend improvements in care from the conservatively-managed ESKD population, to those on dialysis nearing end of life. Fliss Murtagh, in close collaboration with Katie Vinen, led the successful bid to become a national test site for this work, which began in 2010.

Related clinical research includes a study to describe trajectory of illness and care received during the last year of life for those people with ESKD who die following withdrawal of dialysis, who have rarely been described or studied.

A renal nurse who successfully gained a PhD Training Fellowship from the NIHR Biomedical Research Centre, Guy’s and St Thomas’ NHS Foundation Trust and King’s College London is carrying out this work.

**Liaison with skin services**

Teresa Beynon and Professor Rob George (Guy’s & St Thomas’) have developed specific expertise and liaison with the Mycosis Fungoides and Epidermolysis Bullosa teams. This takes the shape of joint ward rounds, consultation work and development of research protocols.

**Translational research**

Over the last three years, the clinical PCTs have extended their clinical and translational research and further developed the strong joint working with academic staff. Fliss Murtagh is the Research & Development Governance Lead for Palliative Care at King’s College Hospital, and regularly attends the Divisional Research & Development Governance meetings to liaise on clinical research governance, accruals, research and development funding, and related issues.

Many of the studies already described are being carried out in the King’s Healthcare Partners palliative care services, with joint membership of projects. For example, the studies of palliative care in the ITU setting, developing and testing the question prompt list, testing the breathlessness support service, work on outcomes development and testing and new evaluations of Cutaneous T cell lymphoma and the use of Vitamin K in malignant disease.
Education and Outreach

PhD in Palliative Care

The Cicely Saunders Institute has a vibrant and enthusiastic group of PhD students, who are an integral part of the research work streams within the department, and who gain much from the internal programme of researcher development. This development programme includes bi-monthly journal clubs, monthly researchers meeting, skills development workshops, clinical update sessions, and our Open Seminar series which welcomes a variety of national and international speakers (see below for details). There is also a departmental PhD support group run by those studying for PhDs themselves to provide mutual support, exchange experiences, and foster rapid learning. They also benefit from the extensive range of training and support provided through the College, which they access and use according to their individual training and development needs.

Profile

Dr Thomas Osborne, PhD Training Fellow

Thomas completed his first degree in Experimental Psychology at Cambridge University in 2001. He then finished his clinical training at Guy’s, King’s and St Thomas’ Medical School and graduated in 2004. Since 2004 he has trained within the NHS in a range of medical specialties, and began specialist training in palliative medicine in 2008.

He joined the academic department at the Cicely Saunders Institute as a Clinical Research Fellow in 2010, and is working towards a PhD on a programme of research investigating quality of life in myeloma and follicular lymphoma; in particular, he is using mixed methods to study the best way to measure quality of life in this group of patients.

Doctoral students who choose the 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 between 8-10 professionals studying with us for their PhD. These students come from a wide range of backgrounds - currently medical, nursing, social science, physiotherapy, psychology, and anthropology graduates are represented.

PhDs completed and awarded during 2008-11 include:

- Murtagh FEM. Understanding and improving quality of care for people with conservatively-managed Stage 5 Chronic Kidney Disease - the course of symptoms and other concerns over time: King’s College London; 2009. Supervisors: Higginson, Morgan and Addington-Hall
- Bausewein C. Course and non-pharmacological management of breathlessness in advanced disease – a comparison between COPD and cancer. King’s College London; 2009. Supervisors: Higginson, Gysels and Booth
- Selman L. Spiritual well-being and its assessment among patients receiving palliative care in South Africa and Uganda. King’s College London; 2011. Qualitative work exploring the spiritual and religious beliefs of people with HIV disease and/or cancer in South Africa and Uganda. Supervisors: Harding and Higginson

Topics currently being studied by PhD students include:

- Assessment of functional improvement in the hemiparetic arm following focal rehabilitation intervention. Supervisors: Turner-Stokes, Slade
- 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: Higginson, McCrone, Hall
- A mixed methods 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: Murtagh, Wiseman, Higginson
- A mixed methods study to improve the measurement of quality of life in people with multiple myeloma. Supervisors: Higginson, Siegert, Edmonds
- Developing and evaluating a Hospital2Home palliative care service for patients with severe Progressive Idiopathic Fibrotic Interstitial Lung Disease. Supervisors: Riley, Higginson, Ross
- A longitudinal outcomes study of HIV palliative care provision in Kenya and Uganda. Supervisors: Harding, Higginson
- Ethnographic study of cancer patients’ experience of their illness and care at the end of life in Greece. Supervisors: Wiseman, Richardson, Higginson

MSc, Postgraduate Diploma and Postgraduate Certificate in Palliative Care

This MSc (and the recently introduced PG Diploma and PG Certificate) in palliative care based at King’s College London and St. Christopher’s Hospice, recently entered its 12th year. The underpinning philosophy of these three courses is to develop students’ skills to critically appraise research and evidence on issues of palliative care in order to ensure evidence based clinical practice and social care. This is necessary as palliative care is a relatively new specialty; knowledge about which interventions have the potential to enhance quality of life of patients with advanced disease and their families, be they pharmacological, psychological, social or service based are emerging. Clinicians need to develop the skills to appraise evidence as it emerges in the future, especially as healthcare changes rapidly.

To date, the inter-professional MSc in Palliative Care has led to demonstrable gains for the specialty both
nationally and internationally. A total of 287 students from a diverse range of disciplines have participated in the MSc programme, of which 216 have successfully completed or are due to complete their studies by January 2011; they have included those working in medicine, nursing, therapeutic radiography, music therapy, psychology, social work, physiotherapy and occupational therapy, among others.

Moreover, the course is truly international. The student body represents countries all over the world including two recent graduates (a research nurse and a doctor) from Uganda, both generously sponsored by the Halley Stewart Trust (see Figure 19). As part of the MSc these two students conducted research study projects that examined the experience of symptom clusters among patients living with and dying from HIV/AIDS and the prevalence of life-limiting illness among patients at the Mulango National Referral Hospital located in Kampala, Uganda. The findings from these research studies will be used to progress the delivery of care to patients with HIV/AIDS in Sub-Saharan Africa.

The course has also benefited from four new scholarships supported by the Samuel Sebba Trust for MSc students with specific interest in pain-related research. Two of these students (a doctor and a physiotherapist) are now engaged in research exploring the meanings and impact of breakthrough cancer pain as perceived by family members, and developing an understanding of cancer pain attributions and how these influence behaviour and day-to-day activities.

In the last five years, many course alumni have progressed within their careers. At least five UK-based nurses have been promoted to the new role of Nurse Consultant in Palliative Care with prescribing powers, one nurse is now working as Chief Executive of a large hospice in south east London serving a complex and challenging population, Specialist Training Registrars (STRs) in palliative medicine have progressed to Consultant level with significant clinical responsibilities and responsibilities to develop and evaluate palliative care and related services. Indeed, the course is designed to fulfil many of the core competencies required by the Specialty Training Curriculum for Palliative Medicine (August 2010).

Many students have also successfully disseminated findings from their research study projects to audiences at national and international scientific meetings and conferences, and worldwide in scientific journals including the British Medical Journal, Social Science and Medicine, the Journal of Pain and Symptom Management, the Lancet Infectious Diseases and Palliative Medicine. A growing number of UK and international students have progressed to successfully conduct postgraduate research at PhD level, four of whom are now working in the Cicely Saunders Institute on innovative research study programmes examining previously under-researched issues affecting people with advanced disease and their families.

**Undergraduate education**

King’s College London School of Medicine, at Guy’s, King’s and St Thomas’ Hospitals is one of the largest medical providers of healthcare education in Europe, with over 400 medical students in each year. Polly Edmonds and Rachel Burman lead the development of the undergraduate curriculum in Palliative Medicine, with the course operating as a vertical strand with teaching across the whole five years of the curriculum. This integrated programme of teaching provides students with a variety of experiences from seminars, symposia, student selected components (SSCs) and bedside clinical teaching, to hospice visits in phase five. Using a variety of teaching techniques in all of the sessions, the course is always very well evaluated. It provides comprehensive coverage of the Association of Palliative Medicine undergraduate curriculum.

The most innovative aspects of the undergraduate curriculum are the phase five hospice visits and student selected component (SSC) opportunities. The final year hospice visit, developed in partnership with St Christopher’s Hospice and Trinity Hospice and now also delivered at the Greenwich and Bexley Community Hospice, is particularly well evaluated and gives the students an opportunity to visit a hospice and meet members of the multi-professional team, to gain an understanding of how the work delivered in the hospice differs from other healthcare settings. During the visit students meet day centre patients as part of the highly rated goldfish bowl session. Several SSCs are offered in phase four of the curriculum; most popular is the generic palliative care SSC, delivered in conjunction with St...
Christopher’s and Trinity Hospices. This SSC has been designed to give interested students more detailed exposure to palliative care by attending palliative care ward rounds with the hospital PCT at King’s College Hospital and spending two days at either Trinity Hospice or St Christopher’s Hospice to experience inpatient palliative care, community care and hospice day care. This SSC has been well evaluated by participating students. In addition to the formal undergraduate curriculum, elective placements have been undertaken for Guy’s, King’s and St Thomas’ and overseas students at King’s College London (with the hospital PCT and academic department), Trinity Hospice and St Christopher’s Hospice.

Polly Edmonds is also deputy head of year 4 and the phase 4 OSCE co-ordinator.

Trust-level education and training
The Guy’s & St Thomas’ and King’s College Hospital teams engage in informal teaching to other health professionals on a daily basis, as part of the teams’ advisory role in patient care.

Some of the formal teaching delivered is as follows:
• Specialty training in palliative medicine at King’s Health Partners
Across King’s Health Partners there are five specialty registrars (4 WTE) and 2010 saw the appointment to the first academic clinical lecturer post in palliative medicine, based at King’s College London. The feedback from these posts is consistently good and in the last PMETB/GMC trainee survey Guy’s, King’s and St Thomas’ were positive outliers for: Clinical supervision (King’s College Hospital and Guy’s & St Thomas’), Handover (King’s College Hospital) and Workload (King’s Health Partners). All palliative medicine consultants acting as educational supervisors (Polly Edmonds, Rachel Burman, Wendy Prentice, Irene Carey and Teresa Beynon) are accredited by London Deanery and have undergone appraisal for this role.

• Nursing and allied healthcare professionals
The team provided input into the King’s Nurse Induction programme (including - What is palliative care and how to refer to the team; Communicating with dying patients). Additional teaching sessions given included local inductions in palliative care for surgical ward and liver/hepato-pancreato-biliary ward nurses, use of the Liverpool Care Pathway and general medicine training to develop the end of life care ward champion role.

• Junior doctor teaching
Contributions include a foundation doctors teaching programme (end of life care and oncological emergencies) and pharmacy teaching, subspecialty higher trainees in Gynaecological Oncology and Elderly Care, non-clinical and clinical teaching for MRCP (SHOs) and Liverpool Care Pathway teaching to medical teams.

• Sage and Thyme
A communication skills teaching programme - Sage and Thyme - was introduced by Vicky Robinson with the support of the Modernisation Initiative

Education multidisciplinary meeting
An education multidisciplinary meeting (MDM) was introduced to provide a forum to discuss cases identified at Bereavement and Discharges MDMs 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 visits to the team or invitations to teach or give presentations. Key themes arising out of these
Details of speakers and topics covered included:

2008
- Dr Rob George, Guy’s & St Thomas’, UK: Actions, Causes and Culpabilities: the ascribable, the opaque and the vexing
- Professor Luc Deliens, VU University Medical Centre, Amsterdam, The Netherlands: Place of care and care trajectories at the end of life in Belgium
- Professor Suzanne Hanser, Berklee College of Music, Boston, USA: The effects of music therapy on anxiety and pain
- Professor Jonathan Smith, Birkbeck College, London, UK: The debilitating effect of chronic back pain on sense of self: an idiographic qualitative study
- Dr Steve Pantilat, Department of Medicine, University of California, San Francisco, USA: Palliative care for people with heart failure
- Dr Rachael Addicott, King’s Fund, UK: Improving choice at the End of Life
- Dr Jonathan Koffman, Department of Palliative Care, Policy & Rehabilitation, King’s College London, UK: The cultural meaning and shaping of cancer pain: findings from a mixed methods study
- Dr Barbara Hannatty, Population and Community Health, University of Liverpool, UK: Making ends meet: the neglected consequence of terminal illness
- Professor Irene Higginson, Department of Palliative Care, Policy & Rehabilitation, King’s College London, UK: The cost effectiveness of palliative care in non cancer: the example of Multiple Sclerosis
- Dr William Levack, Rehabilitation Teaching and Research Unit, University of Otago, Wellington, New Zealand: Developing goal theory for brain injury rehabilitation
- Dr Graeme Rocker, Division of Respiriology, Dalhousie University, Halifax, Nova Scotia, Canada: Advanced COPD: Much more than a lung disease
- Masterclass: Professor Jos Twisk, Vrije University, Amsterdam; Dr Sabine Landau, Institute of Psychiatry; Dr Fiona Matthews, MRC Biostatistics Unit; Professor Peter Fayers, University of Aberdeen - Longitudinal Data Analysis Masterclass: A series of short presentations and discussion to debate the issues and address the complexities of longitudinal data analysis within the field of palliative care research

2009
- Dr Louise Jones, University College London, UK: Challenges of patient-centred research
- Dr Matthew Maddocks, University of Nottingham, UK: Therapeutic exercise in patients with incurable cancer
- Jo Hockley, St Christopher’s Hospice, UK: Developing high quality end of life care in nursing homes – an action research study
- Dr Bart Shrieken, University of Amsterdam, The Netherlands: Interapy.com: Research and Practice of Standardized Online Psychotherapy
- Dr Bronagh Walsh, University of Southampton, UK: Older people’s emergency hospital admissions: implications for targeting of end of life care
- Professor Clive Seale, Queen Mary, University of London, UK: Mixed methods research/End of Life decision making study
- Dr Robert Elias, St George’s Hospital, London, UK: Patient and professional perspectives on decisions whether or not to have dialysis
- Professor Mike Bennett, International Observatory on End of Life Care, Lancaster University, UK: Improving the management of cancer pain in the community
- Professor Galina Velikova, Psychosocial Oncology and Clinical Practice Research Group, University of Leeds, UK: Monitoring of patient self-reported symptoms and functioning in oncology practice
- Dr Evi Hatziandreou, Former Director Health and Health Care, RAND Europe, Greece: The cost effectiveness of palliative care: self-evident or evidence-based?

