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Triennial Report 2004/5-2006/7
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1 Highlights

2007 is the 10-year anniversary of the founding of the Department of Palliative Care and Policy, which has grown in that time from a department comprising Professor Irene Higginson and two researchers (both on grant funding) to a large, multi-professional department with well over 40 staff, plus many honorary and visiting appointments. Although very saddened by the loss of Dame Cicely Saunders in July 2005 we have continued to drive forward her vision, through research, education, care and, importantly, the plans to develop an institute in her name.

Our research is mainly applied and translational – concerned with discovering solutions to improve the care, symptom management and support for those affected by life threatening, progressive or profoundly disabling conditions. In this regard, palliative care and rehabilitation have much in common. Both specialties seek to add quality of life to the time available (whether in living with a disability or in dying), rather than finding a ‘cure to a disease’. They seek to cure or reduce the effects of symptoms, promote dignity and social and emotional support. Both involve complex ‘interventions’ from a multidisciplinary team of professionals, and the success of that intervention must usually be judged on a background of deterioration in the person’s condition. Thus, the two fields face similar research challenges. This is reflected in our research activity where there is the potential to learn from each other, and from other fields, in the measurement of outcomes, in the design of evaluations of complex interventions and in the future in seeking potential solutions to symptoms, methods and ways to promote dignity and support for carers. As the remit of palliative care extends beyond cancer to include people with other long term conditions, there is an interface to be explored between rehabilitation and palliative care services to support people who live their lives with complex disability.

In the period of this report, 2004/5 to 2006/7, our research, teaching and policy development have advanced considerably locally, nationally and internationally. We have seen the fuller integration of palliative care and rehabilitation, especially as work in palliative care grows to consider those people with longer illness trajectories, with cancer, non-cancer and multiple conditions. Our results have underpinned some of the most significant national and international guidance, including from the National Institute of Clinical Excellence (NICE) in the UK, the State of the Science Report on End of Life Care in the USA, the UK Government White Paper on Our Health Our Choice Our Lives, the House of Commons Health Committee Report on End of Life Care and several National Service Frameworks, including that on Long Term Neurological Conditions in which Professor Lynne Turner-Stokes and her team played a substantial role.

We have tested and discovered new means to improve the management of symptoms, such as breathlessness and spasticity, and have trialled new services for people with conditions beyond cancer. We have discovered what factors influence whether people are able to be cared for at home and to die at home, making an important contribution to end of life strategies in many countries. We have evolved several new strands of research, particularly on palliative care in Africa, the costs and benefits of rehabilitation, and improving palliative care for older people. During the period of the report, we have seen 53 MSc, Diploma and Certificate students graduate, along with 3 successful PhD awards, while continuing to evolve our undergraduate education programme.

The following pages outline our research activity across four main strands - evaluating and improving care; symptom led research; measuring outcomes; and living and dying in society. It outlines our influences on policy and guidelines, educational and clinical activities, and the plans for the new Institute of Palliative Care. Shortly before her death, Dame Cicely Saunders was delighted to see plans for her brainchild developing – to create the world’s first purpose built Institute of Palliative Care. At the end of the report we list publications, keynote lectures and supporters, along with a full list of staff. We are grateful to a wide range of collaborators and colleagues with whom we work in research, teaching, care and policy. Special thanks go to those organisations, statutory and charitable, and individuals that support our activities. In a climate where in the UK less than 0.2% of the research spend in cancer goes to palliative and end of life care, with probably a lower proportion than this being allocated in non-cancer conditions, their leadership has been vital to our continued work.
Research activity falls into four main programmes (see figure 2.1). Each programme has a series of inter-related projects and sub-programmes, with defined outputs and links to improve practice and care. Across all strands we are active in influencing policy and practice, teaching, dissemination and refining the methods to undertake research. As is clear from the text, we have a particular expertise in mixed methods, combining quantitative and qualitative approaches and in translational and applied research – seeking to make an early and sustained difference to the care of patients and families.

2.1 Evaluating & Improving Care

Overview

Palliative care and rehabilitation both suffer from a lack of evidence about effective models of care and treatment, partly because research among severely ill or disabled people is difficult. However, work in our department has tackled these problems, conducting research and systematic reviews and developing the methodologies to evaluate care and services, often using the MRC framework for the development and evaluation of complex interventions.

Our 2001-3 report showed how palliative care has traditionally focussed on people with cancer, with around 95% of people in hospices and home care teams having cancer. However, 3 out of 4 people who die do so from diseases other than cancer. Therefore while continuing a strong theme of research in cancer (cancer patients still remain an important core of palliative care), we have extended our research into non-cancer. Little is known about their experiences and in particular what services and care might help them. Our work in understanding symptoms found similar symptoms across five common diseases towards the end of life (see section 2.2), suggesting that palliative care may be valuable. But we still needed to answer the question - what models of care or services might help?

Simply taking palliative care as it is offered for people with cancer may not be appropriate because of differences in other existing services, information, expectations and prognosis, and not knowing when is the right time to offer services. Therefore, we began a programme of work to develop and test palliative care services for people affected by conditions other than cancer, focusing on some specific conditions, which might serve as a model for others.
2.1.1 Improving Care and Services for People Affected by Cancer

Gysels and Higginson conducted, for the National Institute of Clinical Excellence (NICE), the first comprehensive robust appraisal of research evidence in Supportive and Palliative Care in Cancer. Published in 2004, this was the culmination of three years research, building on earlier systematic reviews within the department. It combined and appraised findings from 339 studies from across the globe. It showed for the first time evidence for the effectiveness of some components of supportive and palliative care, especially for multi-professional specialist palliative care teams, information provision and communication skills training.

Communication, co-ordination and patient education

In an analysis of effectiveness, 12 studies (15 papers) showed communication skills training improved the communication of doctors and nurses, as assessed by self-report and patients, with effect sizes ranging from 0.15 (modest) to 2 (high). One further study showed deterioration in outcomes. In depth analysis found that to be most effective at changing practice (and not just skills in artificial situations) training programmes need to take into account and address attitudes and beliefs.

These findings led the Department of Health in the UK to support a national roll out of communication skills training, to commit funding to specialist palliative care services and provided for the first time a research basis for supportive and palliative care elements of National Standards in Cancer Care, which now form part of the National Health Service Peer Review for cancer.

However, there is also the problem of communicating between services. Farquhar, Barclay and colleagues studied in depth the concerns of GPs - of most concern was tardiness (with delays of up to eight days) especially at three stages in the patient journeys: (1) in the pre-diagnostic and diagnostic stage; (2) in the active treatment phase; and (3) when oncology withdrew and the focus of care switched back to the community for the terminal phase, leading to suggestions in the NICE guidance about the prompt timing of information and the use of standardised formats.

Interactive technologies and videotapes appear to be a promising method for patient education in cancer care. In an analysis of 1,678 patients, educational technologies showed improved patient knowledge but no change in patient satisfaction although the analysis identified problems of heterogeneity (see figure 2.3).

![Figure 2.2 The NICE Research evidence produced by the team at King’s in 2004, which is now improving how cancer care and support is provided](image)

![Figure 2.3 Meta-analysis showing that video technologies in patient education improve knowledge but not satisfaction](image)
treat symptoms in advanced cancer. An overwhelming picture was found for hypnotherapy used to support for services, but a lack of quantitative studies. Evaluations of palliative day care found qualitative optimism, in patients with advanced cancer, and instead of significance of "positive attitudes", such as hope and cohort. The study brings into question the prognostic indicators - dyspnoea, nausea/emesis and weakness – in regression models, physical health related quality of life. Clinical and demographics variables, using Cox developed and validated - Cohort 2. After adjusting for using the outcome measures that we had previously collected by Professor Irene Higginson and team and Bruera and team - Cohort 1 and 756 patients in Ireland analysed data from two independent cohorts (248 patients in Canada [collected by Professor Eduardo Bruera and team - Cohort 1] and 756 patients in Ireland [collected by Professor Irene Higginson and team and using the outcome measures that we had previously developed and validated - Cohort 2]. After adjusting for clinical and demographics variables, using Cox regression models, physical health related quality of life indicators - dyspnoea, nausea/emesis and weakness – were associated with survival, as were liver metastases, lung tumour and tumour burden. In contrast, emotional functioning, anxiety, spiritual distress, and lack of insight were not associated consistently with survival in either cohort. The study brings into question the prognostic significance of "positive attitudes", such as hope and optimism, in patients with advanced cancer, and instead suggests that physical indicators are more important.

Wider effects of the NICE guidance
In some areas of supportive and palliative care our review found a dearth of robust studies evaluating services or understanding the longitudinal experience of cancer, sometimes because of methodological challenges, in contrast to a relative abundance of cross-sectional studies assessing need. An analysis of evaluations of palliative day care found qualitative support for services, but a lack of quantitative studies. A similar picture was found for hypnotherapy used to treat symptoms in advanced cancer. An overwhelming recommendation was that there should be sustained programmes of research into testing solutions and longitudinal study. Furthermore the work strongly advocated that services should be developed only in the context of robust evaluation. This finding fed into the National Cancer Research Institute's analysis of research in Supportive and Palliative Care to begin to emphasise research to evaluate services and treatments.

But the Gysels and Higginson review had much wider effects. It formed the bedrock for the evidence reviews for the National Service Framework on Long Term Neurological Conditions, led by Turner-Stokes and colleagues, which also found evidence to support some models of rehabilitation and palliative care. In addition, it underpinned appraisals in other countries, including the State of the Science Review on End of Life Care, National Institutes of Health, USA.

Survival and quality of life in advanced cancer
In collaboration with colleagues in the USA and Canada, through a visiting appointment of Dr Antonio Vigano, we analysed data from two independent cohorts (248 patients in Canada [collected by Professor Eduardo Bruera and team - Cohort 1] and 756 patients in Ireland [collected by Professor Irene Higginson and team and using the outcome measures that we had previously developed and validated - Cohort 2]). After adjusting for clinical and demographics variables, using Cox regression models, physical health related quality of life indicators - dyspnoea, nausea/emesis and weakness – were associated with survival, as were liver metastases, lung tumour and tumour burden. In contrast, emotional functioning, anxiety, spiritual distress, and lack of insight were not associated consistently with survival in either cohort. The study brings into question the prognostic significance of "positive attitudes", such as hope and optimism, in patients with advanced cancer, and instead suggests that physical indicators are more important.

2.1.2 Improving Care and Services for People Affected by Neurological Conditions
Through collaboration with colleagues in Neurology we have established the King’s Centre for Palliative Care in Neurology – a 'virtual centre' representing a collaboration to foster and further research to improve the care of patients with neurological conditions who need palliative care and/or rehabilitation.

Developing and testing new palliative care services for people affected by Multiple Sclerosis
Multiple sclerosis (MS) is a chronic disease affecting the central nervous system. It affects over 2.5 million people worldwide, is the commonest cause of neurological disability in adults under 60 years, and is associated with a wide spectrum of physical and psychological symptoms. While the outlook for many is good and some have a normal life expectancy, around 45% of people develop progressive forms, either from the onset or at later stages, with profound effects not only for themselves but also their carers.

Developing and testing palliative care for people affected by MS raises important questions. How should the service be modelled? What sort of staff does it need? When is it really needed? Who might benefit most? Will it replace or supplement existing services? How might it work with these? Nowhere in the world are these questions answered.

To investigate this we embarked on a programme, supported by the UK MS Society, using the MRC Framework for Evaluating Complex Interventions (see in Focus 2.1) to develop and test a new palliative care service for people with MS.

We found that people with the progressive forms of MS had new concerns about losses and changes (including financial worries), as a result of the illness. In addition, they reported 'having to fight for everything' as far as access to care was concerned. This was closely linked to a lack of coordination and continuity of care, difficulties getting appropriate information and a poor quality non-specialist care. While these findings from in depth interviews made great sense to people affected by MS, Edmonds et al's report was the first systematic analysis.

Further interviews and focus groups with healthcare professionals echoed the patients’ concerns with poor continuity of care and limited resources. But in addition doctors and nurses were also bothered by communication between professionals; unequal provision of and access to services; patients’ problems with some symptoms, especially with cognition; bladder and sexual function; and the needs of patients and their carers around the end of a person’s life. All these difficulties were compounded because of the unpredictable course of MS.

This information enabled us to model a new palliative care service for people affected by MS. This consisted of a consultant in palliative medicine, a clinical nurse specialist and a psychosocial worker, some shared with the existing palliative care service and with close integration with neurology services. We evaluated this using our new methods of a fast track versus standard randomised controlled trial and results are currently being analysed.
As part of the project, resources have been developed to support people affected by MS and health and social care professionals, including a referral pathway for care professionals and a paper and web-based service directory (see section 4.1).

**The palliative care needs of people with late stage Parkinson’s Disease (PD), Multiple System Atrophy (MSA), and Progressive Supranuclear Palsy (PSP)**

Building on our earlier research we have commenced a new study, supported by the Department of Health (UK) to understand the experiences and needs of people severely affected by PD, MSA and PSP in order to identify the most effective approaches to enhancing quality of life and providing flexible personalised support. Patients and carers are recruited to a longitudinal study, which measures symptom problems and costs of care.

2.1.3 Evaluating and Improving the Cost-efficiency of Rehabilitation

There is now reasonable evidence to support the cost-effectiveness of rehabilitation following brain injury. But which patients may benefit most?

Routine collection of data in the course of clinical practice is key to the demonstration of effective and cost-efficient practice. Within this three-year cycle, Turner-Stokes et al have analysed a six-year longitudinal cohort to examine whether our rehabilitation programme is effective in reducing long term care needs, such that it could pay for itself through reducing the cost of on-going care. The programme uses measures developed in earlier research (see section 2.3). It is often thought that rehabilitation is not worthwhile for very severely dependent patients because they will remain dependent on care to some degree. However, our study showed that, contrary to expectation, rehabilitation was in fact most cost-effective for these heavily dependent patients. Although they required longer periods of rehabilitation, and thus cost more to treat, the gains in reduction of care costs were much higher than in the less dependent group, so the initial cost of rehabilitation was more quickly offset by savings in on-going care. Moreover, serial analysis of change in dependency for the most dependent and long-staying patients confirmed that they continued to make changes throughout their admission, and that earlier discharge would have led to poor outcomes and increased care needs.

The Functional Independence Measure (FIM) is widely used in the USA and Europe as an outcome measure for rehabilitation and benchmarking of services and FIM-efficiency (Gain in FIM score / Length of stay) is often used as a surrogate for cost-efficiency. A further interesting finding from this study was that the FIM did not demonstrate the additional cost benefits of rehabilitation in the highest dependency group that were revealed by the group’s new measure, the NPDS (see figure 2.4).

2.1.4 Improving Care and Services for People Affected by HIV or AIDS

In the era of antiretroviral therapy (ART), palliative care has a new and evolving role in supporting treatment, as well as caring for those for whom treatment is either not available or cannot prevent disease progression. All of these groups may require palliative care to address the physical, spiritual and emotional pain related to the disease and its treatment. It should be remembered that there are significant excess risks associated with HIV infection for several cancers, including Kaposi’s Sarcoma, lymphoma, vulval and cervical cancer; linking our work in this programme very directly with our cancer programme.

Harding and Higginson have been collaborating in the USA, UK and Africa to investigate the palliative care needs of patients with early as well as advanced disease, both in resource-rich and resource-poor countries.

![Figure 2.4 Comparison of the change in FIM (old measure) and NPDS (new more sensitive measure) scores across the three dependency groups. Box plots show median, inter-quartile range, range and outliers](source: Turner-Stokes et al, Arch Phys Med Rehab 2006; 87(11) e11.)
Evaluation of HIV/AIDS services in the USA and UK

In collaboration with colleagues in the USA, we evaluated new palliative care services for people with HIV and AIDS. Analysis of clients needs entering the three services identified problems of poor mental health, especially clients with history of drug dependence (in Baltimore) and more severe physical symptoms (in New York).

Conversely, better mental health was most strongly correlated with more positive perceptions of interpersonal relationships and of meaning and purpose in life, underlining the need to take a holistic approach to care. Most clients at all programs were socioeconomically disadvantaged, from ethnic minorities, and had a history of substance abuse, although significant differences were noted in the distributions of clients at each program with regard to these characteristics. A common set of medical (ambulatory/outpatient care, laboratory testing, pharmacy) and ancillary (nuritional counselling, transportation) services were identified by at least 25% of clients and staff at each program. These findings suggested there is a need for a mix of “care” and “cure” services to reflect the erratic disease trajectory experienced by some clients who move in and out of treatment as well as the vulnerability and marginalized lives of the clients served by these programs.

Two systematic literature reviews appraised effectiveness of and access to palliative care in HIV disease. Analysing data from 34 studies found that home and inpatient palliative care significantly improved patient pain and symptom control, anxiety, insight, and spiritual wellbeing. Despite this evidence, and the clear symptom and psychological needs care is often poor and less than optimal. The results proposed a model of integrated palliative care from diagnosis to end-of-life, alongside antiretroviral therapy when initiated.