2010
- Professor Catherine Pope, University of Southampton, UK: Joining it all together? Developing methods for the synthesis of qualitative and quantitative research
- Professor Margaret O’Connor, Monash University; President of Palliative Care Australia, Australia: Palliative Care in Australia - strategic and policy directions
- Ms Debbie Snell, Canterbury District Health Board, Christchurch, New Zealand: “It was just a silly knock”: How do patient understanding and injury beliefs influence recovery and outcome after a mild traumatic brain injury (MTBI)?
- Dr Fary Khan, University of Melbourne, Royal Melbourne Hospital, Australia: Use of ICF in Multiple Sclerosis Rehabilitation
- Dr Liz Grant, University of Edinburgh, UK: Living and dying – learning lessons from each other. Sharing perspectives from Africa and Scotland
- Dr Marie Bakitas, Dartmouth-Hitchcock Medical Center, USA: Evolution of a palliative care RCT – challenges and opportunities
- Dr Phillip Larkin, University College Dublin and Our Lady’s Hospice, Dublin, Ireland: The challenges of multi-centred qualitative research at end of life
- Gary Rodin MD, University of Toronto and Princess Margaret Hospital, Toronto, Canada: Life before death – the psychology and psychopathology of metastatic cancer
- Masterclass: Peter Rainey and Carolyn Morris, COMPASS Advisory Group Service User Representatives; Dr Marilyn Kendall, COMPASS User Involvement Lead, University of Edinburgh - COMPASS User Involvement Masterclass: A combination of presentations, discussions and group work to examine practical ways of collaborating with Service Users in order to overcome challenges in the research cycle

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 descendants between 200 to 2007
• Dr Peter Fenwick, King’s College London and Southampton University: End of life experiences
• Dr Mike Connolly and Vicky Robinson, University of Manchester and Cicely Saunders Institute: Sage & Thyme - addressing emotional and psychological distress in palliative care
• Dr Francisco Luis Pimentel, Universidade de Aveiro, Portugal: Improving the Measurement of Quality of life in Palliative Care Using Rasch 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 in Kerala, India: Palliative care in the developing world
• Professor Mike Bennett, University of Leeds: Neuropathic cancer pain - new developments

Successful MSc alumni and their research study project titles

We offer our congratulations to successful MSc, Diploma and Certificate students in these years. Projects have included:

2008
• Patterns of the use of systemic anti-infective drugs in patients on a palliative care unit - survival and factors associated to therapy response. Dr Imke Strohscheer
• The views of doctors and nurses working at an oncology centre in Greece, regarding the palliative care of cancer patients. Dr Maria Kiagia
• To investigate in what way Palliative Care Clinical Nurse Specialists are prescribing medication for patients at home. To discuss both the current perception and impact of this new role and to determine if it is a role that should be taken forward. Ms Julie Kinley
• Voluntary Active Euthanasia and Physician Assisted Suicide in German Media: A triangulated content analysis of medical and non-medical publications. Dr Goetz Skudelny
• The experiences of bereaved Chinese people: a systematic review of the literature. Dr Vai Han Cheong
• End of Life Care of frail older people in a nursing home. Ms Elizabeth Dorey
• Depression among patients with advanced disease: do standardised screening tools improve identification? Dr Emily Brackenridge
• What influences the communication between palliative medicine physicians and their patients on spiritual and religious issues? Dr Louise Mason
• Transitions: A qualitative study exploring the experiences of support workers caring for people with learning disabilities nearing the end of life. Mr Gavan O’Sullivan
• Heads on Spikes? A systematic review of the evidence of effective practice at breaking bad news in the context of progressive or terminal disease. Mr Jonathan Downman
• Meta-ethnography exploring the bereavement experience of widows. Ms Nora Moloney
• Spirituality, religion and patients’ end of life choices: a literature review. Mrs Fiona Paterson

2009
• Advance care planning: healthcare professionals’ perceptions of implementing advance care planning when caring for patients at the end of life: a meta ethnographic systematic review of qualitative papers. Ms Amy Webb
• Feasibility study to determine whether Q methodology is an appropriate means of establishing hospice patients’ attitudes towards artificial hydration. Ms Catherine Malia
• The effect of palliative day care on hope: a comparative study. Dr Margaret Guy
• A secondary analysis study to compare two outcome measures in palliative day care. Ms Tori Nicholson
• Exploration of needs and experiences of patients, families and medical staff to inform palliative care staff in Bangladesh. Dr Roghieh Dehghan Zaklaki
• An exploration of the experience of patients who are discharged from community specialist palliative care. Ms Min Stacpoole
• Critical examination of the evidence base of the drug management of delirium at the end of life amongst patients with advanced disease. Dr Catherine McGowan
• How can carers of a relative or friend with cancer or palliative care needs be supported? A systematic literature review of interventions and their effectiveness. Ms Sally List
• Informal carers’ experiences of a relative’s death: a qualitative study comparing community and hospital settings. Mrs Susan Melihuish
• Benzodiazepines for the relief of breathlessness in malignant and advanced non-malignant diseases in adults - a systematic review. Dr Steffen Simon
• Patients’, informal carers’ and health professionals’ views on dignity: a qualitative study. Ms Carolina Casanas i Comabella
• Translation, cultural adaptation and validation of Palliative care Outcome Scale in Malayalam language. Mr Manoj Marath
• Symptom cluster in advanced cancer, end-stage renal disease and chronic obstructive pulmonary disease: a systematic review of the literature and exploratory data analysis. Ms Helen Jolly
• Prevalence of breathlessness in patients with advanced cancer - depending on primary site and measurement tools: a systematic review. Dr Claudia Linsenmeier
• Antidepressant prescribing for lung cancer patients in primary care. Dr Sarah Nobs
• A survey of experiences and views of doctors in St Vincent’s University Hospital to prognostication. Dr Carol Stone
• Cross sectional survey on the palliative care needs of hospitalised patients. Comparison of the opinions of nurses and physicians. Dr Peter Demeulenaere
• A prospective evaluation of interventional pain management procedures in cancer pain: a quality assurance study. Dr Natasha Michael

2010
• Exploring experiences of palliative care: patient views of a new palliative care service at the Cantonal Hospital of Grisons in Chur, Switzerland. Dr Cristian Camartin
• Living with head and neck cancer: information needs
and communication preferences of Irish HNC patients and carers. Dr Eleanor O’Sullivan
• A phenomenological study to explore the meaning of dignity to care assistants in care homes and if cultural background or ethnicity make a difference on the way dignity is perceived. Ms Beulah Shanthini George
• Pain among patients with motor neurone disease: a pilot study to identify patients with motor neurone disease who experience pain during their illness. Ms Jan Clarke
• To explore the experiences of hospital staff nurses in caring for Bangladeshi people at the end of life with or without using the Liverpool Care Pathway (LCP) discussing the ease and difficulties of the LCP in this group. Miss Dianne Haywood
• A systematic review of the clinical effectiveness and side effects of antiemetics in the management of nausea and/or vomiting in palliative patients. Dr Yolanda Augustin
• Exploring the impact of pain in patients with heart failure: A qualitative study. Dr Shaheen Khan
• A systematic literature review to appraise the effectiveness of in-house training programmes on spirituality. Miss Helen Brown McInnes
• The provision of artificial hydration in terminally ill patients undergoing continuous deep sedation for refractory symptoms: a systematic review. Dr Isabel Chaparro-Moreno
• Corneal donation in palliative care: a doctor’s perspective. Dr Rasha Al-Qurainy
• Effectiveness of communication skills training for healthcare professionals in palliative care and cancer settings. A systematic review update. Dr Pablo Llontop-Garcia
• The encounter between dying patients and medical undergraduates during the course in end of life communication in the medical curriculum: a qualitative approach to insights into the patient perspective. Dr Christian Schulz
• A systematic review of the evidence base for the pharmacological management of cough in patients with advanced disease. Dr Andrew Jenks
• A qualitative study of the use of health services in the last year of life by people with dementia and their carers. Mr Robert Lutyens
• Patients’ views on deactivation of implantable cardioverter defibrillators (ICDs) when contemplating decision making in serious illness. Dr Jane Leithead
• Mass grief; a meta-ethnographic approach to examining the qualitative literature on how people grieve en masse, in response to public events, and the effect of this on their behaviour. Ms Katherine Mardle-Aylett
• A postal survey of palliative medicine doctors’ preferences and priorities. Dr Helen Whalley
• Conceptualisation of volunteering in palliative care: a narrative synthesis of the literature. Dr Libby Sallnow
• Perceptions of patients with advanced head and neck cancer and their caregivers about their disease and plans for care. Dr Eva Lew
• Systematic review to identify and appraise the evidence on which combinations of prognostic indicators influence survival in patients with renal failure. Dr Samantha Edward
• Assessment of palliative care needs of a sample of in-patients at Mulago Hospital, Kampala, Uganda. Dr Jane Graham
• Exploring experiences of bereaved people regarding the end of life care received by cancer patients. Dr Debora Gaudencio dos Santos
• End of life care in ICU: what is the current situation and where is there scope for improvement? Mrs Maida Campbell
• The prevalence of life-limiting illnesses among patients at Mulago National Referral Hospital; Kampala, Uganda. Dr Jacinto Amandua
• Treatments for pain in Multiple Sclerosis: a limited systematic review. Ms Lucy Cunningham
• Team meetings as a strategy to ensure effective collaborative interdisciplinary team working in specialist palliative care. Mrs Eileen Carruthers
• A systematic review examining the barriers to opioid delivery to palliative care cancer patients in the region covered by three member countries in the Middle East Cancer Consortium (MECC) - Cyprus, Egypt and Jordan. Dr Angela Economakis
• Symptom clusters in ambulatory HIV/AIDS adult patients in Uganda. Ms Eve Namisango
• Analysis of the opinions of care home managers on the role of general practitioners in end of life care. Dr Anna Clarke
• The use of lorazepam for the management of anxiety and panic associated with episodic breathlessness in advanced disease. Dr Lucy Pain
• An exploration of palliative care patients’ understanding of research (including randomisation) using a hypothetical example of a ‘virtual’ randomised study of thromboprophylaxis. Dr Hermann Ewald
• Living with breathlessness - burden and experiences of informal carers of patients with breathlessness in advanced cancer or COPD. Dr Eva Hermann-Schildmann
Macmillan Information and Support 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. The Centre, open Monday-Friday 10.00am to 4.00pm, was designed and planned as an integral part of the new institute, and is run by a full time centre manager and a team of volunteers.

The official opening of the Centre in 2010 was timed to coincide with the Macmillan ‘World’s Biggest Coffee Morning’ and was a great success, raising over £1,500 and entertaining more than 250 people on the day, including the Mayor of Lambeth, Dr Neeraj Patil, Mr Michael Marrinan, Executive Medical Director for King’s College Hospital and Donal Gallagher, Regional Development Officer for Macmillan.

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The Centre aims to provide information and offer support, both locally and nationally, and the onsite networked computers are intended to encourage patients to self-manage through contacting support groups and by obtaining robust, reliable advice online. The majority of people who use the Centre have, or care for someone with a cancer diagnosis, but there are increasing numbers being referred by the long term condition teams within the hospital, and a number of families from the liver, paediatric, neurological and cardiac departments are also benefiting from the service provided. Several of the support groups and the wig service from the main hospital have been relocated into the Cicely Saunders Institute and the Macmillan Centre, and feedback on these developments from the users has been exceptional. As well as providing a welcoming and peaceful environment ideally suited to their needs, this also signposts many more people to the Macmillan Centre where they can find the support and help they may need as they go through different chapters of their journey.

The Centre has worked closely with representatives from Carers’ Associations of local boroughs in order to develop together the support currently offered for those caring for patients with long term and life-limiting conditions.

The Centre plays a role in some of the research already taking place within the Institute. For example the new Breathlessness Support Service, which is being tested in an RCT, is being run from the Centre. Over time we hope the Centre will be central to new research looking at the use and efficacy of Complementary Therapies. Considerable numbers of people attending the Centre enquire about the availability of such services and it is hoped that by offering this service here, the wellbeing of many patients and carers from our local area can be improved. We look forward to establishing the robust evidence needed to take this vision forward.

The first year of the Centre was both exciting and challenging; with the volunteers doing an incredible job establishing a service that has already offered information and support to hundreds of people. We look forward to the years ahead which promise to be full of growth and new direction and hope that we will continue to develop in ways that benefit and support those that need us most.
External Work

External committees

Professor Irene Higginson

Awards
• Floriani Award for important scientific and cultural contribution, 2011
• Supervisory Excellence Award, King’s College London, 2009 (awarded for PhD supervisory excellence)
• Order of the British Empire for Services to Medicine, 2008
• American Academy of Hospice and Palliative Medicine Award for Excellence in Scientific Research, 2008

Chair
• Multiple Sclerosis Society Applied Research Board
• National Cancer Research Institute COMPASS Collaborative Management Board - Co-Chair

Membership
• Association of Palliative Medicine - Treasurer
• Canadian Institutes for Health Research
• Cicely Saunders International - Scientific Director
• CRUK Feasibility Board
• Dunhill Medical Trust Grants and Research Committee
• General Medical Council Guidance on Withholding and Withdrawing Treatment
• Italian Ministry of Health
• Marzuza Lefebvre D’Ovidio - Scientific Director
• Multiple Sclerosis Society – Palliative Care Adviser (and member of Science and Development Board)
• National Cancer Research Institute Palliative Care Studies Development Group (and Health Services Research Breathlessness and Primary Palliative Care Subgroups)
• National Cancer Research Institute 2010 Conference Organising Committee
• National Cancer Research Institute 2012 Conference Organising Committee
• National Institute for Health Research - Senior Investigator
• National Institute for Health Research Service Delivery and Organisation Programme Board
• Research Assessment Exercise Cancer Panel - member
• Royal College of Physicians Specialty Certificate Examination Board for Palliative Medicine
• UK End of Life Care Intelligence Network

Professor Lynne Turner-Stokes

Chair
• Guideline Development Group for Low Awareness States (BSRM/RCP)
• Guideline Development Group for Updating Guidelines for use of Botulinum Toxin in Spasticity Management (BSRM/RCP guidelines)
• Healthcare Resource Group Expert Reference Panel for Rehabilitation
• Healthcare Resource Group Expert Working Group for Rehabilitation
• London Neuro-rehabilitation Specialised Commissioning Consortium Clinical and Audit Committee
• Long Term Neurological Conditions Dataset Development Reference Group
• British Society of Rehabilitation Medicine Research and Clinical Standards Subcommittee

Membership
• Civil Justice Council Access to Rehabilitation Group
• Clinical Advisory Panel for Payment by Results
• Expert Reference Panel Payment by Results (Long Term Conditions)
• Expert Working Group Payment by Results (Chapter A - Nervous System)
• Department of Health Long Term Neurological Conditions Project Board
• Major Trauma Network Group (London region) Rehabilitation Subcommittee
• Medical Defence Union Council and Cases Committees
• National Council for Palliative Care Long Term Conditions Group
• North West London Hospital NHS Trust Research and Development Executive Committee
• Royal College of Physicians Joint Specialist Committee for Rehabilitation Medicine
• Royal College of Physicians Joint Specialist Society - Clinical Effectiveness Forum
• Royal Hospital for Neuro-disability Trust Advisory Board for the Institute of Complex Disability

Dr Stephen Ashford

Membership
Guideline Development Group for Botulinum tox-A intervention for Spasticity Management in the United Kingdom

Dr Claudia Bausewein

Chair
• Association for Palliative Medicine National Guidelines Group

Membership
• European Association of Palliative Care Board of Directors
• German Association for Palliative Medicine - Vice-President
• Research Group for Developing a National Policy for Palliative Care in Germany
• German Association for Respiratory Medicine Palliative Medicine Working Group - Co-Chair

Dr Polly Edmonds

Chair
• London/KSS Specialty Training Committee Palliative Medicine
• Royal College Physicians Specialty Certificate Examination Standard Setting Group