HIV/AIDS and cancer research in Africa

Supported by the Princess Diana Foundation, Harding and Higginson researched the nature of palliative care services in Africa. Here the palliative care services support patients with both cancer and HIV/AIDS. The analysis suggested home and community-based palliative care has been largely successful, but community capacity and the resources and clinical supervision necessary to sustain quality care are lacking. Coverage and referrals must be primary concerns. Simple lay and professional protocols have been developed, but opioid availability remains a major constraint to the success of palliative care programmes in Africa. Areas of good practice, and areas where further success may be achieved include: attention to community needs and capacity; explicit frameworks for service development and palliative-care integration throughout the disease course (including antiretroviral provision); further education and protocols; strengthening and dissemination of diverse referral and care systems; increasing advocacy; and funding and technical skills to build audit and quality assessment.

Building from this Logie and Harding found that although morphine regulation had achieved its goal of preventing misuse and leakage from the supply chain, confusion and complexity in storage and authorisation rules led to discontinuation of opioid pain management for patients and also wasted service time in trying to obtain supplies to which they were entitled. The multi-method study also identified under-prescribing, as a result of clinician behaviour and public fear of opioids.

In a new partnership with MEASURE Evaluation (an evaluation team at the University of North Carolina, USA) Harding and Higginson have launched a new programme to evaluate the palliative care for patients with HIV in Kenya and Uganda. This will be the first study in the world to evaluate the clinical, social and psychological outcomes and costs comparing different models of palliative care in Africa. It is being conducted in collaboration with Paul McCrone, Health Economist in the Institute of Psychiatry, King’s College London.

2.1.5 Improving Care and Services in Patients with Chronic Heart Failure

In advance of developing a new clinical service at Guy’s and St Thomas’ Hospital, the end of life preferences of patients and families were explored. Of the 20 patients, all with New York Heart Association Functional classification II – IV, and 11 family carers, none had discussed their end of life preferences with clinicians or were aware of choices or alternatives in future care, such as availability of palliative services. The patients and families appeared to be living with fear and anxiety but were uninformed about the implications of their diagnoses. Interviews with clinicians confirmed that they rarely raised such issues with patients. The results highlighted a need to provide mechanisms to offer sensitively developed information and opportunities for discussion about future care issues, including the end of life and has led to agreed referral criteria and a preliminary care pathway, which will be evaluated through future research.

2.1.6 Improving Care and Services in Primary Palliative Care

Evaluating the National Palliative Care Education and Support Programme for District and Community Nurses

The department was commissioned by the Department of Health (DoH) to evaluate this national palliative care education and support programme for district and community nurses which ran from 2001-2004. Professor Julia Addington-Hall led this multi-professional and multi-site project, with Cathy Shipman as the primary researcher. It aimed to evaluate the acceptability and effectiveness of the programme by assessing whether it had measurable impact on district nurses’ (DNs) confidence in competency and knowledge, on GPs perceptions of the adequacy of communication, on the views of bereaved relatives, on place of death and referrals to specialist palliative care services.

The educational programmes were provided through all 34 Cancer Networks in England and the range of educational models and methods of delivery used were identified and categorised. Both quantitative and qualitative methods were used in a “before and after design” to assess the impact of the programme in eight randomly selected cancer networks on the confidence and knowledge of DNs, views of GPs and of bereaved carers. Quantitative methods included using postal questionnaires and qualitative methods included conducting face-to-face and telephone interviews and focus groups. A major success was the nationwide development of educational programmes across all 34 Cancer Networks.
which focused on a core curriculum although delivering this in varying ways dependent on local needs and resources. The process of establishing and providing the educational programmes led to improved relationships between specialist palliative care providers and primary care practitioners. About one third of members of DN teams in England were estimated to have been in contact with one of the network programmes, and there were small statistically significant improvements identified in DNs perceptions of confidence in palliative care competencies and in palliative care knowledge. Interviews with DNs, programme providers and commissioners identified ways in which the programmes were felt to have been successful. Further details of results can be found in the report to the DoH which can be accessed via www.kcl.ac.uk/palliative.

Working with Primary Care Trusts (PCTs): Perspectives on caring for dying people in London

A two year research and development project was completed in March 2005 for the King’s Fund. This project, which worked with five PCTs across London, found variations between how different PCTs organised their community palliative care services and in the range of services offered. The three key services providing palliative care within primary care were GPs, district nurses and clinical nurse specialists, linked together within a ‘Supportive Triangle.’ Good relationships underpinned this collaboration, but over-stressed services and communication breakdowns could threaten it.

Evaluation of a telephone advice and information line for patients with advanced disease and their carers

One barrier to effective primary palliative care is the fundamental lack of awareness of palliative care and related services among disadvantaged groups within society, such as people over 65, people from black and ethnic minority (BME) communities and those living in socially and materially deprived areas. The usage of traditional routes to access health information and advice, such as NHS Direct, is equally low among these vulnerable groups. On the basis of these findings, a partnership was established between NHS Direct and the King’s Fund to launch a pilot project called COMPASS, a palliative care telephone helpline for patients, carers and health care professionals.

Longhurst, Koffman and Shipman conducted a process evaluation of COMPASS, auditing calls, conducting qualitative interviews with staff, managers and key stakeholders and follow-up interviews with callers to the helpline. The results suggested that COMPASS provided information to previously underserved population groups such as ethnic minorities, and was a resource for health professionals.

Scoping exercise on generalist services for adults at the end of life: research, knowledge, policy and future research needs

Higginson and Shipman are leading a multi-site international team that won, in 2006, the NHS Service Delivery & Organisation R&D Programme (SDO) call to undertake a scoping exercise on generalist services for adults at the end of life. The work maps current research, knowledge and policy to identify specific topics for research to inform the future commissioning by the SDO programme. This exercise presented an important opportunity to identify priorities for research to improve generalist services for adults at the end of life, which will lead directly to a call for research by SDO in 2008, and may influence the support by other research organisations.

2.1.7 Improving the Methods to Evaluate Care and Treatments

Because of the lack of evaluative studies our work has focused on refining the methods to evaluate services and treatments, building on the MRC framework for the evaluation of complex interventions (see In Focus 2.1), and applying this in two recent studies. Through this and other methods we have developed and refined randomised controlled trial (RCT) methods, seeking to overcome many of the problems found in previous palliative care and rehabilitation trials. In addition to using for the first time in palliative care a delayed intervention randomised trial (In Focus 2.1). Separately Harding and colleagues developed methods for, and conducted, a community based RCT of multi-session group work for HIV prevention among 50 gay men in the UK. At eight weeks, those attending the group reported significant gains over their control in making sexual choices, physical safety, HIV and STI transmission knowledge, and sexual negotiation skills. The trial also demonstrated that high-risk community samples could be recruited to multi-session interventions, and provided feasibility data for future evaluations.

Health economic evaluation in palliative care is in its infancy, and yet there is a desperate need to understand better the costs of, and choices between, services. Standard utility measures based on survival, such as Quality Adjusted Life Years, do not reflect the needs and concerns in palliative care or rehabilitation. Working with colleagues at the London School of Hygiene and Tropical Medicine, we found that a new approach, the Choice Experimentation Method, could be used in palliative day care to help patients prioritise between different service elements. In 79 patients attending four day care centres, the Choice Experimentation Method found that access to specialist therapies was three times more important than medical support, and twice as important as staying all day. More recently, working with Dr Paul McCrone and colleagues at the Institute of Psychiatry, we have begun to measure costs of health and social care, the costs incurred by patients and families, and the cost effectiveness of treatments in some of our studies.
In focus 2.1 New methods to evaluate services

Refining the MRC Framework in palliative care and developing a new approach to randomised controlled trials

Patients and families in palliative care and rehabilitation have complex needs, often needing multi-professional and complex services. Therefore, we looked to follow the latest developments in health care research and found valuable the Medical Research Council’s (MRC) ‘Framework for the Development and Evaluation of RCTs for Complex Interventions to Improve Health’ (MRC, London 2000). This provides investigators with guidance in recognising the unique challenges that arise in the evaluation of complex interventions, as well as suggesting strategies for addressing these issues in the development of trials.

Complex interventions are built from a number of components which may act independently and interdependently. The framework suggests that a series of phases of investigation take place which may, in reality, be more iterative (Campbell et al, BMJ 2000;321:694-696) including: 1) a ‘Pre-clinical’ or theoretical phase; 2) Phase I or modelling; 3) Phase II or exploratory trial; 4) Phase III or definitive RCT; and 5) Phase IV or long-term surveillance (see figure). We believed that this framework would be especially useful because our earlier systematic reviews (Higginson et al, JPSM 2003;25:150-168, Harding and Higginson, Pall Med 2003;17:63-74; see also 2001-3 report) and the results of the NICE guidance on supportive and palliative care had found a poor understanding of what services did, wide variation in practice, as well as poor evaluation designs, which led to failed studies.