Membership
• London Deanery/Kent, Surrey and Sussex Palliative Medicine Specialty Training Committee - Training Programme Director
• London Specialty School Executive Committee and Small Specialties Group
• Royal College Physicians Palliative Medicine Specialty Advisory Committee
• Royal College Physicians Palliative Medicine Regional Specialty Advisor
• Royal College Physicians Continuing Professional Development - Advisor for Palliative Medicine
• Royal College Physicians Palliative Medicine (Question writing for Specialty Certificate Examination)
• Marie Curie Delivering Choice Programme Southeast London Executive Board - Clinical Lead
• Lambeth and Southwark Modernisation Initiative End Of Life Care Programme - Clinical Champion
King’s College Hospital NHS Foundation Trust - Assistant Medical Director (and Cancer Lead Clinician)

Dr Catherine Evans
Membership
- International Conferences Community Health Nursing Research Committee

Dr Wei Gao (Gao Wei)
Membership
- Royal Statistics Society
- Chinese Preventive Medicine Association

Dr Richard Harding
Membership
- African Palliative Care Association Conference Scientific Board
- AIDS Impact Conference Scientific Board
- National Institute for Health Research Service Development and Organisation Programme College of Experts
- European Association of Palliative Care Conference Scientific Board
- European Partnership Against Cancer European Commission Health Directorate
- International Association for Hospice and Palliative Care Board
- Program Council for International Palliative Care PhD Programme (NNTU)
- World Health Organization Group “Decent Care Values in Palliative Care”

Dr Jonathan Koffman
Chair
- King’s College London School of Medicine Committee for Postgraduate Teaching
Membership
- St Christopher’s Hospice Research Ethics Committee
- Palliative Care Research Society

Dr Wendy Magee
Chair
- British Society for Music Therapy
Membership
- Department of Health Stroke Training Allied Health Professions Forum Representative
- Department of Health Stroke Strategy - Advisor
- World Federation of Music Therapy Commission of Research and Ethics

Dr Fliss Murtagh
Membership
- Royal Society of Medicine Palliative Care Section - President
- National Health Service Kidney Care End of Life Care for Advanced Kidney Disease Project Board
- Royal Society of Medicine Palliative Care Section Council Member, 2009-10 (and Treasurer 2010)
- US Renal Physicians Association International Working Group to revise the clinical practice guideline on ‘Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis’
- Palliative Care Research Society Executive Committee
- Working party on ‘Development and implementation of a renal version of the Liverpool Care Pathway for the dying’ (guidelines published 2008)

Tom Osbourne
Membership
- Royal Society of Medicine Palliative Care Section - Trainee (and Editorial Representative)

Lucy Selman
Membership
- National Council for Palliative Care Meaning, Faith and Belief Advisory Group

Editorial roles
Professor Irene Higginson
- British Medical Journal Supportive and Palliative Care - Assistant Editor
- Palliative Medicine Editorial Advisory Board
- Journal of Palliative Care Editorial Board
- Journal of Palliative Medicine (US) - Senior Associate Editor
- Journal of the Royal Society of Medicine International Editorial Advisory Board
- Psychological Reports: Perceptual and Motor Skills (US) - Consulting Reader
- Palliative and Supportive Care Editorial Board
- Quality of Life and Health Outcomes Editorial Board

Professor Lynne Turner-Stokes
- ‘Concise guidance series’ in Clinical Medicine - Editor
- Clinical Rehabilitation Editorial Board
- Journal of Rehabilitation Medicine Editorial Board

Dr Claudia Bausewein
- German Journal for Palliative Medicine - Co-Editor
- German Journal for Palliative Medicine Editorial Board

Dr Barbara A Daveson
- Australian Journal of Music Therapy Editorial Board

Dr Wei Gao (Gao Wei)
- Chinese Journal of Pharmaco-epidemiology
- Journal of Palliative Care & Medicine
- Journal of Open Epidemiology

Dr Wendy Magee
- Australian Journal of Music Therapy - Associate/Assistant Editor
- Journal of Music Therapy Editorial Committee
- British Journal of Music Therapy Advisory Editorial Panel
- Music and Medicine - Guest Editor

Dr Richard Harding
- AIDS Care - Editor
- British Medical Council Research Methods - Associate Editor

Dr Fliss Murtagh
- End of Life Care Journal Editorial Board
- Journal of Renal Care Editorial Advisory Board

Dr Richard Siegert
- Disability and Rehabilitation Editorial Board
Referee work for peer-review journals and funding bodies

Journals

Age and Ageing
AIDS Care
American Journal of Public Health
Archives of General Psychiatry
Archives of Physical Medicine and Rehabilitation
Australian Journal of Music Therapy
BMJ Health Services Research
BMJ Palliative Care
BMJ Public Health
BMJ
BMJ Supportive and Palliative Care
Brain Injury
British Journal of Music Therapy
Clinical Rehabilitation
Cochrane
Cognitive Neuropsychiatry
Disability and Rehabilitation
Emergency Medicine
European Journal of Epidemiology
European Journal of Public Health
European Respiratory Disease
German Journal for Palliative Medicine
German Weekly Medical Journal
Health and Quality of Life Outcomes
Health Trends
Jessica Kingsley Publishers
Journal of Clinical Oncology
Journal of Epidemiology and Community Health
Journal of Music Therapy
Journal of Neurology, Neurosurgery and Psychiatry
Journal of Pain and Symptom Management
Journal of Palliative Care
Journal of Palliative Medicine
Journal of Palliative Medicine, Disability and Rehabilitation
Journal of Psychosomatic Research
Journal of Public Health Medicine
Journal of Surgery
Journal of Wound Care
Lancet
Lancet Oncology
Music Therapy Perspectives
Neuropsychology
Neurorehabilitation and Neural Repair
Nordic Journal of Music Therapy
Pain
Palliative Medicine
Physiotherapy Research International
Primary Health Care Research and Development
Psychological Medicine
Psychology of Music
Psycho-Oncology
Public Library of Science (PLoS)
Quality in Health Care
Schizophrenia Research
Sexually Transmitted Infections
Social Science and Medicine
Stroke
Supportive Care in Cancer

Funding bodies

AIDS Foundation
Arts and Humanities Research Council
British Heart Foundation
Department of Health Policy Research Programme
ESRC
Health Research Council (New Zealand)
Intercollegiate Working Party for Stroke
King's College Hospital NHS Trust
Macmillan
Marie Curie Cancer Care
Myeloma UK
MRC
Motor Neuron Disease Association
NIH
NIHR programmes
New Zealand Health Research Council
New Zealand Lottery Grants Board – Health Research
St Christopher's Hospice
Stroke Association
The Prostate Cancer Charity
Wales Office of Research and Development for Health and Social Care
Wellcome Trust

International keynote presentations

Professor Irene Higginson

- End of life care for cancer patients in Europe
- WHO Guidance for a better practice in palliative medicine
  EUGMS Glasgow Congress, Royal College of Physicians & Surgeons of Glasgow, UK, 2009
- Implementing the End of Life Care Strategy: Delivering quality markers for end of life care. Measuring and monitoring clinical outcomes in end of life care
  10th National Palliative Care Conference, London, UK, 2009
- Palliative Care in MS
  14th Annual Conference of Research Challenges in Multiple Sclerosis Rehabilitation, Genoa, Italy, 2009
- Palliative Care: Facing the end together with dignity. Voices from the Member States - The UK Forum Against Cancer Europe, Brussels, Belgium, 2010
- Trends in End of Life Care; Celebratory Lecture
  Garden House Hospice, Hertfordshire, UK, 2010
- Creativity in palliative care through international collaboration and partnership in research
  3rd APCA Conference, Windhoek, Namibia, 2010
- Outcomes, quality indicators and complexity in palliative care FILE and Project PRISMA
  Florence, Italy, 2010
- Research Methodology in Bereavement: Practical and Scientific Issues in Conducting Research in Bereavement
  EAPC Research Congress, Glasgow, UK, 2010
- Fast track RCT Trials
  Cancer Experiences Collaborative Conference, Glasgow, UK, 2010
- Epidemiological Trends in Death and Dying
  Annual Marie Curie Research Conference, London, UK, 2010
**Professor Lynne Turner-Stokes**

- Development of guidelines for management of long term neurological conditions at the interface between neurological rehabilitation and Palliative care: Neuro-palliative rehabilitation
  - Royal Society of Medicine, UK, 2008
- Evidence for the effectiveness of multi-disciplinary rehabilitation following acquired brain injury: a synthesis of two systematic approaches
- Defining person-centred outcomes for evaluation of treatment of spasticity
  - Adelaide, Australia, 2008
- Measuring rehabilitation needs and inputs
  - A series of workshops in Auckland and Hamilton, New Zealand, 2008
- Payment by Results: Developing case-mix Classification for Rehabilitation, A UK update
  - Philip Wrightson Centre of Excellence Annual Conference, Auckland, New Zealand, 2008
- The future of the NSF for Long Term neurological Conditions
- Goal attainment scaling as a measurement of outcome in real life settings
- Theory and use of goal attainment scaling in neurological rehabilitation
  - Peter Jay Sharp Foundation lecturer, Cornell University, New York, USA, 2009
- Evidence based practice or practice-based evidence? New approaches to guiding healthcare interventions: Grand Round Interstate visitor
  - Royal Melbourne Hospital, Melbourne, Australia, 2009
- Opening the black box of rehabilitation – measuring needs, inputs and outcomes
  - Royal Melbourne Hospital, Melbourne, Australia, 2009
- Assessing pain and depression in people who cannot talk to you
  - Grand Round, Royal Melbourne Hospital, Melbourne, Australia, 2009
- Overview of the evidence for neurorehabilitation and making the case for resources
  - Auckland University of Technology, Auckland, New Zealand, 2009
- Building goal attainment scaling into clinical practice workshop for Nordic physicians enrolling patients in ULLIS-II (the Upper Limb International Spasticity programme), Stockholm, Sweden, 2009
- Interpreting the evidence for rehabilitation following brain injury
  - Ollie Hook Lecture, Swedish Society for Rehabilitation Medicine, Stockholm, Sweden, 2009
- Specialised commissioning and casemix in rehabilitation - past present and future
  - Acquired Brain Injury Forum for London, UK, 2010
- Use of GAS (Goal attainment scaling) in spasticity management
  - World Congress of Neurorehabilitation, Vienna, Austria, 2010
- Goal attainment scaling – what is it and does it provide added value over standardised measures
  - Royal Princess Alexandra Hospital, Brisbane, Australia, 2010
- Using patient centred outcomes in spasticity management
  - Brisbane, Australia, 2010
- Outcome measurement – towards a common language
  - Western Australia Stroke Network, Perth, Australia, 2010
- Innovative assessment of depression in acquired brain injury
  - Royal College of Psychiatry Annual Congress, Edinburgh, UK, 2010
- The National Dataset: casemix, costing and benchmarking in Rehabilitation (4 lectures)
  - The British Society of Rehabilitation Medicine, Larnington Spa, UK, 2010
- Measuring Needs Inputs and Outcomes: The UK Rehabilitation Outcomes Collaborative (UKROC): Dataset
  - The Kemsley Conference, Wyboston Lakes, UK, 2010

**Dr Claudia Bausewein**

- High person – low technology: palliative care myth or reality
  - 7th German Palliative Care Conference, Wiesbaden, Germany, 2008
- Verständnis von “end of life care” in England und Deutschland – eine qualitative pilot studie
  - 8th German Palliative Care Congress, Dresden, Germany, 2010

**Dr Richard Harding**

- Beyond virology: are we enhancing quality of life and the patient experience of HIV disease?
  - 9th AIDS Impact Conference, Gaborone, Botswana, 2009

**Dr Jonathan Koffman**

- Reaching out to those in the palliative care phase - from Black and Minority Ethnic Groups, Evolving MS Services/Palliative Care for people affected by MS, MS Society, London, UK, 2010
- Pain and culture: Dignity with Difference : Cross cultural practice at the end of life, Hospiscare, Exeter, Devon, UK 2010
- Experiences of illness and death in different cultures, SELKAM, London, 2011
- Cultural relativism: implications for palliative and end of life care. International Observatory for End of Life, Lancaster, UK 2011
- How Religious and Cultural Beliefs Shape End of Life Care: The BME Perspective, Primary Care 2011, Nottingham and Oxford, UK, 2011
- The experience and expression of pain: does ethnicity and culture make a difference? The Oxford Advanced Pain and Symptom Management courses, Newcastle, Nottingham and Oxford, UK, 2011
- How Religious and Cultural Beliefs Shape End of Life Care: The BME Perspective, Primary Care 2011, Birmingham, UK, 2011
- Servicing multi-cultural needs at the end of life “getting it right, getting it wrong 40th EDTNA/ERCA International Conference, Ljubljana, Slovenia, 2011
- Britain Pain Society: Special Interest Group for Philosophy and Ethics
  - The experience and expression of pain: Does ethnicity and culture make a difference? Britain Pain Society: Special Interest Group for Philosophy and Ethics, UK 2011
Dr Wendy Magee
• Music Technology in Therapeutic and Health Settings, Berklee College of Music, Boston, USA, 2010
• Music Therapy with Neurological Populations: Insights from Research and Practice
  International Symposium on Music Therapy and Rehabilitation, Buenos Aires, 2009

Dr Fliss Murtagh
• Managing patients who do not wish to have dialysis
  37th EDTNA/ERCA International Conference, Prague, Czech Republic, 2008
• Sources and Resources
  Association for Palliative Medicine Research Study Days, Newport, Wales, UK, 2008
• Opioids in patients with renal impairment
  The 4th Bristol Opioid Conference, Bristol University, Bristol, UK, 2008
• Maximum Conservative Management
  UK Advanced Nephrology Course Part 1, Royal College of Physicians, London, UK, 2009
• Conservative care: symptoms and patient trajectories and when to refer to palliative care Supportive Care for the Renal Patient, Hammersmith Hospital, London, UK, 2009
• Palliative care for patients with advanced renal disease
  2009 Hospice and Palliative Care Seminar in Britain, King’s Fund, London, UK, 2009
• Palliative care for people with primary renal disease or co-incident renal impairment
  The Oxford Advanced Pain and Symptom Management courses, Newcastle, Nottingham and Oxford, UK, 2009
• Conservative management of kidney failure in older people
  World Congress of Nephrology, Milan, Italy, 2009
• Dialysis Dilemmas: starting and stopping. Who decides?
  38th EDTNA/ERCA International Conference, Hamburg, Germany, 2009
• Conservative management of end-stage renal disease - without dialysis
  10th NHPCO Clinical Conference ‘Palliative care for dialysis patients’, Denver, Colorado, USA, 2009
• Research Methods and Tools in Renal Palliative Care and Conservative management of end-stage renal disease - without dialysis
  Regional Nephrology Conference, Baystate Hospital, Mass, USA, 2009
• Understanding the symptoms of patients with advanced CKD
  EuroPD conference, Strasbourg, France, 2009

Dr Richard Siegert
• Dignity, rights and capabilities in rehabilitation
  Australasian Rehabilitation Nursing Association 19th Annual Conference, Melbourne, Australia, 2009
• Goal-setting in rehabilitation: Perhaps it is rocket science!
  Australasian Rehabilitation Nursing Association 19th Annual Conference, Melbourne, Australia, 2009