We worked with the framework and are using it in two studies to evaluate palliative care ‘complex interventions’: (a) A new palliative care service for people severely affected by MS (see section 2.1.2); and (b) A Breathlessness Intervention Service (see section 2.2).

The randomised trial; gave good recruitment and was acceptable in palliative care

Although use of the MRC framework in palliative care evaluation is in itself innovative, we also have tested a further new development for palliative care research – that of using fast-track versus standard (or wait-list/delayed intervention) designs for their Phase II trials.

This design has been used in studies of behavioural interventions in education (Flannery et al, Dev Psychol 2003;39:292-308), health education (Morgan et al, Rev Med 1996;25:346-354) and occasionally in health care (Fonda et al, Age and Ageing 1995;24:283-286). In the trial, the ‘fast-track’ group receive the intervention or service immediately after baseline interview, whereas the control group also receive the intervention, but only after a period of delay. As a result, potentially every participant is offered the intervention, potentially reducing selection bias and disappointment. In the health services some delay is often common, and even in palliative care there are waiting lists for some services and others that are not widely available.
Our trials using this design have achieved substantially better uptake and recruitment than previous palliative care randomised trials. While many factors may have contributed to our improved recruitment, to date we have found the use of the MRC framework and the ‘fast-track’ versus ‘current best practice’ design acceptable to staff, patients, families, patient representative organisations, funders and research ethics committees.

In both studies we have found that attention is needed to decide the ‘correct’ period of control before the intervention is offered. This had to be different in our two studies - because we had to base it on how stable the patients were and how quickly we expected the service to have an effect. We have also found that using the MRC Framework was more costly than traditional designs, in the short term, because of the need to undertake phase I and II work. However, in the long term, if the trial is successful it represents a good investment in research, especially as traditional designs have often failed.

Almost all studies within the department employ mixed method approaches - where quantitative and qualitative methods are used together, one informing the other. We are further developing the ways that these methods are integrated and work to give a rounded picture of the issues faced by patients and families, whose problems are usually complex and multi-dimensional, requiring a multi-professional and multi-method approach, especially to capture less tangible aspects such as quality of life, quality of care, dignity and caregiver needs.
2.2 Symptom Led Research

Our research into symptoms assessed both the range of symptoms in different conditions, and the management of individual symptoms, which can be common across several conditions.

2.2.1 Measuring Symptoms Across Five Far Advanced Diseases

Research by Solano, Gomes and Higginson, and supported by Cicely Saunders International, established that patients’ symptoms, especially pain, fatigue and breathlessness, are as common and as high in four non-malignant diseases as in cancer. This evidence has been instrumental in advocating the expansion of palliative care beyond cancer, so that patients with other advanced and progressive diseases such as chronic heart disease, AIDS, COPD and end stage renal failure can benefit. It also produced symptom profiles for these groups of patients, which can be used as a preliminary basis to model services.

The comparative grid (see table 2.1) showed that the prevalence of the 11 symptoms is widely but homogeneously spread across the five diseases, thus there appears to be a common pathway towards death for malignant and non-malignant diseases.

2.2.2 Symptoms and Care Needs Among People Dying with End-Stage Renal Disease

In collaboration with the Renal Units at King’s College Hospital, Guy’s Hospital, and Canterbury Hospital this innovative study, led by Murtagh and Higginson, is at the forefront of research into the palliative care needs of patients with end-stage renal disease who are managed conservatively, without dialysis. Nephrology services are recognising that this steadily increasing group of patients have unmet palliative care needs. There is however little evidence to underpin service development. This study is beginning to address this gap, supported by the Guys and St Thomas’ Charity.

A systematic review of symptom prevalence in renal disease found no studies among patients who are conservatively managed, as well as a lack of longitudinal studies. The similarity of symptoms between end-stage renal disease and cancer were confirmed in a pilot survey. This led to the development of a longitudinal study, which is due to report in 2007/8.

However, our first cross-sectional data on the epidemiology of symptoms shows levels of symptom prevalence and overall symptom burden that are comparable to those experienced by patients with cancer and other non-cancer diseases (see figure 2.6). Opioid use for analgesia in these patients is especially challenging, and as a result, evidence-based detailed clinical recommendations have been prepared. Qualitative data on the impact of symptoms, information and care preferences of this very elderly population is currently being analysed.

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Cancer</th>
<th>AIDS</th>
<th>Heart Disease</th>
<th>COPD</th>
<th>Renal Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>35–96%</td>
<td>63–80%</td>
<td>41–77%</td>
<td>34–77%</td>
<td>47–50%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>32–90%</td>
<td>54–85%</td>
<td>69–82%</td>
<td>68–80%</td>
<td>73–87%</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>10–70%</td>
<td>11–62%</td>
<td>60–88%</td>
<td>90–95%</td>
<td>11–62%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>30–92%</td>
<td>51%</td>
<td>21–41%</td>
<td>35–67%</td>
<td>25–64%</td>
</tr>
<tr>
<td>Confusion</td>
<td>6–93%</td>
<td>8–34%</td>
<td>30–65%</td>
<td>18–32%</td>
<td>18–33%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>13–79%</td>
<td>10–22%</td>
<td>49%</td>
<td>51–75%</td>
<td>39–70%</td>
</tr>
<tr>
<td>Depression</td>
<td>3–77%</td>
<td>3–8%</td>
<td>10–82%</td>
<td>9–36%</td>
<td>37–71%</td>
</tr>
<tr>
<td>Insomnia</td>
<td>9–69%</td>
<td>34–35%</td>
<td>9–63%</td>
<td>36–48%</td>
<td>55–65%</td>
</tr>
<tr>
<td>Nausea</td>
<td>6–68%</td>
<td>74%</td>
<td>17–48%</td>
<td>55–65%</td>
<td>31–71%</td>
</tr>
<tr>
<td>Constipation</td>
<td>23–65%</td>
<td>43–49%</td>
<td>38–42%</td>
<td>55–65%</td>
<td>31–71%</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>3–29%</td>
<td>30–90%</td>
<td>12%</td>
<td>27–44%</td>
<td>29–70%</td>
</tr>
</tbody>
</table>

Table 2.1 Prevalence of Symptoms in Five Advanced Diseases; results of a systematic review

2.2.3 Symptoms in Multiple Sclerosis (MS)
As part of the development and evaluation of palliative care services for people affected by MS (see 2.1.2) we found that people severely affected by MS had an average of nine (median = 8.5, mode = 12) symptoms. As for other conditions, pain and fatigue/lack of energy were found in over 50% of the 52 study participants, but four other symptoms were equally common - problems using legs, problems using arms, spasms, and feeling sleepy. Higher levels of disability were correlated with greater symptom severity for nine symptoms (Spearman \( r \)ho 0.28-0.56, p < 0.05), suggesting that there was a weak to modest link between increasing disability and more severe symptoms231.

2.2.4 ‘Improving Breathlessness’ Programme
A five-year integrated programme on breathlessness commenced in September 2004. Primarily supported by Cicely Saunders International and led by Higginson, Gysels and Booth, it builds on work within King’s and Cambridge, with specific projects winning external funding. Individual projects are testing treatments and new models of care and are providing a better understanding of the experience of breathlessness among patients and their carers over time. Their results are being combined to discover multi-professional multi-dimensional means to alleviate breathlessness.

Improving the experience of breathlessness in different conditions
Exploring the experience of breathlessness in 27 patients with chronic heart failure, Edmonds and colleagues identified three dominant experiences of breathlessness, “everyday”, “worsening” and “uncontrollable”, predominantly focused on physical functioning. Worsening breathlessness was a symptom that patients were unable to manage and prompted a hospital admission, whereas uncontrollable breathlessness was experienced as a symptom that even health care professionals struggled to control140. However, it is not known whether heart failure patients’ descriptions of breathlessness are different to those of cancer patients. Therefore, Gysels, Bausewein, Malik and Higginson are embarking on an integrated series of studies to further explore the experiences of breathlessness among patients with different conditions (lung cancer, COPD, cardiac failure, MND) and in different care settings. Gysels has completed interviews with patients and carers in all groups, and Bausewein is investigating for her PhD, the experience of breathlessness over time and the effectiveness of a hand-held fan in the home. Here a pragmatic trial is embedded as part of the longitudinal component where patients are randomised either to the use of a handheld fan or a wristband. As an initial phase, we have completed a systematic literature review to identify the appropriate measures for the trial317.