Representation at conferences
5th EAPC Conference on Research in Palliative Care, Trondheim, 2008
6th EAPC Conference on Research in Palliative Care, Glasgow, 2010
7th EAPC Conference on Research in Palliative Care, Lisbon, 2011
5th World Congress for Neurorehabilitation, Brazilia, Brazil, 2008
7th German Palliative Care Conference Wiesbaden, Germany, 2008
7th Palliative Care Congress, Glasgow, 2008
8th German Palliative Care Congress, Dresden, 2010
9th International AIDS Impact Scientific Meeting, Botswana, 2009
11th EAPC Congress, Vienna, 2009
12th EAPC Scientific Congress, Lisbon, Portugal, 2011
18th International Congress on Palliative Care, Montreal, 2010
35th Australian Music Therapy National Conference, Sydney, 2009
African Palliative Care Association Conference, Windhoek, 2010
American Academy of Physical Medicine and Rehabilitation, Seattle, 2010
Australasian Federation of Rehabilitation Medicine, National Institute for Rehabilitation Research, New Zealand Rehabilitation Association – Joint Conference, Queenstown, 2009
Australian Society for Study of Brain Injury 32nd Pain Impairment Conference, Sydney, 2009
British Association for the Study of Spirituality Conference, Windsor, 2010
Chartered Society of Physiotherapy Congress, Liverpool, 2010
Conference on Clinically Assisted Nutrition and Hydration, Royal Society of Medicine, London, 2011
COMPASS conference, Edinburgh, 2011
Congress of the German Association for Internal Medicine, Wiesbaden, 2009
Disability and Rehabilitation – Special issue meeting on outcomes in rehabilitation, Queenstown, New Zealand, 2009
Emotional Health in People with Cancer, Liverpool, 2010
European Health Psychology Society Conference, Bath, 2008
European Public Health Association Conference, Amsterdam, 2010
Fondazione Italiana di Leniterapia, Florence, 2010
German Cancer Conference, Berlin, 2010
German Respiratory Conference, Mannheim, 2009
German Respiratory Conference, Dresden 2011
Headway National Conference and Exhibition, Stratford-upon-Avon, 2009
HIV Implementers’ Meeting, Uganda, 2008.
IAS Vienna, 2010
Indian Association of Palliative Care (IAPC) Conference, India, 2008 & 2009
Indian Journal of Medical Ethics Third National Bioethics Conference, New Delhi, 2010
International Society for Quality of Life Research 16th Annual Scientific Meeting, New Orleans, 2009
International Society for Study Transmitted Diseases Research/British Association for Sexual Health and HIV, London, 2009
Marie Curie Annual Palliative Care Research Conference, London, 2011
Motor Neurone Disease Study Day, Newcastle
National Cancer Research Institute Conference, Liverpool, 2010
PABIN Study Day, Northwick Park Hospital, Harrow
Palliative Care Association of Uganda Conference,
Our UK projections of numbers of deaths by place of death were the first in the world to project the influence of socio-demographic trends onto palliative care needs by setting of care. The work is strongly referenced in the UK government’s Strategy and the National Audit Office’s report on end of life care.

Non-pharmacological interventions play an important role in the management of breathlessness. This Cochrane Review assessed the effectiveness of twelve different interventions in 47 studies. Breathing training, walking aids, neuro-electrical muscle stimulation and chest wall vibration appear to be effective non-pharmacological interventions for relieving breathlessness in advanced stages of disease.

This article describes the research strategy for the development of a computerized assessment tool as part of a European Union (EU)–funded project, the EPCRC. The ongoing change in society towards greatly increased use of communication as well as information transfer via digital systems will rapidly change the healthcare system. Therefore, patient-centred outcome assessment tools applicable for both clinic and research should be developed. In the future, patients may find that a combination of a face-to-face interview plus a transfer of information of subjective symptoms by electronic means will optimize treatment.

There are 1.7 million deaths from cancer in Europe each year and by 2020 the WHO estimates that, globally, more than 15 million people will experience cancer and 10 million will die from it each year. This epidemiologically based needs assessment showed that the quality of life of virtually all cancer patients with advanced disease is impaired by one or more symptoms, emotional, social, spiritual and communication concerns. In Europe there are up to 1.6 million patients with pain each year, and in around one third of these it will be severe, requiring complex treatment. Almost an equal number are affected by fatigue, and more than 1 in 2 are affected by anxiety and/or depression, breathlessness, insomnia, nausea, constipation and/or anorexia.
<table>
<thead>
<tr>
<th>Authors and Title</th>
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<th>Summary</th>
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<tr>
<td>Turner-Stokes, L.</td>
<td>Clinical Rehabilitation 2009;23(4): 362-370</td>
<td>22</td>
<td>Goal Attainment Scaling (GAS) provides a person-centred approach to evaluation of outcome. It is conceptually different from other measures, recording the achievement of expectations for treatment, as opposed to outcome itself. Therefore it compliments, but does not replace standardised measures. This paper provides a practical guide to using GAS in the course of routine clinical practice – the ‘GAS-light’ method.</td>
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<tr>
<td>Harding, R., et al.</td>
<td>Journal of Pain and Symptom Management 2008;36(2): 149-156</td>
<td>21</td>
<td>There is a lack of evidence on how best to meet policy guidance in fulfilling the information needs of patients with chronic heart failure (CHF) and their families. We aimed to generate guidance for appropriate information provision to CHF patients and their families through a cross sectional qualitative methodology with constant comparison of emergent themes. We identified four types of barriers to the discussion of disease progression: disease specific; patient-specific; specialism-specific; and staff time and resources. This is the first study to integrate cardiology, palliative care, and patient and family views to develop feasible recommendations on meeting information needs.</td>
</tr>
<tr>
<td>Booth, S., Moosavi, S.H., Higginson, I.J.</td>
<td>Nature Clinical Practice Oncology 2008;5(2):90-100</td>
<td>18</td>
<td>This summary of a Cochrane Review presents what we know from research about the effect of multidisciplinary rehabilitation programmes following joint replacement at the hip or knee. Multidisciplinary rehabilitation that happens very soon after hip or knee replacement may improve a person’s ability to move. Multidisciplinary rehabilitation that takes place at home may improve a person’s quality of life and their ability to do normal daily activities after a hip replacement. None of the studies included in this review found any adverse effects that might have been caused by the rehabilitation.</td>
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<td>Gysels, M., Higginson, I.J.</td>
<td>Journal of Pain and Symptom Management 2008;36(5):451-460</td>
<td>15</td>
<td>The aim of this study was to explore the experience of breathlessness in patients with chronic obstructive pulmonary disease (COPD) through patients’ accounts of their interactions with services. The study has a qualitative design based on Grounded Theory. Data were collected through semi-structured, in-depth interviews over a 9 month period. The study is part of a wider program, “Improving Breathlessness.”</td>
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<tr>
<td>Khan, F., et al. Multidisciplinary rehabilitation programmes following joint replacement at the hip and knees in chronic arthropathy</td>
<td>Cochrane Database of Systematic Reviews 2008;(2): CD004957</td>
<td>18</td>
<td>This summary of a Cochrane Review presents what we know from research about the effect of multidisciplinary rehabilitation programmes following joint replacement at the hip or knee. Multidisciplinary rehabilitation that happens very soon after hip or knee replacement may improve a person's ability to move. Multidisciplinary rehabilitation that takes place at home may improve a person's quality of life and their ability to do normal daily activities after a hip replacement. None of the studies included in this review found any adverse effects that might have been caused by the rehabilitation.</td>
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<tr>
<td>Gysels, M., Higginson, I.J. Access to services for patients with chronic obstructive pulmonary disease: The invisibility of breathlessness</td>
<td>Journal of Pain and Symptom Management 2008;36(5): 451-460</td>
<td>15</td>
<td>The aim of this study was to explore the experience of breathlessness in patients with chronic obstructive pulmonary disease (COPD) through patients’ accounts of their interactions with services. The study has a qualitative design based on Grounded Theory. Data were collected through semi-structured, in-depth interviews over a 9 month period. The study is part of a wider program, &quot;Improving Breathlessness.&quot;</td>
</tr>
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<td>Playford, E.D., et al. Areas of consensus and controversy about goal setting in rehabilitation: A conference report</td>
<td>Clinical Rehabilitation 2009;23(4): 334-344</td>
<td>15</td>
<td>This report considered clinical issues surrounding goal setting in neurological rehabilitation, and identified priorities for future research. The Delphi studies highlighted and confirmed areas of general agreement with consensus that goal setting is a core component of the rehabilitation process, and that goals should be specific, ambitious, relevant and time limited, with incremental steps that lead to progressive achievement. It was also agreed that goal setting has a major impact on the relationship between patient and professional, with the availability of professional time and expertise being key to the success of the process.</td>
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**Despina Anagnostou**  
**PhD student**

Despina is currently completing the final stages of her PhD at King’s College London. She is also a Research Associate on the MORECare project, led by the Department of Palliative Care, Policy & Rehabilitation. Despina completed her first degree in Nursing in Athens and was awarded an MSc in Advanced Nursing with a focus on cancer and palliative care from the University of Edinburgh. Following her undergraduate degree, Despina worked in several clinical settings in Greece before she moved to the UK. Despina’s PhD examines the dying processes of cancer patients in Greece and their experience of illness and care over their last months of life. This is an ethnographic study, which followed 92 patients, families and health professionals over a period of 18 months. The findings of this study are expected to improve our understanding of the experiences and preferences of people dying from cancer in Greek hospitals and is the first study of its kind to be undertaken in Greece. Following completion of her PhD, it is Despina’s ambition to further help advance the care of patients with a life threatening illness and work towards the establishment of palliative care services in Greece. She is involved in the development of the Greek palliative care policy and a home and hospital palliative care team in Greece. Despina has been supported in her studies by the Red Cross Hospital of Athens. She also holds a scholarship from the State Scholarship Foundation of Greece which is awarded by the Schilizzi Foundation. She is a member of the European Academy of Nursing Sciences.

**Bárbara Antunes**  
**Marie Curie PhD Training Fellow**

Bárbara Antunes is a Clinical Psychologist who graduated in 2003 from Instituto Superior de Ciências da Saúde - Norte, Portugal, where she also gained her Masters in the Psychology of Pain in 2006. Bárbara has worked in Liga Portuguesa Contra o Cancro - Região Norte in Portugal and Instituto Cuf in Porto working with oncology patients and their families. She has also been a clinical consultant in private practice. She is a researcher at Centro de Estudos e Investigação da Universidade de Coimbra and joined the EU funded PRISMA project in May 2009. In 2010 Bárbara was invited to spend a few weeks at the Cicely Saunders Institute to write a paper and attend meetings. In early 2011 Bárbara was accepted for the EU funded EUROImpact project and is now a Marie Curie PhD Training Fellow at the Cicely Saunders Institute supervised by Professor Irene Higginson. Her PhD refers to the predictors of poor outcomes in advanced cancer patients and their families and how that data can be used to facilitate outcome measurement and improve practice in palliative care. Bárbara has research interests in the following areas: mental health in palliative care; quality of life and outcome measurements; evaluation of palliative care; and effectiveness and implementation of outcome measures in clinical practice.

**Stephen Ashford**  
**Clinical Specialist and Research Physiotherapist**

Stephen trained in Physiotherapy at Salford University and qualified in 1993. He completed an MSc in Neuro-rehabilitation at Brunel University in 1998 then undertook a Postgraduate Certificate in Education through the University of Greenwich while working at the Royal Hospital for Neuro-disability, Putney. He subsequently became part-time lecturer and course director for the MSc Neuro-rehabilitation at Brunel University from 2001 to 2003, while working clinically at the Regional Rehabilitation Unit (RRU), Northwick Park Hospital.

Since 2003 Stephen has been full time Clinical Specialist and Research Physiotherapist at the RRU and an Honorary Research Fellow at the Department of Palliative Care, Policy & Rehabilitation. Stephen is currently nearing completion of a PhD investigating the measurement of arm function following focal interventions, such as botulinum toxin for arm spasticity. Stephen’s current clinical role involves coordinating the outreach service from the Regional Rehabilitation Unit at Northwick Park Hospital (across Northwest London and the Eastern region) and the related spasticity management service. The service provides consulting input to professionals, patients and families in the management of complex neuro-disability including spasticity.
Sabrina Bajwah  
Clinical Research Fellow  
Sabrina 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.  
She is now working in full time research, on developing and evaluating a complex intervention for patients with end-stage interstitial lung disease. This will consist of an evidenced-based guideline and a case conference model of care which may improve symptom control and enhance co-ordination of care at the end of life between terminally ill patients, their carers and health care professionals. Clinical experience indicates these patients are poorly symptom controlled, have a poor quality of life whilst dying and are being admitted acutely to the inpatient setting. This project is to be clinically based at the Royal Brompton Hospital and King’s College Hospital.

Claudia Bausewein  
Senior Clinical Research Fellow & Saunders Scholar  
Claudia 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. From 2004 to 2010, Claudia was 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 with the Department of Palliative Care, Policy & Rehabilitation, 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. Claudia is now working as Senior Clinical Research Fellow and also the first Saunders Scholar in the Department. Claudia’s work is focussing on breathlessness, outcome measurement and palliative care in non-cancer patients as well as on research methodologies. She is leading Work Package 4 in the European Commission funded PRISMA project.

Hamid Benalia  
Research Assistant  
Hamid worked for the NHS as Programme Coordinator at Kingston Primary Care Trust (London), before joining the Department. He is also a member of a Research Ethics Panel at King’s College London.  
Hamid has been working on the PRISMA project, a major European-wide project funded by the European Commission under the 7th Framework Programme. The principal aim of the PRISMA Work Package 4 is to map and harmonise approaches and experiences in end-of-life cancer care measurement and quality indicators and to develop online resources to support and enhance Pan-European measurement and research in end-of-life care for cancer patients. He is also involved in a research project looking at experiences of episodic breathlessness in patients with advanced disease.
Emma Bennett
Research and Dissemination Facilitator

Emma joined the administrative team at the Cicely Saunders Institute in October 2010 and assisted the PRISMA Project Manager in preparing for the project’s final symposium and report to the European Commission.

In August 2011 Emma was appointed to work alongside Professor Irene Higginson and Dr Barbara Daveson on a new project called BuildCARE (Building Capacity, Access, Rights and Empowerment), which has been generously supported by Cicely Saunders International and The Atlantic Philanthropies.

Having previously worked at the Academy of Medical Sciences and The Royal College of Art, Emma has extensive experience of working with a wide range of people from pre-eminent scientists, senior academics and policy makers to students and public audiences. BuildCARE is an ambitious project that aims to make a fundamental change to the way palliative and end-of-life care is regarded, implemented and prioritised internationally and Emma’s role within this focuses on the dissemination of research findings and clinical good practice to healthcare professionals, policy makers and funders, along with public engagement and empowerment.

Sian Best
Education and Finance Manager

Sian 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 the Department in 2005.

Her administrative responsibilities include the MSc, PG Dip and PG certificate programmes, research grants, the Cicely Saunders Institute website, finance and supporting a variety of events.

Teresa Beynon
Consultant Palliative Medicine and Honorary Senior Lecturer

Teresa is currently investigating the needs of patients with Cutaneous T cell lymphoma and their carers which is funded by Dimbleby Cancer Care. Recent work has identified the high prevalence of itch, for which a proposal is currently being developed to test possible interventions. Previous collaborative work explored the needs of patients and their carers with heart failure has resulted in a further proposal to test an intervention aimed at identifying who should be referred to palliative care services.