Figure 2.6 Symptom prevalence at first symptom assessment in patients (N=65) with conservatively managed end-stage renal disease
PhD, Malik is exploring the experiences of caregivers, and how patient symptoms and care affects them, with a particular focus on sleep.

**Evaluation of a new breathlessness intervention service in Cambridge**

One specific new intervention for Breathlessness is being tested with Addenbrooke’s NHS Trust, Cambridge, UK. The Breathlessness Intervention Service (BIS) is a service for patients with intractable breathlessness (regardless of their diagnostic group) and their carers, located within the Palliative Care Team. The evaluation follows the MRC’s framework for the evaluation of complex interventions, see section 2.1.7.

Booth and Higginson, after winning support from the Gatsby Charitable Foundation, conducted Phase I (the modelling phase) consisted of a qualitative study of service users and audit of breathlessness management locally. This built on a Pre-Clinical (theoretical) phase – which showed that lung cancer and COPD patients found breathlessness a frightening, disabling and restricting condition. Carers also reported severe anxiety and helplessness and felt powerless. Existing services were highly valued, but were described as inconsistent and sporadic.

In Phase I the BIS service was commenced and Farquhar conducted qualitative interviews with patients (n=10) and carers (n=9) using it, GPs (as referrers, n=4), respiratory nurses (as referrers, n=2) and BIS staff themselves (n=2). Patients and carers valued BIS; positive aspects included: its positive, educational approach which emphasised what was possible (not what was lost); non-pharmacological strategies which were described as helpful and new; and the open access to advice and flexibility of BIS, which was especially helpful when patients were frightened. However, some aspects required development, including carers’ need for more support and information; the problem of the historical location of BIS within oncology; and the need for prior information about BIS before patients were seen by the service. In addition, referrers valued the educational role and second opinion that BIS provided.

The results from phase I led to modification of BIS and in Phase II (exploratory trial phase) we are conducting a pilot pragmatic fast-track (delayed intervention) randomised controlled trial of the service with COPD patients (see In Focus 2.1). The trial uses a mixed methodology including clinical outcomes, quantitative measures and qualitative elements to explore the impact of the intervention (patient experience) and its outcome on patients’ quality of life. Uniquely among evaluations of breathlessness services to date, carer outcomes and the views of staff and referring agencies are also being collected. The pilot trial is providing the opportunity to: (1) examine the acceptability of a fast-track RCT methodology with breathless patients in a palliative care setting; (2) test the protocol and randomisation strategy; and (3) assess the acceptability and suitability of the various outcome measures for both patients and carers before a formal Phase III trial of all patients referred to the service (regardless of diagnostic group) commences.

**2.2.5 Managing Symptoms in Complex Neurological Disability**

The Regional Rehabilitation Unit at Northwick Park provides in-patient rehabilitation for younger adults with complex neurological disabilities whose needs for rehabilitation are beyond the scope of their local services. The prompt management of symptoms such as pain, depression and spasticity is key to the success of rehabilitation in this group.

We have developed a series of integrated care pathways (ICPs) which not only guide clinical management, but also support systematic on-going data collection to evaluate the success of our interventions. As a first step we have focused on the development and evaluation of tools for the assessment of symptoms in patients with cognitive / communication problems who have difficulty with reporting their symptoms through the normal methods. In this period, the ICPs have provided the following:
ICP for assessment and management of hemiplegic shoulder pain:

- The ShoulderQ, which we have developed to assess shoulder pain in this context, was shown to provide a specific and sensitive assessment of response to treatment252.
- The Scale of Pain Intensity (SPIN) was developed as a simple and accessible tool for assessing pain in people who are unable to complete the ShoulderQ. Preliminary evaluation suggests that it has potential for use in this context, and further evaluation is now underway234. (see In Focus 2.2)

ICP for assessment and management of depression:

- The Depression Intensity Scale Circles (DISCs) is an equivalent scale to the SPIN. Evaluation using the ICP showed it to provide a valid and reliable assessment of depression in the context of brain injury (see In Focus)164.
- National clinical guidelines on the assessment and management of depression in patients following stroke and acquired brain injury have been modelled on the ICP189.

ICP for the management of spasticity

- Our on-going evaluation of the functional benefits of botulinum toxin in the management of spasticity was a significant factor in the successful achievement of a UK licence for its use in the management of upper limb spasticity6.
- Our first successful use of goal attainment scaling (GAS) to measure meaningful change in this context is now being taken up in other studies209.

In focus 2.2

Assessment Of Pain & Depression

Assessing symptoms in people with cognitive and communication problems: A novel approach to a difficult problem

Assessing symptoms is essential for the successful management of medical conditions. However, people with cognitive or communication problems, for example due to acquired brain injury, confusion or other severe illness, may have difficulty in using traditional measures. As visual cues may help communication, we have developed and evaluated a pictorial measure that can help patients report on their symptoms.

This work has been carried out in the context of developing Integrated Care Pathways (ICPs) for the management of depression and pain respectively, in which regular symptom assessment plays an integral part.

The Depression Intensity Scale Circles (DISCs)
The concept of increasing depression is represented by a sequence of five dark grey circles increasing in size.

The mode of administration is adapted to suit the individual’s cognitive and communicative abilities. Their ability to make reliable ‘yes/no’ responses is established using a screening questionnaire, the AbilityQ, and is followed by a verbal explanation of the scale reinforced by gesture or pictures as appropriate.

The DISCs has been shown to have acceptable convergent validity, reliability and responsiveness as a simple graded tool for the screening and assessment of depression in patients with complex disabilities following acquired brain injury and is now one of the recommended tools for assessing depression in the Royal College of Physicians guidelines for depression following brain injury284.

The Scale of Pain Intensity (SPIN)
The SPIN uses the same idea as the DISCs, except that the circles are coloured red to convey the concept of pain. To reinforce its meaning, the colour red is also used on separate body drawings to indicate the region of the body where pain may be a problem.

A preliminary study to validate the SPIN in a general population with pain has found that it could quantify pain as well as the current preferred tool, a 0-10 numeric rating scale. Subsequent observation of verbal and non-verbal interaction between speech and language therapists and patients with severe dysphasia, together with the experience of clinicians in using the SPIN, has informed its administration280;234. This tool is now an integral part of the multidisciplinary ICP for managing shoulder pain in stroke patients in daily use on our regional rehabilitation unit.
2.3 Measuring Outcomes

Palliative care and rehabilitation are relatively new fields, and evaluations have been weakened by inappropriate or insensitive measures of benefit, such as the outcome of care and quality of life. To evaluate or set standards of care, or to assess need, we need appropriate tools to measure quality of life, outcomes and evidence about the most cost-effective models.

The department has led the development of measures in palliative care, principally: the Palliative Outcome Scale (POS) and the earlier Support Team Assessment Schedule (STAS), with a programme building on 20 years experience in outcome measurement and assessment.

Outcome measurement is also important in rehabilitation. Since 1995, Professor Turner-Stokes has spearheaded a drive to develop 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 interventions, and exploration of the relationship between different measures in current use in the UK.

### 2.3.1 Patient Centred Palliative Outcome Scales

**Support Team Assessment Schedule (STAS)**

The Support Team Assessment Schedule (STAS) was developed by Higginson when based at University College London. The psychometric testing was presented in her PhD thesis. It is a unique tool that assesses the clinical outcomes and 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. It has nine core or up to 20 optional items covering physical, psychosocial, spiritual, communication, planning, family concerns and service aspects. Although POS has replaced some aspects of STAS, there are elements of the original STAS, e.g. communication, insight, and professional education, which remain solely part of STAS. It is still used in many studies. This results in many services continuing to use STAS, with over 118 users in 17 countries. Further details are in Clinical Audit in Palliative Care (ed. Higginson I) published by Radcliffe Medical Press. You can download a copy of STAS from the Questionnaires & tools section of www.kcl.ac.uk/palliative.

**Palliative Outcome Scale (POS)**

The POS was devised following a systematic review of outcome measures used in palliative care. This concluded that there was a paucity of clinical questionnaires that could adequately reflect the holistic nature of palliative care (Hearn and Higginson, Pall Med 1997;11:71-72). The POS was, therefore, designed to overcome some of the limitations associated with existing outcome measurement scales in palliative care. It evolved using 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. The POS was then piloted in hospice, home, hospital and other community settings. The questionnaire covers physical symptoms, psychological symptoms, spiritual considerations, practical concerns, emotional concerns and psychosocial needs. Importantly, it also has an open question so respondents can identify their most important concern.