Teresa has recently published work identifying the high potential level of palliative care needs of older people admitted to emergency departments in collaboration with the Emergency and Palliative Care Departments at King’s College London and Guy’s & St. Thomas’ Hospitals.

A 2-day research workshop was piloted in 2010 for STRs following a meeting which Teresa organised for educational supervisors, as research lead for rotation 4 on the London/KSS higher specialty programme. This well evaluated programme will be repeated annually with the endorsement of the training committee.
Lucy Bradley  
Research Manager  
Lucy joined the Department in December 2008 as a Project Assistant to support the research work of Dr Richard Harding and the management of the European Commission-funded PRISMA project.  
In July 2011, she began a new role as Research Manager, continuing to work alongside Dr Harding in managing the administrative and financial aspects of a portfolio of international research projects. She also forms part of the departmental administration team and acts as Health & Safety Officer.  
Lucy graduated with first class honours in Sociology from the University of Nottingham in 2005. Following her undergraduate studies, she worked for a time in student support at Nottingham University in the Department of Computer Science & IT before moving to Oxford to work as a Qualitative Research Executive for a market research company.

Katherine Bristowe  
Research Assistant  
Katherine joined King’s College London in 2010 as a Research Assistant on the ARC (Advanced Renal Care) Project, working with Dr Fliss Murtagh.  
Previously, Katherine worked at the University of the West of England as a Research Associate working on a project funded by North Bristol NHS Trust, investigating the role of teamwork, team communication, and leadership in the management of obstetric emergencies, and the development of a teamwork assessment tool.  
Katherine read English Language and Linguistics at the University of Wales Bangor, completing her BA (Hons) in 2000. She completed an MA in Linguistic Studies at the University of Essex in 2004. Her MA thesis was a sociolinguistic analysis of doctor-patient interaction in outpatient urological oncology clinics.  
Drawing on the findings of her MA research, Katherine completed a PhD in Linguistics at the University of Essex in 2009. This was a sociolinguistic analysis of doctor-patient interaction in outpatient plastic surgery clinics. The study focused on the management of patient initiated topics and questions in consultations. In addition, it involved the implementation of two interventions: a patient information leaflet designed to encourage patients to participate actively in their consultations, and a seminar for doctors designed to improve awareness of common communication problems in doctor-patient interaction.

Dr Rachel Burman  
Consultant in Palliative Care, 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.
Natalie Marie Campbell
Research PA (Maternity cover)
Natalie studied BA English Literature, before going on to study for an MA in Cultural Diversity Policies at London Southbank University. Natalie worked at The Society of London Theatre from 2007 until 2008, then as Project Coordinator at graphic design agency, Strudel Design Ltd, and later as Administration and Accounts Officer at a local college. Natalie commenced work at King’s College London in July 2011 as Research, Academic and Clinical Personal Assistant to Professor Lynne Turner-Stokes.

Natalia Monteiro Calanzani
Research Associate
Natalia joined the Department in 2010. She has a BSc in Psychology from the Federal University of Minas Gerais (Brazil) and an MSc (Distinction) in International Business from the University of Birmingham. She has research experience in psychological evaluation and occupational health psychology. In Brazil Natalia worked as a Junior HR Consultant, carried out research to adapt the Wais III verbal scale for blind people and investigated the occurrence of mental disorders in bus drivers. She lived for two months in China where she investigated the impact of the new Chinese Labour Contract Law on employee relations and Human Resources Management. Natalia is currently working with Barbara Gomes on the PRISMA project investigating public preferences and priorities for end-of-life care in seven European countries. She is also working with Barbara on the QUALYCARE study examining the quality of care provided to people in the last three months of their life.

Susan Chandler
Executive Administrator (Maternity cover)
Susan is locum Executive Assistant to Professor Irene Higginson, covering the position while Nancy Patel is on maternity leave. Over a period of 30 years Susan previously worked for Cancer Research-UK in Oncology, Histopathology, Immunology and the Clinical Director’s Office.
Jo Clark  
Research PA  
Jo is the Personal Assistant to Professor Lynne Turner-Stokes, working between the sites of Northwick Park Hospital and the Cicely Saunders Institute. Jo is part of the administrative team contributing to the organisational, administrative and financial elements of the rehabilitation section as well as the general administrative duties of the department. Jo is the organiser of the UK FIM+FAM training programme and also assists with other training courses associated with the NIHR National Minimum Dataset Project (UKROC). This brings together the collaboration between Northwick Park Hospital, Regional Rehabilitation Unit and King’s College London, Department of Palliative Care, Policy & Rehabilitation. Jo has an educational background in Business and Computer Management and has worked in varying positions in other multi-professional organisations.

Massimo Costantini  
Visiting Professor  
Massimo qualified in Medicine in 1985 at the University of Genoa (Italy). He spent the next five years in specialising in oncology and training in clinical epidemiology at the National Cancer Research Institute (IST) of Genoa (Italy). Since 1990 his main interests were focusing on palliative care. He worked as palliative home care physician, at the G.Ghirotti Association of Genoa for two years. 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 2007, he was appointed visiting Professor in Palliative Care at the Department of Palliative Care, Policy and Rehabilitation, at King’s College London.

At present, he is the Head of the Regional Palliative Care Network (IST Genoa), with the mission to implement a network of specialised palliative care services, quality assurance and total quality management programmes for each of the five Local Health Districts of the Ligurian Region, according to different needs and educational programmes in palliative care. A 12 bed inpatient hospice is part of the IST Unit. He has published over 80 papers in peer-reviewed journals, and a numbers of international book chapters on methodological aspects of palliative care research. In 2002 he coordinated the Italian Survey of the Dying of Cancer (ISDOC), a post-bereavement Italian survey that is providing a national picture of the problems experienced by terminal cancer patients and of the type and quality of care provided. In 2006 he coordinated the first implementation and assessment of the Liverpool Care Pathway for the dying (LCP) in an Italian hospital. The program is going on with a cluster-randomised trial aimed at assessing the effectiveness of LCP in improving the quality of end of life care in hospital.

He was member of the study groups of the Italian Ministry of Health that developed the national guidelines and standards for palliative care organisation. He is member of the Scientific Committee of the Maruzza Lefebvre d’Ovidio Foundation (Rome) to lead the development of a qualified program of research and teaching in palliative care.
Barbara Daveson
PRISMA Project Manager and Research Fellow

Dr Barb Daveson joined the Department in 2009 as a Research Fellow. She is the Project Manager of the PRISMA project, a major European-wide project funded by the European Commission under the 7th Framework Programme. PRISMA aims to deliver an integrated programme to identify and harmonise research priorities and practice for end-of-life care across Europe and beyond. Barb is also working academically on a number of work packages within PRISMA, including a large European survey to determine European citizen’s preferences and priorities regarding end-of-life care, and work to determine best practice and resources for the use of end of life care quality indicators.

Barb’s PhD used grounded theory methodology to examine music therapists’ and service-users’ experiences of time within the context of music therapy (University of Melbourne, 2006). Her interest in this topic stemmed from clinical experience with people living with time-limiting diseases in a palliative care setting.

After graduating in music therapy (University of Queensland, 1993), Barb worked clinically in acute care, oncology, palliative care and neuro-rehabilitation. Barb was the Head of the Music Therapy Department at the Royal Hospital for Neuro-disability in Putney (London, UK) from July 2004 to April 2009. Prior to this she worked in Melbourne, Australia, for a range of palliative care providers, including Eastern Palliative Care, Caritas Christi Hospice and Day Hospice and the palliative care unit at St. Vincent’s Hospital. Barb also worked clinically and academically with the Royal Children’s Hospital and the University of Queensland. Her healthcare, research and project management experience includes work in rehabilitation, neuro-disability, oncology and palliative care, and is complemented by formal healthcare service management training. Barb has also been involved in primary studies in special education, cancer care and rehabilitation in Australia and the UK.

Barb’s current academic interests include the relationship between music and medicine, time (i.e., temporal phenomena), scale development, service-user inclusion, with a special interest in grounded theory methodology and grounded theory development.

Chiara De Biase
Manager of the Macmillan Information & Support Centre

Chiara trained as a Physiotherapist at Brunel University in 2002. Once qualified she worked for Bart’s and the London NHS Trust, and finally specialised in Oncology and Palliative Care in 2006. Chiara worked as the Senior Physiotherapist in Oncology and Palliative Care at St. Bartholomew’s Hospital until she started work at the Macmillan Centre in February 2010. Since the centre opened in May 2010, it has received nearly 500 visitors as well as an additional 250 people at the World’s Biggest Coffee Morning on 24th September 2011 when £1500 was raised for Macmillan Cancer Support. Chiara’s role in the centre focuses on face-to-face contact with people using the service. She is also continuously working with the hospital teams to try and raise the profile of the Centre amongst the staff. Chiara holds several responsibilities in the SELCN including Chair of the Network Family and Carers Group. Last year she was also involved in the roll-out of the South East London Marie Curie ‘Delivering Choice’ project and this year she will be Chair of the ‘Facilities’ stream of the End-of-Life Care Strategy for the King’s College Hospital NHS Trust. The priorities for the Centre this year are Caring for Carers, National Awareness Days, implementation of NCAT Information Prescriptions and working towards securing a Complementary Therapy Service in the Centre.
Rachael Dodd
Academic Administrator

Rachael studied for her BSc in Psychology at Leeds University, and was awarded an MSc in Health Psychology from King’s College London in 2010, where her interests focused predominantly around the diagnosis of Motor Neurone Disease and the psychological impact on patients and their caregivers. During her MSc, Rachael worked as a Research Worker in the Health Psychology Section, working on an internet-based vignette study on ‘The effects of cause and vulnerability on perceived effectiveness of different types of treatments for risk of Heart Disease’.

In February 2010, Rachael joined the Department as an Academic Administrator, providing support for Dr Sue Hall and Dr Fliss Murtagh. Rachael has been particularly involved in an NIHR systematic review on place of care and place of death in non-cancer patients and Dignity Therapy research, alongside forming part of the departmental administration team.

Dr Polly Edmonds
Consultant in Palliative Care, Honorary Senior Lecturer in Palliative Medicine

Polly is a consultant and lead clinician in Palliative Medicine at King’s College Hospital NHS Trust and honorary senior lecturer in the Department of Palliative Care, Policy & Rehabilitation, King’s College London. She qualified from St Mary’s Hospital Medical School, and trained in General Medicine, Medical Oncology and Palliative Medicine prior to taking up her consultant post in 1997. She has led the development of the clinical Palliative Care Team at King’s and is closely involved in the undergraduate curriculum at the King’s College London School of Medicine, as Palliative Medicine teaching lead, deputy head of year 4 and year 4 OSCE coordinator. Jointly with Rachel Burman, Polly is programme director for the London and KSS Deanery Specialty Training Programme for Palliative Medicine. She has previously chaired the South East London Palliative Care coordinating Group of the South East London Cancer Network and remains an active participant. Her research interests include palliative care for non-cancer patients.

Susie Edwards
Research Support Officer, COMPASS Research Collaborative

COMPASS is a National Cancer Research Institute (NCRI)-funded Supportive and Palliative Care Collaborative comprised of researchers and clinicians based at three main centres (King’s College London, University of Leeds, University of Edinburgh) and 13 additional UK institutions. The overall aim of COMPASS is to make a major contribution to supportive and palliative cancer care research. Susie currently takes care of the administrative aspects of the Collaborative at KCL. More information about COMPASS can be found at HYPERLINK “http://www.compasscollaborative.com”www.COMPASScollaborative.com
**Eleni Epiphaniou**  
**Research Associate**

Eleni studied for a BSc in Psychology at the University of Cyprus where she contributed to various research programmes. She was then awarded an MSc in Health Psychology and pursued a PhD and Charter in Health Psychology at Surrey University. During her time Eleni worked both as a tutor and a part-time academic tutor. The positions included teaching undergraduate and postgraduate psychology students, marking essays and providing feedback.

She examined the significant influence of sudden life triggers to healthy behaviour change and assessed how these events are related to sustained behaviour change when they are accompanied by three other sustaining mechanisms for her PhD. It included both quantitative and qualitative analysis (IPA analysis).

Eleni’s research interests concentrate on exploring family and patients’ experiences, coping, adjustment and needs when they are diagnosed with a chronic condition or while living with a chronic condition. She is also interested in qualitative research and behavioural interventions. She is currently involved in a study targeting informal cancer carers funded by the CRUK, an SDO project aimed at exploring the coordination and collaboration of care in end of life care and a systematic review exploring Gay, Lesbian, Bisexual and Transgender patients’ needs, preferences, experiences and attitudes in palliative and end-of-life care.

**Catherine Evans**  
**National Institute of Health Research (NIHR) Lecturer**

Dr Catherine Evans joined the Department as a Research Fellow in 2010. She manages an MRC/NIHR funded project developing guidance on evaluation methods in end-of-life care (EoLC). This is a collaborative study between King’s College London, University of Manchester, University of Aberdeen and University of Edinburgh. The project aims to identify, appraise and synthesise ‘best practice’ methods for evaluating end-of-life care, particularly complex-service delivery interventions and reconfigurations.

Catherine joined the Department from the Centre for Research in Primary and Community Care, University of Hertfordshire, where she worked as a research fellow managing an NIHR funded project developing and evaluating an intervention to support people with dementia at the end of life living in a care home (EVIDEM EoL).

Prior to this Catherine completed her PhD in 2008 which examined experiences and representations of older people’s health living in care homes to inform the development of district nursing practice.

After qualifying as a nurse at the Royal Free Hospital in 1985, Catherine worked clinically in acute care, haematology and oncology, completing post-basic training in oncology at the Royal Marsden in 1990. Catherine worked as a ward sister in the haematology unit and then the oncology unit at the Royal Free Hospital from 1987-1990. Catherine completed a BSc (Hons) in Community Nursing with district nurse and health visitor qualification at King’s College London in 1994. Catherine worked as a health visitor in North London managing a mixed caseload of families with children under-five and older people. Catherine moved into research in 1998 as a lecturer at the Department of Primary Care and Population Health, University College London, and pursued her research interests in health care for the very old and developing primary care nursing practice. Catherine led studies on practice nurses’ management of the very old, research priorities for primary health care, and the equitable distribution of health visiting resource.

Catherine completed an MSc in Gerontology at King’s College London in 2001.

Catherine's current academic interests focus on methods to evaluate complex-interventions, particularly processes of informed consent and the role of qualitative research in trial designs, end of life care for older people and the development of primary care nursing practice.
Amanda Fahy
Research Administrator
Amanda graduated with a BA in Psychology from the National University of Ireland, Maynooth in 2009 where she completed her dissertation focusing on the role of message framing in mothers’ intentions to get the HPV vaccine for their daughters. She has since gone on to work on a number of research projects in the domains of education and health psychology including an investigation of the impact of transitioning into secondary school on children with special educational needs and the role of mindfulness in reducing the effects of psychological avoidance with regard to anti-smoking campaigns.
Amanda has recently completed an MSc in Social Cognition at University College London. Her MSc dissertation focused on the role of self-regulation in social decision-making in childhood. Amanda is currently working as a Research Administrator on the Long Term Neurological Conditions (LTNC) study with Dr. Richard Siegert.