There are two main versions of the POS questionnaire, one for patients to complete, the other for staff. Bringing together these two complementary perspectives allows

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<table>
<thead>
<tr>
<th>Total Registered (so far)</th>
<th>457</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Europe</strong></td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td>288</td>
</tr>
<tr>
<td>Italy</td>
<td>5</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>2</td>
</tr>
<tr>
<td>Portugal</td>
<td>2</td>
</tr>
<tr>
<td>Switzerland</td>
<td>2</td>
</tr>
<tr>
<td>Spain</td>
<td>2</td>
</tr>
<tr>
<td>Greece</td>
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</tr>
<tr>
<td>France</td>
<td>1</td>
</tr>
<tr>
<td>Poland</td>
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</tr>
<tr>
<td>Sweden</td>
<td>2</td>
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<td><strong>North America</strong></td>
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<tr>
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<tr>
<td>Canada</td>
<td>15</td>
</tr>
<tr>
<td>Mexico</td>
<td>1</td>
</tr>
<tr>
<td><strong>Rest of the World</strong></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>8</td>
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<tr>
<td>South Africa</td>
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<tr>
<td>New Zealand</td>
<td>4</td>
</tr>
<tr>
<td>Argentina</td>
<td>3</td>
</tr>
<tr>
<td>Brazil</td>
<td>3</td>
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<tr>
<td>Peoples Republic of China</td>
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<tr>
<td>Singapore</td>
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<tr>
<td>Hong Kong</td>
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<tr>
<td>Taiwan</td>
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<tr>
<td>Thailand</td>
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<tr>
<td>Puerto Rico</td>
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<td>Malawi</td>
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<td>Botswana</td>
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<td>Republic of Korea</td>
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<tr>
<td>Uganda</td>
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<td>Japan</td>
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</tr>
<tr>
<td>Nigeria</td>
<td>1</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Independent Validations/Translations of POS</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK – Stevens et al, Support Cancer Care 2005;13:1027-34</td>
</tr>
<tr>
<td>Italian</td>
</tr>
<tr>
<td>German – Bausewein et al JPSM 2005;30:51-62</td>
</tr>
<tr>
<td>Urdu</td>
</tr>
<tr>
<td>Spanish – Serra-Prat et al Med Clin (Barc) 2004;123:406-12</td>
</tr>
<tr>
<td>Portuguese</td>
</tr>
</tbody>
</table>
the POS to identify patient’s problems and enables staff to provide individualised care. It is a flexible tool, the usage of which can be determined by the needs of local services. A version completed by the family/caregiver has also been developed.

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. It has also been shown to be a credible, clinical, research and audit tool, which is acceptable to both patients and staff and quick (five minutes) to complete (Hearn and Higginson Quality in Healthcare 1999;8:219-277). The POS can be used routinely to guide clinical practice and monitor service interventions. Moreover, the POS is a valuable audit tool that can help meet the current statutory requirements on clinical governance. You can download free copies of the POS questionnaires from the Questionnaires & tools section of our website (www.kcl.ac.uk/palliative). A user’s guide to the POS with further details on the origins of the POS, as well as suggestions for its implementation in clinical practice and analysis of data is also available. Table 2.2 shows details of current users of POS, and external validations which independently confirm the value of POS assessment and measurement. A next step with the POS is to test: its utility in identifying patients who would benefit from referral to palliative care and potential to assess complexity and costs using a similar approach to rehabilitation measures (see 2.3.3); culturally appropriate formats; and additional modules assessing symptoms or other aspects in more detail.

Comparison of quality of life scales in palliative care
Using data collected on 140 patients to evaluate palliative day care we further explored the factors within the Palliative Outcome Scale (POS) and other measures of hope and quality of life. Using these different tools, we were able to identify a relative factorial structure of all scales combined. Four components appeared to be reflected in the different measures – self sufficiency, positivity, symptoms and spiritual needs. The results suggest ways in which items within the POS might be further improved, and suggests that the POS could form the basis of a measure in the future containing 11 (rather than 10) items which would explain the variability of needs within patients and might be useful for identifying individuals for referral to palliative care 116.

The German translation of POS
The German version of the POS was translated forward and backward according to EORTC recommendations for translation procedures and then validated in palliative care (hospital support team, hospice, home care) and a pain clinic. The German POS version was well accepted by patients and staff, and appears to be valid. The study identified some areas where the scale would benefit from expansion to more closely capture staff and patient concerns 117.

The APCA African POS
This collaboration between the African Palliative Care Association (APCA), KCL and National Hospice and Palliative Care Organisation (NHPCO) (USA), along with partner agencies in 11 sites across South Africa, has developed and begun the validation of an African Palliative Outcome Scale (POS) for use across the region. This important collaboration will enable future evaluative efforts to be conducted using a valid outcome tool, something missing to date. Work is currently underway to develop an African POS for children.

Funded by the BIG Lottery in the UK, The Encompass Project (Ensuring Core Outcomes and Measuring Palliation in Sub-Saharan Africa) unites five sites across South Africa and Uganda: The Hospice Association of the Western Cape, Philanjalo Hospice in Tugela Ferry, South Coast Hospice, The N’Doro project at Chris Hani Baragwanath Hospital in SOWETO, and Hospice Africa Uganda. The project aims to complete validation of the African APCA POS and to work with the partners above to act as “model” audit centres, conducting a full audit cycle during the second year. This project has achieved a number of successes: the recruitment and training of a cadre of African palliative care nurses; the generation of a large original dataset; and has laid the foundation for audit in these new services. Harding, Selman and Higginson are now planning the analysis of the data, so it can be fed back to services, and the utility of this new version of POS can be tested.

2.3.2 Common Language Outcome Measures for Rehabilitation in the UK
In the last triennial report we described the tools we have developed to measure outcomes from rehabilitation and provide a common language with which to compare different populations, programmes and practices. These include the Northwick Park Dependency and Care needs assessment (NPDS/NPCNA) and the UK Functional Assessment Measure (UK FIM+FAM). A recent survey has demonstrated that these are now widely taken up and used in clinical practice in rehab units across the UK 118.

The NPDA/NPCNA provides a generic measure of care needs in the community and thus the cost of continuing care provided by health and social services. Work is ongoing to develop hospital versions of these scales (the NPDS-H and NPRNA) which could ultimately be used to determine the nursing staff required for a rehabilitation
ward, adjusted in relation to case-mix\(^{363,364}\); and also to develop an equivalent scale for assessment of needs for therapy input – the Northwick Park Therapy Dependency Assessment (NPTDA)\(^{276}\).

In her capacity as national lead for the development of Healthcare Resource Groups for Rehabilitation, Professor Turner-Stokes is currently working in collaboration with the Department of Health through The Information Centre, Connecting for Health and the Payment by Results Team to develop suitable tools for banding cost tariffs for rehabilitation when Payment by Results is introduced for rehabilitation services.

- The NPDS and NPTDA have been put forward as the tools likely to be used for costing rehabilitation inputs for patients with complex rehabilitation needs.
- A much simpler tool, the Rehabilitation Complexity Scale (RCS) has been developed for use at the less specialised end of the service spectrum. See figure 2.8.

### Measuring function outcome from focal interventions such as the use of botulinum toxin for upper limb spasticity

Intramuscular injection of botulinum toxin is increasingly recognised as a safe and effective intervention for reducing spasticity in the arm and hand due to stroke or other brain injury. However, whilst there is good evidence for its effect on muscle tone, it is harder to demonstrate that this translates into actual benefit for patients. Focal changes that arise form the localised injection of one or two muscles may be lost against a background of unchanging items in the commonly used disability measures.

Pooling data on stroke patients in two randomised controlled trials of intra-muscular botulinum toxin (BTX), Wade, Turner-Stokes and colleagues showed that it was possible to demonstrate a relationship between changes in spasticity and functional gain. However, functional benefits were often not observed until 6-8 weeks after relieving spasticity, due to the time needed to practice functional skills. These functional gains may therefore be missed in trials which use a single time-point for assessment of outcome based on maximal effect on spasticity.\(^5\)

A second reason for failure to demonstrate functional gain is because measurement tools evaluate the wrong

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**Figure 2.8 Current proposals for use of costing tools to develop banded cost tariffs for rehabilitation services under payment by results:**

Source: Turner-Stokes et al, Clinical Medicine, 2007, in press
tasks. Some patients, especially early in the recovery phase, may expect to regain voluntary control of their arm and hand following relief of spasticity, but for more severe and longer-standing paralysis, the goals for intervention tend to be ‘passive function’ such as improving the ease of caring for the person – for example making it easier to maintain hygiene or to put the arm through a sleeve while dressing. A systematic review of the literature revealed no suitable tools currently available for measuring both passive and active functions of the upper limb that would properly assess the functional benefits of managing upper limb spasticity, so we have developed a new tool called ArMA, which is now undergoing evaluation.