Wei Gao (Gao Wei)
Medical Statistician
Dr Gao is a medically trained statistician and epidemiologist. She has substantial experience in managing, manipulating, linking and analysing various large scale data, ranging from health related registries, and population-based epidemiology data to gene-environment interaction data. She has been working with the Centre for Molecular Epidemiology at the National University of Singapore, Postdoctoral Station in Clinical Medicine at the Jinan University (Guangzhou, part-time), Singapore Cancer Registry (Honorary), Department of Infectious Disease Epidemiology at the Imperial College before joining the Department.
She has worked as the main statistical analyst for the largest trial data in the world---the Randomised Badger Culling Trial (RBCT). She is a visiting staff member at the Department of epidemiology and health statistics, a statistical reviewer for national and international medical journals including the Lancet and Lancet series journals, and a referee for NIHR programme grants. She has rich experiences in applying various classical and modern statistical models (eg. GLM, GEE, NN, survival models) to health data analysis.
Gao Wei’s research interest is further extending to psychometric analysis of health related quality of life and latent trait modelling. In addition she is contributing to Strand I of COMPASS (COMPlex interventions: Assessment, trialS and implementation of Services) to develop assessment and outcome measures. She is co-leading a project using the world’s largest primary care data (GPRD) to improve end of life care and will co-lead a NIHR funded project to understand the geographical and temporal variation in place of death (GUIDE_CARE). She also provides statistical support for the researchers in the Department and teaches MSc students.

Professor Rob George
Consultant in Palliative Care, Professor in Palliative Care.
Rob trained in Respiratory and General Medicine with his doctoral research looking at novel ways to treat breathlessness. He pioneered HIV & non-cancer palliative care from 1987 to 2003 at University College London Hospitals, during which time he was part of a number of health service research projects with the King’s College Hospital palliative care team. From 2003-2006, as a management consultant, he worked across all palliative care settings supporting teams in crisis. He is now responsible at Guy’s & St Thomas’ for community palliative and end-of-life Care. He leads End-of-life Care for London, advises Government and sits on various ethics committees. Before joining the Cicely Saunders Institute, he was Senior Lecturer in Ethics at UCL publishing on end-of-life ethics, advance care planning, continuity of care, risk management and distributive justice. His overarching academic interests are to understand the nature of suffering in postmodern culture, its response and the complexities that this introduces to care modelling and service delivery.
Cassie Goddard
Research Associate

Cassie studied for her BSc in Applied Psychology at Liverpool John Moores University, and was awarded an MSc in Health Promotion and Psychology from the University of Nottingham in 2006, where her research interests focused predominantly around smoking cessation.

In May 2007 Cassie joined the Department as a Research Assistant. She has worked on a number of studies focusing on end of life care issues for older people in care homes. Cassie is currently working with Dr Jonathan Koffman on a study exploring and comparing the experience and costs associated with the care of people with multiple sclerosis from different cultural backgrounds.

Barbara Gomes
Cicely Saunders International PhD Research Training Fellow

Barbara completed her first degree in Psychology and Health at the University of Porto and an MSc in Palliative Care at King’s College London with distinction. Having gained experience in research (in topics such as healthcare staff training, family influence on adolescent life expectations and grief experiences amongst the Gipsy community), she worked for one year in a palliative care unit in Portugal, before moving to London.

She joined the Department in 2004, and is now undertaking a PhD. Together with Professor Irene Higginson, Barbara leads a long-term project supported by Cicely Saunders International aiming to understand where people die and to discover ways of empowering patients to die in the place of their choice, with quality care, dignity and with support for their families. She coordinates a population-based survey with around 600 bereaved relatives of cancer patients in London – the QUALYCARE study – examining variations in the quality of care, costs, preferences and outcomes for patients and families. She is also leading a pan-European survey with around 10,000 members of the general public on their preferences and priorities for end of life care, funded by the European Commission as part of the PRISMA project.

Barbara’s interests and current projects fall within the following areas: decision-making at the end of life; integration of psychological, social, spiritual and cultural aspects in palliative care; symptom control in advanced disease; health economics of palliative care; public expectations and public education about end of life care issues; bereavement research; cross-national studies; systematic reviewing; understanding risk; trends analysis and the evaluation of palliative care services.

Iris Groeneveld
Research Assistant

Iris completed a BSc in Biomedical Sciences at University College Utrecht (The Netherlands) in 2008. She then pursued an MSc in International Public Health at VU University Amsterdam to feed her broad interest in (global) health. As part of this degree she researched the psychosocial services for people living with HIV in the Johannesburg area. Iris moved to London in 2009 for the MSc Health Policy, Planning and Financing, a joint degree at the London School of Economics and the London School of Hygiene and Tropical Medicine, during which she developed a strong interest in financing and evaluating health services and health systems.

After an internship on Health Workforce Migration and Retention at the World Health Organization, she started work at King’s College London in December 2010. Iris is currently working on a development grant for the C-CHANGE project with Dr Fliss Murtagh, laying the groundwork for a palliative care casemix classification to inform palliative care funding models.
Marjolein Gysels  
Senior Research Fellow  

Marjolein 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 the Democratic Republic of the Congo on Swahili and oral literature. Marjolein also 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 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. Her current role as Senior Research Fellow involves conducting 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.

Sue Hall  
Herbert Dunhill Senior Lecturer in Palliative Care  

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 Research & Development Consultant. In March 2006, she joined the Department as Herbert Dunhill Lecturer in Palliative Care. She is currently developing a programme of work to improve palliative care for older people. This includes producing a new booklet for the World Health Organisation on better practices in palliative care for older people; a Cochrane systematic review of interventions to improve palliative care for older people; a Cochrane systematic review of interventions to improve palliative care for older people; a Cochrane systematic review of interventions to improve palliative care for older people; and two Phase II randomised controlled trials (one with residents in care homes, one with people with advanced cancer) of a brief psychotherapy to reduce psychological and spiritual distress experienced by people reaching the end of life.

Richard Harding  
Reader in Palliative Care  

Richard originally read social anthropology and conducted fieldwork in the Netherlands, followed by a Masters in Social Policy & Social Work Studies with a qualification to practice Social Work. His PhD at King’s College London addressed informal carers in palliative care. The thesis and subsequent papers appraised current evidence, undertook qualitative developmental work, and then designed and evaluated a short-term group intervention that aimed to provide peer support and multi-professional information across two home palliative care services. His clinical experience includes HIV and palliative care management, acute adult health hospital social work and community care management, and community-based group work focused on behavioural change. His academic interests and primary areas of current research, include informal carers, HIV quality of life and symptoms, palliative care provision in Africa, and evaluation of complex interventions. His current work is focused primarily on palliative care in Sub-Saharan Africa.
Leonie Hayes
Academic Administrator
Leonie gained a BA Visual Art (Painting) from Sydney College of the Arts in 1983. She moved to Lismore in Northern New South Wales and gained a BA Visual Art (Fibre & Textiles) from Southern Cross University in 1990. She worked as Public Programmes/Gallery Coordinator at the Lismore Regional Art Gallery for 8 years and spent 6 years in administration at the Southern Cross University. Leonie moved to London in 2001 and worked at the Academic Centre for Medical Education, Royal Free & University College Medical School before joining the Department as Academic Administrator to Professor Irene Higginson in 2009. Leonie gained a NVQ in Management in 2008.

Professor Irene Higginson OBE
Head of Department, Director of Cicely Saunders Institute, Professor of Palliative Care & Policy
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. Before coming to King’s College London she was a Senior Lecturer/Consultant at the London School of Hygiene and Tropical Medicine and Director of Research and Development at Kensington & Chelsea and Westminster Health Authority.

She has research interests and publications in the following areas: quality of life and outcome measurements, evaluation of palliative care especially of new services and interventions, epidemiology, clinical audit, effectiveness, psychosocial factors and care, symptom assessment, cachexia/anorexia, and elderly care. In addition she has advised several governments, charities and other bodies on palliative care.

Yuen King Ho
Research Assistant
King is working on the GUIDE_CARE project. The aim of the project is to describe the variations in place of death and the factors that affect these in order to improve the quality of care at the end of life and enable more patients to die in their preferred place.

He has recently completed the MSc Statistics course at the London School of Economics and joined the Department in August 2011 as a Research Assistant. Prior to moving to London, King worked in the financial industry in Hong Kong and obtained a BSc in Actuarial Mathematics from the University of Michigan. He is proficient in R statistical programming language and SQL.
Helen Horsley
Academic Administrator
Helen joined the Department in 2011 as an Academic Administrator to Dr Fliss Murtagh and Dr Claudia Bausewein. Her responsibilities include supporting their research work, coordinating PhD enquiries and assisting with departmental administration. Helen graduated with a BA (Hons) in Film and English Studies from the University of East Anglia in 2007. She previously worked in television production as a casting researcher.

Diana Jackson
Senior Research Fellow
Diana trained as a physiotherapist at King’s College Hospital and worked in a variety of clinical settings before specialising in neurological rehabilitation. A desire to learn more about the effectiveness of rehabilitation practices led to a change in direction towards research. After taking an MSc in rehabilitation studies she joined the Regional Rehabilitation Unit at Northwick Park Hospital in 1996, where she researched aspects of the rehabilitation and after care of people with complex problems after acquired brain injury. This included developing a multi-disciplinary integrated care pathway for managing post-stroke shoulder pain. A particular focus was the design and evaluation of pain assessment tools accessible to patients with communication and cognitive deficits, and this work formed part of her PhD on the assessment of post-stroke shoulder pain at Southampton University.

Another main research interest concerns carers. In collaboration with researchers from King’s College London, The Institute of Psychiatry and The University of Dundee, Diana has been the lead coordinator on a recently completed seven year programme of three Department of Health funded studies into the needs and experiences of carers of adults with a range of long term neurological conditions, including a number of rare ones. Findings are being widely disseminated and will inform the development of support services for carers as part of the National Service Framework for Long Term Neurological Conditions (LTNC).

Hannah Jones
Research Associate
Hannah is currently working with Richard Harding on the ‘Development and pilot testing of the “Question Prompt List (QPL)” intervention to meet information needs of advanced cancer patients’. Alongside her main project she continues to contribute to other projects including: “How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness.” and a “Systematic review to identify the needs of patients with Cutaneous T cell Lymphoma (CTCL) and their carers”.

Hannah has a background in psychology, having completed a BSc in Psychology from the University of Sheffield and an MSc in Health Psychology at the University of Nottingham. Her current interests include communication in clinical settings and communication skills training, staff burnout and the prevalence of mental disorders in palliative care. Hannah hopes to pursue a career in clinical psychology in the future.
Yvonne Kaloki
Research Assistant

Yvonne completed her BA (Hons) in Economics and Management Science at Keele University in 2008, where she developed an interest in asymmetric information in health care markets. She pursued and was awarded an MSc in Health Economics from the University of York in 2010. For her MSc thesis, she worked as an analyst for the Department of Health analysing and evaluating the causes of variation in treatment thresholds across England using Patient Reported Outcome Measures (PROMs) data. This experience increased her interest in identifying and analysing the causes of variation in the provision and access of healthcare, medical and social services.

In March 2011, Yvonne joined the Department as a Research Assistant on the C-Change project with Dr Fliss Murtagh to develop and validate a case-mix classification system that will aid palliative care funding models.

Bernadette Khoshaba
Research Associate

Bernadette studied life sciences at undergraduate level but then moved into the field of social research. After obtaining a PhD entitled "A patient derived disease activity score in Rheumatoid Arthritis" from King’s College London, she undertook research studies ranging from clinical trials to measuring patient reported outcomes and systematic reviews.

Her previous post as Research Fellow at the London School of Hygiene involved working on a European funded project developing indicators of health system performance from the concept of ‘avoidable mortality’. As Research Associate she will be working alongside Richard Siegert and Lynne Turner-Stokes on the Long Term Neurological Conditions (LTNC) Project. Bernadette’s interests lie within the health-related quality of life of chronically ill patients with the main focus on patient centred outcomes.

Jonathan Koffman
Senior Lecturer in Palliative Care, MSc Coordinator and Sub Dean of Taught Postgraduate Studies in the School of Medicine

Jonathan has a BSc in Social Administration and an MSc in Sociology with Special Reference to Medicine. His PhD explored the experience of living with, and dying from, advanced cancer among black Caribbean and white patients living in south east London. Prior to joining the Department, Jonathan worked for the National Health Service (NHS) as a public health specialist, involved in implementing the reforms of the early 1990s. He is now Senior Lecturer in Palliative Care and Course Coordinator for the inter-professional Postgraduate Certificate, Diploma and MSc in Palliative Care. Jonathan is also Sub Dean of Taught Postgraduate Studies in the School of Medicine.

His research interests include end-of-life experiences of black and minority ethnic groups; social exclusion; qualitative research; and palliative care education. He has published in all these areas. He is presently undertaking research that aims to explore the experience of severe Multiple Sclerosis among different ethnic groups in addition to examining the experience of providing end-of-life care to patients in critical care settings. Jonathan received the King’s Award for Excellence in Teaching in 2007.
Keira Lowther
PhD Student

Keira Lowther has a background in paediatric nursing with a special interest in HIV. After working for the NHS in various North London hospitals, she completed an MSc in Public Health Nutrition at the London School of Hygiene and Tropical Medicine in 2007, with a focus on infant feeding in the context of HIV. Subsequently, Keira worked for Action Against Hunger in Chad, China and more recently Swaziland, where she ran a community capacity building project which used nutrition education to mitigate the impact of HIV related malnutrition.

Keira joined the Department in March 2011 under a King’s PhD studentship to work on a randomised controlled trial of palliative care in HIV in Sub Saharan Africa.

Wendy Magee
Honorary Senior Research Fellow

Wendy is a specialist in neuropalliative rehabilitation having worked for over 22 years as a music therapy clinician, researcher and manager. She has been based at the Royal Hospital for Neuro-disability in Putney since 1990. Her research has used mixed methodologies to examine music therapy methods for treating the symptoms associated with acquired brain injury following disease or trauma. Other research activities include developing measurement tools for complex conditions and exploring the use of electronic music technologies in clinical practice. Wendy currently holds a postdoctoral fellowship at the Institute of Neuropalliative Rehabilitation, London. In 2009 she was awarded a Leverhulme Study Abroad Fellowship to research Music Technology in Therapeutic and Health Settings based at Berklee College of Music, Boston, MA. Wendy is a Cochrane reviewer (Music Therapy for Acquired Brain Injury) and she is passionate about promoting evidence-based practice in music therapy. She has published widely on Multiple Sclerosis, low awareness states, Huntington’s disease, neuro-rehabilitation and music technology.

Farida Malik
The Cicely Saunders Foundation Research Training Fellow

Farida qualified in medicine at University of London and completed her Specialist Registrar training in Palliative Medicine. She has recently been appointed as a Consultant in Palliative Medicine in Eastbourne.

Previously Farida undertook an intercalated BSc in Psychology at University of London and an MSc in Palliative Care at Kings College London. Farida is currently undertaking a PhD examining the experiences of caring for a breathless patient, which has been funded by the Cicely Saunders International programme for breathlessness research.

Her research interests include the areas of breathlessness and sleep disturbance in patients with advanced disease and their caregivers, the use of steroids in brain tumours and symptom assessment.
Professor Kathryn McPherson
Visiting Professor

Kathryn has a clinical background in nursing training in Australia and moved to the United Kingdom to study midwifery and then Health Visiting, both in Edinburgh. Whilst working as a health visitor, Kath completed a psychology degree before undertaking a research position at the Astley Ainslie Hospital in Edinburgh. She then went on to complete a PhD exploring the effects of brain injury on the individual and their family in the transition from inpatient rehabilitation to home.

Prior to her current appointment, she held academic posts at the University of Edinburgh, the University of Otago, New Zealand and the University of Southampton. Kath’s research focus is on: investigating outcomes in ways that matter most to people with chronic conditions (both conceptual and psychometric issues); improving effectiveness of rehabilitation processes such as goals and goal setting and teamwork; clinical decision making in rehabilitation; and rehabilitation workforce development.

She has been an Associate Editor with the BMJ group journal Quality and Safety in Healthcare since 2001, now BMJ Quality and Safety. She is also on the editorial board of Disability and Rehabilitation, Clinical Rehabilitation, the Journal of Occupational Rehabilitation and the International Journal of Nursing Studies. As Visiting Professor at the Department, Kath works with Professor Lynne Turner-Stokes and others in continuing work addressing the identified lack of knowledge about the impact of chronic neurological conditions and the development of more robust and relevant evidence base in rehabilitation.

Katrien Moens
Marie Curie PhD Training Fellow

In 2005, Katrien gained a degree in nursing with distinction from the ‘Europese Hogeschool Associatie Leuven’ (EHSAL) in Brussels, Belgium. In the last year of her training she did a voluntary internship on a palliative care unit in Belgium. Katrien went on to graduate from a Masters in Nursing Sciences with distinction at the ‘Vrije Universiteit Brussel’ in 2007 with a thesis on ‘Complementary care giving by nurses in all Flemish palliative care units.’ In 2007 Katrien started working at the ‘Federatie Palliatieve Zorg Vlaanderen’ in General Policy and Education. This position was combined with work as a lecturer within the college of Nursing at the Hogeschool Universiteit Brussel (HUB). From 2008 to 2010 she worked half-time as a lecturer within the HUB and half-time as a researcher within the research centre PRAGODI of the HUB. Under the supervision of Prof. Dr. Mieke Grypdonck she obtained funding for a project entitled: ‘The image of palliative care among the general population: development, testing and application of a scientific measuring instrument.’ From 2010 to 2011 Katrien worked as a lecturer within the HUB until she was given the opportunity to do a PhD at the Cicely Saunders Institute within the EUROIMPACT programme. Over the next 3 years Katrien will conduct research on the quality of palliative care among non-cancer patients in different European countries.

Emma Murphy
BRC Clinical Research Training Fellow

Emma has worked in the field of nephrology nursing for 15 years. She has completed an MSc in Advancing Professional Healthcare Practice at King’s College London, Florence Nightingale School of Nursing and Midwifery. Emma has been awarded a PhD training fellowship from the National Institute for Health Research (NIHR) Biomedical Research Centre, Guy’s & St Thomas’ NHS Foundation Trust.

Emma’s research interests include symptom prevalence in Chronic Kidney Disease and end-of-life experiences of patients withdrawing from dialysis. She has completed a qualitative study to explore the healthcare needs of patients withdrawing from dialysis which has identified the priorities for further research in an area where there is little prior evidence. Emma developed and published a clinical symptom assessment tool for renal patients, and has recently completed a systematic review of the dialysis withdrawal literature. 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.
**Fliss Murtagh**  
**Clinical Senior Lecturer**

Fliss qualified in medicine at the University of London and came from a background of general practice into specialist medical training for palliative medicine.

Fliss undertook her PhD in the Department, she went on to gain one of the HEFCE ‘new blood’ Clinical Senior Lectureships in 2009 - one of the first nationally in palliative care. Currently, 50% of her time is clinical work, as a Consultant in Palliative Medicine at King’s College Hospital NHS Foundation Trust, and 50% is academic, teaching and research based in the Department of Palliative Care, Policy & Rehabilitation. She is Postgraduate Coordinator for Palliative Care, and also coordinates the Core and Advanced Symptom modules for the MSc in Palliative Care.

Her main current research interests are: the palliative care needs of patients dying from end-stage renal failure, including those following a conservative (non dialysis) pathway, those failing to thrive on dialysis, and those discontinuing dialysis; improving the quality of palliative and end of life care for other non cancer populations; and costs and complexity in palliative care.

Fliss currently leads studies in: developing best ways to deliver quality and cost-effective care across the range of complexity for those with advanced conditions in the last year of life - including the development of a tool to measure clinical complexity in palliative care, across settings and conditions, and development of a case-mix classification to underpin emerging funding models such as payment by results; a national test site work supported by NHS Kidney Care to develop services for patients with advanced kidney disease approaching last year of life; and understanding place of death for patients with non malignant conditions – a systematic literature review, which is evaluating and synthesizing existing evidence on the factors affecting place of care and death for those with non cancer conditions, including preferences and transitions in the last year of life.

**Christine O’Connell**  
**Research Administrator**

Christine studied for her BA in Psychology at the National University of Ireland, Maynooth where her dissertation focused around brain exercise and neural plasticity. After graduating, Christine worked on a research project which evaluated Mindfulness Based Cognitive Therapy (MBCT) as a treatment for depression and anxiety. During this time she also co-facilitated an MBCT group.

In December 2010, Christine joined the Department as a Research Administrator, working with Dr. Richard Siegert on the Long Term Neurological Conditions (LTNC) project.
Thomas Osborne  
**Clinical Research Fellow**

Thomas completed his first degree in Experimental Psychology at Cambridge University in 2001. He then went on to complete his MBBS at Guy’s, King’s & St. Thomas’ Medical School and graduated with distinction in 2004. Since completing his undergraduate training he has worked within the NHS in a range of specialties. In 2008 he became a Member of the Royal College of Physicians and began specialist training in Palliative Medicine.

Thomas joined the Department as a Clinical Research Fellow in 2010. He is currently working on a programme of research investigating the quality of life of people with multiple myeloma and follicular lymphoma. He has a particular interest in the supportive care needs of people with haematological malignancies.

Caty Pannell  
**Senior Research Nurse**

Caty 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 and is presently helping on the Intensive Therapy Unit documentation study, the Breathlessness Support Service and on the use of the Palliative care Outcome Scale in clinical practice. Her role also involves working with local palliative care clinical nurse specialists, encouraging their interest in research.

Nancy Patel  
**Executive Administrator**

Nancy has a BA Hons from Carleton University in Canada and studied Criminology and Criminal Justice with a concentration in Law. She worked for the Ontario Provincial Police and Peel Regional Police Service for over 5 years before moving to the UK, where she spent a year working for Oxford University as a Projects Officer in the Faculty of Philosophy. Nancy relocated to London and joined the Department in March 2010 as Executive Administrator to Professor Irene Higginson.
Hristina Petkova  
**Health Economics and Research Training Fellow**

Hristina's current role is dedicated to studying the cost associated with end-of-life care, cost drivers and future costs in palliative care. Prior to this appointment, her work in the Department involved conducting an NIHR SDO funded systematic review of the literature on place of care, place of death, preferences and transitions in the end of life care of patients with non-cancer diseases. This followed on from her role as a contributor to the World Health Organization (WHO) guide “Palliative care for older people: Better practice”.

Previous work involved contribution to another WHO project - Medical Devices: Managing the Mismatch, an outcome of the Priority Medical Devices project in Geneva, Switzerland. Hristina was also a Research Fellow at the Brocher Foundation, Geneva, Switzerland. In January 2009 she attained her PhD award in Health Policy and Innovation from EGENIS, ESRC Centre for Genomics in Society, University of Exeter. Her thesis explored how medical innovation of a “niched” type, i.e. genetic testing for single-gene disorders with clear diagnostic and treatment benefits, diffuses or “travels” through different health care systems and the extent to which the translation from research to clinical practice ensures that the technology is utilized to its full potential for patient care. During her PhD Hristina had the opportunity to teach 1st and 4th year medical students at Exeter University, UK.

Prior to this, Hristina studied for an MA in European Studies at Exeter University, which she finalised with a dissertation project on the structures of health service provision in the UK and Germany. She also obtained a certificate in the law and politics of the European Union from the Alpbach Summer School on European Integration 2003, Austria. Hristina holds a BA in Economics from the University of Varna, Bulgaria.

Wendy Prentice  
**Consultant/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. Throughout her career Wendy has been interested in the better integration of specialist palliative care services within non-specialist settings. At King’s College Hospital NHS Foundation Trust she established and chairs the End of Life Strategy Group and is involved in a current research 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.

Eloise Radcliffe  
**Research Associate**

Eloise has a BSc in Sociology from the University of Surrey and an MSc in Sociology from the London School of Economics. She is currently studying part time for a PhD in Medical Sociology at the Division of Health and Social Care Research in the Department of Primary Care and Public Health Sciences at King’s College London. Her PhD explores the experience of stroke in relation to the self-identity of older people based on a biographical approach. She is carrying out qualitative biographical-narrative interviews with individual stroke survivors (aged 75 years and over) and joint interviews with stroke survivors and their spouses recruited from the South London Stroke Register. Eloise joined King’s College London in 2006 as a Research Associate in the Division of Health and Social Care Research in the Department of Primary Care and Public Health Sciences on a mixed methods study on older people’s medicines use and later a qualitative study on long term needs after stroke with Dr Christopher McKeveit. She joined the Department of Palliative Care, Policy and Rehabilitation in March 2011 and is currently working on a qualitative study identifying the needs and experiences of people with cutaneous T-cell lymphoma and those of their informal and professional caregivers, with the aim of developing a model of best practice.
Christina Ramsenthaler
Research Assistant
Christina Ramsenthaler qualified in clinical psychology and clinical neuropsychology at Bremen University in 2009. Her dissertation addressed the topic of the concept of core attitudes in the care of critically ill and dying patients. It focused on the attitudes and beliefs which form the basis and underlie the work of professionals in palliative care. From 2005 to 2009, she worked as a research assistant, first in the Department for Neuropsychology at the University of Oldenburg / Germany, then in the Palliative Care Research Group at the same university. Christina is completing the MSc course in the Department of Palliative Care, Policy and Rehabilitation at King’s College London. She joined the Department in 2010 as a Research Assistant on a study investigating quality of life in myeloma. She is working towards a PhD and also works part-time for a project on episodic breathlessness in advanced disease.

Her research interests include psychometrics and research methodology, psychosocial care, palliative care in neurological diseases and non-malignant diseases.

Lauren Rayner
Research Associate
Lauren has a BSc in Anthropology from University College London. She worked as a Research Assistant for the Tropical Health and Education Trust, before joining the Royal College of Psychiatrists’ Research Unit in 2005. There she coordinated an accreditation programme for electroconvulsive therapy services and conducted research into patients’ experiences of ECT. She joined the Institute of Psychiatry in 2007 to work on a survey of doctors’ attitudes to the Assisted Dying Bill and a study of depression in palliative care. She joined the Department of Palliative Care, Policy and Rehabilitation in January 2008 to further her work on depression in patients receiving palliative care.

She has undertaken a Cochrane review of the effectiveness of antidepressants for patients with a physical illness and a systematic review of antidepressants in palliative care. She has also developed a clinical guideline on the management of depression in palliative care on behalf of the European Palliative Care Research Collaborative.

Lauren is currently studying for a PhD on the clinical epidemiology and management of depression in palliative care. Her current research interests include the clinical epidemiology, conceptualisation and management of common mental disorder in physical illness and palliative care.

Charles Reilly
Research Associate
Charles studied Physiotherapy at Brunel University, London and qualified in 2005. Charles’ clinical background is that of cardio - respiratory physiotherapy, with a special interest in cystic fibrosis. In 2007 he completed an MSc in Human and Applied Physiology at King’s College London, following which he was awarded a Medical Research Council (MRC) PhD studentship. He undertook his PhD within the Division of Asthma, Allergy and Lung Biology, King’s College London. The primary focus of his PhD was an investigation into the potential use of respiratory muscle electromyography (EMG) as a new measure of lung disease severity in cystic fibrosis. One of Charles’ main research interests is the pathophysiology of breathlessness in cystic fibrosis.

Currently, Charles is evaluating the new Breathlessness Support Service at King’s College Hospital. This project is supported by the National Institute for Healthcare Research, Research for Patient Benefit and is a collaborative project between the Department of Palliative Care, Policy & Rehabilitation and Respiratory Medicine. The aim of the project is to evaluate the efficacy of a multidisciplinary interventional service in improving patient’s mastery over their breathlessness.
Caroline Rumble  
**Research Associate**

Caroline trained in medicine at the University of Leeds and qualified in 2002. She worked clinically in emergency and elderly medicine in England before moving to Australia to work in palliative care medicine at The Sacred Heart Hospice and then in the community setting in Sydney.

In 2007 she undertook a Masters in Public Health at the University of Essex, focusing her dissertation on the changing socioeconomic distribution of cardiovascular disease risk factors in England. Following this she worked as Senior Research Officer to Professor Paul Hunt in his mandate as Special Rapporteur to the UN on the right to the highest attainable standard of health. During this role she concentrated on a project to develop and collect data on indicators to reflect right to health features of health systems around the world.

Caroline is currently working on a project researching end-of-life care pathways in the intensive care setting.

Tariq Saleem  
**Research Fellow**

Tariq has a BSc (Hons) in Psychology from Royal Holloway and a Masters in Health Psychology from King’s College London. He joined King’s College London in 1998 where he has worked on a variety of research projects including identification of barriers to uptake of breast, cervical and prostate screening services; predictors of testicular self-examination; evaluating a bilingual health advocacy service in ethnic minority cancer patients; evaluating impact of a Sickle cell & Thalassemia information technology leaflets on counselling experience.

He joined the Department in 2003 where he initially worked on developing a postal questionnaire (VOICES-Stroke) for use in a population-based survey of the experiences of people who die from stroke from the perspective of bereaved relatives. Working in collaboration with Clinical Neurosciences at the Institute of Psychiatry he had a leading role as Research Fellow and Centre Coordinator for the King’s Centre in Palliative care in Neurology.

Tariq has worked on a number of research projects examining a range of neurological conditions including: Parkinson’s disease; Multiple System Atrophy; Progressive Supranuclear Palsy; Multiple Sclerosis and Motor Neurone Disease. He is currently completing a three year longitudinal study funded by the Department of Health looking at the symptoms and palliative care needs of patients and family carer in advanced Parkinson’s disease and related movement disorders. He has recently started a new project evaluating palliative care in primary care.

Lucy Selman  
**Research Associate**

Lucy read Philosophy at Nottingham University, and completed an MPhil in Philosophy at Birkbeck College, writing her thesis on the influence of social prejudice on scientific theories. In 2006 she completed the PG Certificate in Palliative Care at King’s College London, and is currently studying for a PhD in Palliative Care.

Before joining the Department in July 2005 Lucy travelled India for 8 months, working as a Fieldworker for the International Observatory on End-of-Life Care at Lancaster University. As a Research Associate at King’s College London she initially worked on a project modelling a palliative care service for heart failure patients at St Thomas’ NHS Foundation Trust.

From 2006 to 2008 Lucy worked for Cicely Saunders International on the ENCOMPASS project, validating an African version of the Palliative care Outcome Scale (the APCA African POS). ENCOMPASS was a collaboration between King’s College London, the African Palliative Care Association and palliative care centres in South Africa and Uganda.