Patient-centred outcomes in rehabilitation - the use of Goal Attainment Scaling (GAS)
Goal attainment scaling (GAS) was first introduced in the 1960s as a tool for evaluating individualised outcomes in complex interventions in patients with learning disabilities, but it has only relatively recently gained popularity outside in other fields. One of the major challenges for outcome measurement in rehabilitation is the wide variety of different goals that patients may have for their rehabilitation programme. GAS absorbs much of this variation within the process of goal setting, making it a potentially valuable tool for this context. Moreover, a patient-centred instrument that specifically evaluates the outcomes that are important to the patient and their family provides an important perspective that is not included in most standardised measures of outcome.

In our preliminary application of GAS as a measure for assessing focal changes during the management of upper limb spasticity (see above) Ashford and Turner-Stokes found that GAS provided a useful measure of functional gains in response to treatment, and was more sensitive than global measures such as the Barthel Index. Further work is underway to address the benefits of GAS over currently applied standardised outcome measures in our wider rehabilitation programme.
2.4 Living & Dying in Society

2.4.1 A Good Death at Home: Committed to Making it an Achievable Goal

Most people in many countries of the world do not die where they wish. The latest data for England & Wales shows that nearly 300,000 people died in NHS hospitals and less than 94,000 at home. This project, now funded by Cicely Saunders International, aims to improve the evidence base on how best to support patients and families to achieve a good death at home if they wish.

Over the last 12 years, Higginson inaugurated a series of studies scrutinising variations in place of death, the preferences of patients, families and general public, the effect of services and the reality for specific groups of people (e.g. children and young people, the elderly).

Through international collaborations including with the US, Italy and Ireland, our team investigated differences and commonalities across countries. We found, for example, that death demographics and the place where people die are similar in London and New York.220 In London, however, older people are much less likely to die at home, whereas in New York they die at home more often than their younger counterparts.

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Figure 2.9 Proportions of cancer deaths at home, 1995-1998 by age in London and New York

Figure 2.10 Model of variations in place of death
Source: Gomes and Higginson, BMJ, 2006, 332:515-521
In the attempt to find out what needs to be in place for patients to die at home, Gomes and Higginson analysed 58 studies, involving 1.5 million patients in 13 countries. They identified strong evidence for the effect of a complicated network of 17 factors associated with death at home. The findings, depicted in an evidence-based model (figure 2.10), were welcomed by many policy makers and professionals committed to planning and providing care that meets patients’ wishes.

The team has taken this research further to understand and monitor changes in where people die over time. We unveiled a longstanding dying trend away from home in England & Wales from 1974 to 2003, that has sustained for cancer and non-cancer, both genders and all people aged 45 and over. Concerned by the implications of a continuation of this trend into the future, a series of national long-term projections are being prepared accounting for different scenarios. The data from this study will be of great value to plan for future palliative care. Gomes and Higginson then plan to research ways to improve the quality of palliative care at home to discover more cost-effective models of home care so that more people feel supported and can benefit from it.

### 2.4.2 Carer Experiences in Long-term Neurological Conditions

The health and happiness of family carers who look after people with long-term neurological conditions can be put at risk because many of those cared for have multiple problems affecting their functioning in all aspects of daily life and need round-the-clock care.

The Government’s National Service Framework (NSF) for Long-Term Conditions (2005) set out specific initiatives to transform the way that health and social care services support these family carers. To inform its implementation, Jackson and Turner-Stokes have conducted a Department of Health funded programme of research into carer experiences in neurological conditions. In collaboration with researchers from the Social Policy Research Unit at York University, the Institute of Psychiatry and voluntary organisations, they completed a national survey of the needs and experiences of carers of adults with acquired brain injury (ABI) (figure 2.11).

This comprised:
- Systematic literature reviews of the sociological, medical and psychological literature.
- A national questionnaire study, which compared and contrasted the experiences of carers looking after a relative of working age with ABI against a group of carers of people with dementia studied previously.

Results showed that high levels of burden, a diminished quality-of-life and poor health were common in both carer groups (figure 2.12). ABI carers fared worse than dementia carers, probably because more of them lived with the person cared for and because they spent more hours caring per week.
The problem behaviours shown by the person cared for had different effects on carer well-being. Looking after someone with aggressive problems was more of an issue for ABI carers, whereas passive/low mood problems caused more difficulty for dementia carers.

Having to cope with a relative displaying violent/aggressive behaviour was of particular concern for carers with young children or other dependent relatives. As one mother told us…

“Constantly tired, haven’t got any available time to play or do things with the children. Our relationship as husband and wife has suffered because he cannot understand there are others in the house and he can’t have everything done immediately and starts screaming and yelling at me and the children which is getting us all down. Because of memory problems I have to do everything over and over again. I can’t leave the children with him and can’t leave him either.”

Support for carers with multiple caring roles in the context of long-term neurological conditions

As a result of this work, a further Department of Health grant has been awarded for a follow-on study to investigate the experiences of carers according to their differential family circumstances, and the condition-specific problems they have to cope with, in a range of other long-term neurological conditions. The aims of this study are to:

• Investigate the support needs of people caring for an adult with a long-term neurological condition, especially those with other family dependents (i.e. with multiple caring roles).
• Identify differences in support needs between caring for people with ‘hidden’ (cognitive, behavioural, emotional) versus ‘visible’ (physical) disabilities.
• Investigate carers’ changing needs during the first 1-2 years after onset.
• Estimate costs and identify predictors of both current informal care & support and potential support.

Findings will inform a good practice guide, which will be disseminated through major service providers in the NHS and voluntary sector to assist in the planning of appropriate support services for these carers, and to evaluate the cost implications of service provision.

2.4.3 Ethnicity and Culture

One question raised about patients common preference for home care and home death, is whether this varies by culture. We explored this as part of a wider study assessing the effects of advanced disease, particularly cancer, among the local black Caribbean and white populations. Bereaved relatives reported that 34% of black Caribbean patients and 27% of white patients had expressed a firm preference for location of death, and of these in both groups more than 80% wanted to die at home. Thus, at least in this group, home preference was similar. However, fewer respondents representing Caribbeans rather than white patients stated that they ($x^2 = 8.9, p= 0.001$) nor the patients ($x^2 = 8.6, p = 0.03$) where given sufficient choice about the actual location of death, suggesting that further training and support is needed to elicit the preferences of, and to meet the needs of, the local Caribbean community.

Further exploration of the experiences of the family members also showed higher psychological morbidity among the Caribbean individuals, highlighting an urgent need for better focused support in primary care. The comparison of the bereavement effects on family and close friends of 50 deceased first generation black Caribbean and 50 native born white patients, using standardised scales, found that although there were no differences in the intensity of grief; depression and anxiety; was significantly higher among black Caribbean respondents (28 vs 21.2, T test = -2.28, p = 0.025). Multiple regression analysis revealed that this difference was best accounted for by the ethnicity of the deceased (OR 7.0, CI 0.08-13.14, p=0.03) and bereavement concerns such as legal and housing problems (OR 5.0, CI 0.07-9.37, p=0.02). The majority of respondents had visited their General Practitioner subsequent to bereavement suggesting this as a possible means of support.

Work in this area is progressing through a qualitative study exploring and comparing the experience of living with and dying from advanced cancer among the black Caribbean and white British communities living in south east London supported by the Guy’s and St Thomas’ Charity. The study is exploring differences in the meaning of symptoms and mechanisms of support, in order that this information can be used to improve future treatment and care.

2.4.4 Better Palliative Care for Older People

The fastest growing section of the population is the “oldest old” and this trend is forecast to continue, but little research to date has focused on the needs, attitudes or the experience of this group. As preventive healthcare reduces disease-related death at a younger age, more people can expect to die eventually in old age, but data are scarce on the patterns of decline due to age-related causes of death. Disability, frailty and dementia are all increasingly common in advanced old age, and there is evidence of steeper cognitive decline preceding death.

Although many of the studies reported elsewhere include partially, or often primarily older people (for example, research into renal palliative care), we have launched a specific programme seeking to improve palliative care for older people, supported by the Dunhill Medical Trust and Cicely Saunders International. Within this, three main sub-programmes have been developed:

I. Supporting dignity at the end of life

A systematic review of older peoples’ perceptions of dignity and interventions to support their dignity and a qualitative study to explore residents’ perceptions of dignity are underway. Pilot studies to assess the feasibility, acceptability effectiveness of a novel dignity therapy intervention for older people at the end-of-life are planned in collaboration with Professor Harvey Chochinov, Canada, who pioneered this approach. These will be conducted in two settings: care homes and hospital (people being seen by a hospital-based palliative care team).