For her PhD Lucy is conducting a study exploring patients’ spiritual well being and the provision of spiritual care in South Africa and Uganda, with funding from the Halley Stewart Trust. Based on her PhD data and collaborative work with advisory groups in the UK and Africa, two sets of spiritual care recommendations were launched in 2010 for palliative care services in the UK and in Africa.

Lucy is also a qualified yoga teacher, interested in psycho-spiritual interventions and complementary medicine. In 2006 she was awarded a Churchill Travelling Fellowship to conduct research in India into the use of yoga and meditation in end-of-life care.
Kate Shepherd  
**Clinical Project Manager**
Kate qualified as a registered nurse in 2001 at Leeds University and has been employed by King’s College NHS Foundation Trust since then. She has worked in the field of nephrology nursing for 9 years. Previously, Kate worked as a clinical nurse specialist in renal palliative care in the renal unit at King’s College Hospital, and was actively involved in developing and implementing the renal palliative care service.
Kate completed the BSc in Critical Care Nursing in 2007 at Kings College London, School of Nursing and Midwifery and is currently completing the MSc in Palliative Care at the Cicely Saunders Institute.
She has developed a teaching program on renal palliative care at BSc level, which is now a core component of the renal course within the School of Nursing, King’s College London.
Kate’s current role is Clinical Project Manager for the Advanced Renal Care (ARC) project working alongside Dr Fliss Murtagh. The project aims to improve care for people with advanced kidney disease, particularly those who are doing less well on dialysis or have chosen not to have dialysis, and who may be approaching the last year(s) of life.

Cathy Shipman  
**Senior Research Fellow**
Cathy Shipman is a Senior Research Fellow in the Department and is currently working with colleagues on a Research for Patient Benefit funded study to develop and evaluate interventions to improve end of life care in Intensive Therapy Units. She is also working with colleagues on an evaluation of the Modernisation Initiative’s, Community End of Life Care Programme in Lambeth and Southwark funded by Guy’s & St. Thomas’ Charity.
Much of Cathy’s work has been within primary palliative care including a national scoping exercise to determine research priorities in generalist end of life care for the SDO. She has worked on a study based in the Department of General Practice & Primary Care on the palliative care needs of patients in the community with severe COPD and continues to collaborate with primary care colleagues. She has also worked on the evaluation of the Department of Health Funded national palliative care education programme for District Nurses and an evaluation of the Policy Unit for the National Council of Palliative Care.

Richard Siegert  
**Reader in Rehabilitation**
Richard began his career as a clinical psychologist in New Zealand and has worked clinically in diverse settings including mental health, intellectual disability, criminal justice and neurology. After completing his PhD in 1989 he lectured in clinical psychology specialising in clinical neuropsychology.
Since 2002 he has worked in academic rehabilitation and also collaborates with colleagues in palliative care. Richard’s primary research interests include psychometrics and measurement, neurological rehabilitation, rehabilitation theory and outcome measurement for complex health conditions. He has published 70 articles in peer-reviewed rehabilitation and psychology journals, four invited articles and six book chapters.
Vicky Simms  
Research Associate/Assistant MSc Coordinator  
Vicky is completing a PhD on the palliative care needs of adults in Uganda and Kenya in the first three months after diagnosis with HIV. She joined the Department in 2006 to work on an evaluation of HIV care and support for the President’s Emergency Plan for AIDS Relief and is now working on a randomised controlled trial of palliative care alongside antiretroviral therapy in Africa. She is also Assistant Coordinator of the Palliative Care MSc programme. Her research interests are in epidemiology, public health and Sub-Saharan Africa.

Steffen Simon  
Honorary Research Fellow  
Steffen Simon is working as an Honorary Research Fellow for the breathlessness programme at the Cicely Saunders Institute. He qualified in medicine at the University of Witten/Herdecke in Germany and trained in internal medicine and specialised in palliative medicine. From 2004 to 2007 he was responsible for establishing the Centre of Palliative Care in Oldenburg and worked in the Palliative Care Unit as Consultant. In 2008, Steffen and his colleagues founded the Institute of Palliative Care (ipac) to conduct research in Palliative Care. After completing the MSc course at King’s College London 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 non-cancer patients and core attitudes of professionals in palliative care.

Katherine Sleeman  
Clinical Lecturer  
Katherine completed her first degree in Developmental Biology at University College London in 1996. She finished her clinical training at University College Hospital, graduating in 1999. After training in general medicine and oncology, Katherine completed a PhD at the Institute of Cancer Research on breast cancer stem cells. She began specialist training in Palliative Medicine in 2007. Katherine joined the Cicely Saunders’s Institute as a Clinical Lecturer in 2010. She shares her time between the academic department and the clinical team.
Reverend Peter Speck
Researcher and Former Health Care Chaplain, Honorary Senior Lecturer

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 Senior 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 Honorary Senior Lecturer, King's College London (Palliative Care, Policy and Rehabilitation), Peter is author of several books on pastoral care, chapters on aspects of palliative care, and spiritual care, bereavement and teamwork. 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 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.

Professor Lynne Turner-Stokes
Herbert Dunhill Chair of Academic Rehabilitation

Lynne was educated at Oxford University, qualified in Medicine at University College Hospital. After ten years in general medicine and rheumatology she accredited in Rheumatology and Rehabilitation, and took up her consultant appointment to set up and direct the Regional Rehabilitation Unit (RRU) at Northwick Park Hospital. The unit provides tertiary specialist rehabilitation services for younger adult patients with severe complex disabilities, mainly resulting from acquired brain injury. Lynne and her colleagues have built up a coordinated network of specialist rehabilitation services across North-West Thames. Within this network 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 the Herbert Dunhill Chair of Rehabilitation at King’s College London in 2001, with a view to developing a two-site academic department of rehabilitation between King’s College London and Northwick Park. Academic Rehabilitation joined forces with the Department of Palliative Care and Policy in 2003.

Lynne’s research interests include the development of outcome measures, establishment of the evidence base for effective intervention in rehabilitation, and development of evidence-based guidelines and integrated care-pathways to support best practice in clinical care.

Since 1997 she has led on the development of guidelines and clinical standards for the British Society of Rehabilitation Medicine. From 2002-5 she was the Deputy Chair and Clinical Lead of the External Reference Group of the National Service Framework (NSF) for Long Term Conditions, and continues as advisor to the Department of Health, providing in lead role in rehabilitation and dataset development towards implementation of the NSF.

Since 2005 she has chaired the Department of Health Expert Working Group and Reference Panel overseeing development of casemix and commissioning tariffs for rehabilitation services.

She is currently leading a five year NIHR-funded programme (2008-13) to develop a UK national dataset for specialist neurorehabilitation – which is being developed in collaboration with colleagues from the Australia Rehabilitation Outcome Centre.

Lynne is committed to enhancing the quality of rehabilitation and support services for patients with chronic disability and also to championing the views of users and carers in development of better services for the future.
Sasha Wade
Research Assistant
Sasha has a BA (Hons) in Psychology from the University of Victoria and an MSc in Speech-Language Pathology from the University of Alberta, Canada. She recently served as a board member for the Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA) in 2009-2010 and is currently a CASPLA-certified Speech-Language Pathologist.
Sasha has worked in research across a wide range of projects in Psychology and Speech-Language Pathology in academic settings as well as with a professional research firm. Her clinical and academic interests in rehabilitation medicine led her to join a research team at the Department in 2010.

David Williams
Research Associate
David has a BSc in Psychology from the University of Wales, Swansea and a PhD from Cardiff University. He also has four years of post doctoral experience in the field of dental public health at King’s College London. His PhD was concerned with the social consequences of tooth discolourment, and the first year of his post doctoral research looked at antecedents of dissatisfaction with facial appearance in female patients undergoing or having recently undergone orthognathic surgery (surgery to reposition the jaws) and a control group. David was also involved in a service evaluation of the provision of specialist oral surgery services in primary care settings.
His research project in the Department investigated the use of and need for replacement (respite) care among carers of people with a long-term neurological condition.

Heather Williams
Dunhill Research Training Fellow
Heather is a qualified Orthopaedic nurse. She worked for many years as an orthopaedic ward sister at Northwick Park Hospital before moving into Clinical Audit. Heather completed further education in “Evaluation of Clinical Practice”, which helped to develop her research interests. She joined the Regional Rehabilitation Unit at Northwick Park in February 2002, and is currently conducting a research project to further develop the Northwick Park Dependency Score to calculate in-patient nursing staff provision within a rehabilitation setting.
### Previous Members of the Department (since 2008)

<table>
<thead>
<tr>
<th>NAME</th>
<th>POSITION</th>
<th>YEAR OF DEPARTURE</th>
</tr>
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<tbody>
<tr>
<td>Toki Allison</td>
<td>Secretary/Transcriber</td>
<td>2008</td>
</tr>
<tr>
<td>Sarah Baber</td>
<td>Secretary/Transcriber</td>
<td>2008</td>
</tr>
<tr>
<td>Dorothee Bechinger-English</td>
<td>Research Associate</td>
<td>2010</td>
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<tr>
<td>Emma Camplejohn</td>
<td>Secretary/Transcriber</td>
<td>2008</td>
</tr>
<tr>
<td>Rebecca Charikar</td>
<td>Executive Administrator</td>
<td>2009</td>
</tr>
<tr>
<td>Dalia Dawoud</td>
<td>Health Economic/Research Training Fellow</td>
<td>2010</td>
</tr>
<tr>
<td>Dr Alison Evans</td>
<td>Research Fellow</td>
<td>2008</td>
</tr>
<tr>
<td>Dr Morag Farquhar</td>
<td>Research Associate</td>
<td>2008</td>
</tr>
<tr>
<td>Lindsay Flood</td>
<td>PRISMA Administrator</td>
<td>2010</td>
</tr>
<tr>
<td>Karen Gillett</td>
<td>Research Nurse</td>
<td>2009</td>
</tr>
<tr>
<td>Dr Geraldine Goh</td>
<td>Health Economic/Research Training Fellow</td>
<td>2009</td>
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<tr>
<td>Deirdre Howley</td>
<td>Research Assistant</td>
<td>2009</td>
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<tr>
<td>Anna Kolliakou</td>
<td>Maruzza Foundation Research Assistant</td>
<td>2008</td>
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<tr>
<td>Jennifer Lunan</td>
<td>PA to Professor Higginson</td>
<td>2008</td>
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<tr>
<td>Dr Farida Malik</td>
<td>Cicely Saunders International Research Fellow</td>
<td>2011</td>
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<tr>
<td>Pauline Martin</td>
<td>Research Assistant</td>
<td>2009</td>
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<tr>
<td>Dr Helena Morris</td>
<td>Research Associate</td>
<td>2010</td>
</tr>
<tr>
<td>Diana Opio</td>
<td>Research Nurse/psychologist</td>
<td>2009</td>
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<tr>
<td>Dr Susan Penfold</td>
<td>Research Fellow</td>
<td>2009</td>
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<tr>
<td>Alastair Price</td>
<td>Research Administrator</td>
<td>2010</td>
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<tr>
<td>Lauren Rayner</td>
<td>Research Associate</td>
<td>2011</td>
</tr>
<tr>
<td>Laura Skingle</td>
<td>Research Assistant</td>
<td>2008</td>
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<tr>
<td>Steffen Simon</td>
<td>Research Fellow</td>
<td>2011</td>
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<tr>
<td>Francis Stewart</td>
<td>Research Assistant</td>
<td>2009</td>
</tr>
<tr>
<td>Suzanne Taylor</td>
<td>Research Fellow</td>
<td>2009</td>
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</tbody>
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### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>APCA</td>
<td>African Palliative Care Association</td>
</tr>
<tr>
<td>ARC</td>
<td>Advanced Renal disease Care</td>
</tr>
<tr>
<td>ArmA</td>
<td>The Arm Activity measure</td>
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<tr>
<td>AROCC</td>
<td>Australasian Rehabilitation Outcome Centre</td>
</tr>
<tr>
<td>BoNT</td>
<td>Botulinum toxin</td>
</tr>
<tr>
<td>BoNT-A</td>
<td>Botulinum toxin type A</td>
</tr>
<tr>
<td>BIS</td>
<td>Breathless Intervention Service</td>
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<tr>
<td>BSRM</td>
<td>British Society of Rehabilitation Medicine</td>
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<tr>
<td>CKD</td>
<td>chronic kidney disease</td>
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<tr>
<td>COPD</td>
<td>chronic obstructive pulmonary disease</td>
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<tr>
<td>EoLC</td>
<td>end of life care</td>
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<tr>
<td>EPIC</td>
<td>European Palliative Care Research Collaborative</td>
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<tr>
<td>ESKD</td>
<td>end-stage kidney disease</td>
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<tr>
<td>GAS</td>
<td>Goal Attainment Scaling</td>
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<tr>
<td>HHF</td>
<td>hand-held fan</td>
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<tr>
<td>LTNCs</td>
<td>long term neurological conditions</td>
</tr>
<tr>
<td>MORECare</td>
<td>methods for evaluating service delivery models for end of life care; development of best practice guidance</td>
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<tr>
<td>MRC</td>
<td>Medical Research Council</td>
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<tr>
<td>NHS</td>
<td>National Health Service</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence</td>
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<tr>
<td>NPDS</td>
<td>The Northwick Park Dependency Scale</td>
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<tr>
<td>NPTDA</td>
<td>The Northwick Park Therapy Dependency Assessment</td>
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<tr>
<td>POS</td>
<td>Palliative care Outcome Scale</td>
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<tr>
<td>POS-S</td>
<td>Palliative care Outcome Scale - Symptoms</td>
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<tr>
<td>PRISMA</td>
<td>reflecting the Positive diveRsities of European priorities for resSearch and Measurement in end of life cAre</td>
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<tr>
<td>PROMs</td>
<td>patient-reported outcomes measures</td>
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<tr>
<td>PAG</td>
<td>project advisory group</td>
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<tr>
<td>QPL</td>
<td>Questionnaire Prompt List</td>
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<tr>
<td>MS</td>
<td>Multiple Sclerosis</td>
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<tr>
<td>MND</td>
<td>motor neurone disease</td>
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<tr>
<td>MDM</td>
<td>multidisciplinary meeting</td>
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<tr>
<td>NCRI</td>
<td>National Cancer Research Institute</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence</td>
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<tr>
<td>PCT</td>
<td>Palliative Care Team</td>
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<tr>
<td>PD</td>
<td>Parkinson’s disease</td>
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<tr>
<td>PEPFAR</td>
<td>President’s Emergency Plan for AIDS Relief</td>
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<tr>
<td>RCS</td>
<td>Rehabilitation Complexity Scale</td>
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<tr>
<td>RCT</td>
<td>randomised controlled trial</td>
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<tr>
<td>SSC</td>
<td>student selected component</td>
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<tr>
<td>STAS</td>
<td>Support Team Assessment Schedule</td>
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<tr>
<td>SuPaC</td>
<td>supportive and palliative care</td>
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<tr>
<td>UKROC UK</td>
<td>specialist Rehabilitation Outcomes Collaborative dataset</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>ZBI</td>
<td>Zarit Burden Inventory</td>
</tr>
</tbody>
</table>
We welcome enquiries about any aspects of our work which may be of interest to you.

Contact:
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