II. The effectiveness of interventions to improve palliative care for older people

This includes (a) a systematic review to assess the
effectiveness of palliative care interventions for older people in care homes, and (b) producing a booklet for the WHO on better practice in palliative care for older people, with additional support from the international charity, Fondazione Maruzza Lefebvre D'Ovidio Onlus.

III. Exploring the barriers to implementing the Gold Standards Framework for Care Homes
The Gold Standards Framework for Care Homes is one of the UK's national tools to improve end-of-life care, which has been developed and recognised nationally through the Department of Health’s End of Life Care Programme. Interviews with care home managers, nursing staff, care assistants, residents and their families are planned, in research supported by the Guy's and St Thomas's Charity.

Dr Sue Hall (Lecturer) and Susan Longhurst (Research Associate) have been supported to work with Irene Higginson on the programme.

In addition, Dr Morag Farquhar is providing a link and collaboration to the study on living and dying in extreme old age. This qualitative and quantitative study, from the Department of Public Health and Primary Care, University of Cambridge, and supported by the BUPA Foundation, aims to gain a fuller understanding of what it means to live so long and die so old.

The long-running study of ageing, the Cambridge City over-75s Cohort, provides a unique opportunity to explore these issues by re-interviewing the survivors (now all aged 94-100), their family and other carers. The research takes account of personal experiences, attitudes and preferences using qualitative methods, and quantifies patterns of health, cognition, social networks and service support at the end of life, building on 20 years’ quantitative data.

This BUPA Foundation funded study consists of three linked projects to examine living and dying in extreme old age within the framework of an on-going longitudinal observational study, the Cambridge City over-75s Cohort (baseline n=2609). King’s College London is a co-applicant on this phase of the study, providing expertise in qualitative methods, interviewing older people and quality of life measurement.
3
Policy, Guidelines and Needs Assessments

The work of the department has had a considerable impact on policy, through the National Institute of Clinical Excellence (NICE) Guidance on Supportive and Palliative Care in Cancer, and through its general research being adopted in policy documents. In addition, work was undertaken by Turner-Stokes and colleagues on the National Service Framework for Long Term Neurological conditions. Many of the members of the department are members of local, national and international strategic groups, further aiding the development of the fields (see section 7).

As Deputy Chair of the External Reference Group and as Chair of the Research and Evidence group, Professor Turner-Stokes played a key role in its development. Gathering the evidence to underpin the NSF recommendations was a major undertaking. As part of this, the group developed a new research typology that is quick and simple enough to be used by clinicians; encompasses both qualitative and quantitative research, providing it is rigorously conducted; and values the experience of users and carers who live with long term neurological conditions as well as research-based evidence. Application of this typology allows different conclusions to be drawn from the literature than the much more restrictive approach of the Cochrane Review methodology, which may resonate more closely with the experience of users, carers and professionals in the field.

3.1 Guidelines
Professor Turner-Stokes chairs the Research and Clinical Standards Committee for the British Society of Rehabilitation Medicine and is also editor of the Concise Guidance series for the Royal College of Physicians. As part of this, guidelines have been produced in the following areas:

- Vocational assessment and rehabilitation following acquired brain injury;
- Rehabilitation following acquired brain injury;
- Assessment and management of the use of anti-depressants following acquired brain injury;
- Chronic kidney disease (Burden and Thompson, Clinical Medicine 2005;5:635-642);

In addition, Cochrane reviews have been undertaken and the methodology developed (see In Focus 3.1).

3.2 Needs Assessments
The department is active in both epidemiologically/population based needs assessments to improve care for the community and also individual patient needs assessments, adapting many of its existing measures.

3.2.1 Epidemiological Based Needs Assessment
For the Open Society Institute we have conducted a global needs review collating all the data on all the different approaches to needs assessment which have been conducted across the globe, and are in the process of analysing this.

In addition, for a local hospice Longhurst, Shipman and Higginson conducted a needs review to assess how the local community and hospice would like to see that hospice develop in response to local need and available resources. This involved collating epidemiological data, interviewing relevant stakeholders, including patients, local doctors and nurses, the primary care trusts and, of course, hospice staff.

3.2.2 Individual Based Needs Assessments
Many of the measures described in section 2.2 are being used to assess needs. For example, many services across the globe are using POS to assess patient needs and to aid communication between staff. The Ministry of Health in Portugal has recommended it for all services, and in the UK it is proposed in End-of-Life and Palliative Care Guidance. In addition, Williams and Turner-Stokes have been developing the Northwick Park Nursing Dependency Care Needs Assessment (NPDS/NPCNA). While this assessment was designed to work in the community a preliminary evaluation of care hours demonstrated that the NPCNA over-estimated the time required to deliver nursing care in hospital when it was compared with the total nursing and care hours available. In addition, it failed to identify specialised interventions in a rehabilitation setting. The work will lead us to seek ways to improve and find the assessment tool for the future.
Clinical Services

There are well established clinical palliative care services at both King’s College Hospital NHS Trust (KCH, one hospital palliative care team) and at the Guy’s Foundation and St Thomas’ NHS Foundation Trust (GST, two hospital palliative care teams and two community palliative care teams). The services provide a seven day a week visiting service and consultant-delivered integrated 24-hour telephone advice across both Trusts and the University Hospital Lewisham.

Two of the clinical consultants have honorary academic contracts with the Department of Palliative Care, Policy and Rehabilitation – Dr Polly Edmonds (lead clinician at KCH) and Dr Rachel Burman (KCH) and of course Professor Higginson is a consultant (honorary), primarily for KCH, but in on call integrated across all units. There are joint monthly clinical update meetings between the KCH palliative care team and academics from the Department of Palliative Care, Policy and Rehabilitation, in order to share key clinical issues, especially where they relate to policy and to update on research projects, and a joint journal club. The clinical services lead the delivery of the undergraduate curriculum – this is discussed more fully in section 5.4.

There are many examples where the research findings are influencing local, national and international clinical practice, but two specific local examples are given below.

4.1 Improving Care for People Affected by Multiple Sclerosis (MS): Translation of Study Outcomes to the Clinical Setting

During its evaluation phase the new MS service saw 94 patients, assessed by the referrer to be severely affected by their MS. Most of the people referred for assessment of symptom control problems had other specialist palliative care issues identified on assessment by the clinical service. This was less likely where referrals were made for other reasons. No patient required more than three visits by the clinical team, and only a minority of people (n=15, 16%) were subsequently referred on to community specialist palliative care services for ongoing management.

Drawing on the lessons learned as part of this project, and following a detailed option appraisal, it was decided that the most realistic and sustainable option for the future was that of a step-down service leading to full integration of the MS palliative care service with the generic King’s College Hospital Palliative Care Team. In addition, a new referral pathway was developed (see figure 4.1).
Where new referrals are received by the clinical service, these are now triaged by one of the consultants in Palliative Medicine at King’s College Hospital NHS Trust, using the referral pathway based on the information available. The consultant then contacts the referrer by telephone to discuss the patient in more detail and give appropriate telephone advice with a view to:

- Sign-posting patient to appropriate service(s);
- If palliative care issues are identified as urgent and complex, the palliative care consultant facilitates referral to local community palliative care team (CPCT);
- If it is difficult to engage the local CPCT or other professionals, the palliative care consultant could offer a joint patient assessment either with the CPCT, referrer, or other appropriate health or social care professional;
- For one local area (Lambeth, Southwark and Lewisham) patients there is the option of an appointment in the neurology palliative care clinic.

New patients may also be seen by the hospital palliative care team in the new complex MS patient clinic that is held monthly at King’s College Hospital NHS Trust, led by Dr Peter Brex.

A further outcome from the project is the development of several resources to support people severely affected by MS, carers, health and social care professionals in learning from this project and developing local collaborations to improve care for those people with MS that are severely affected. These are:

- A Resource for Health and Social Care Professionals;
- MS Essentials series: Support for people severely affected by MS;
- A Service Directory listing statutory and voluntary services in Southeast London; it is available as a paper version or via a website http://www.selmss.org.uk/.

4.2 Improving Care for People with Chronic Heart Failure: Translation of Heart Failure Study to Clinical Setting

This service development programme was designed to review current cardiology/palliative provision at Guy’s and St. Thomas’ NHS Foundation Trust for heart failure patients and to measure need for and appropriateness of a new service. Led by Beynon and Harding, and involving a multi-professional academic and clinical team, this study, which was funded by the Guy’s and St Thomas’ Charitable Foundation, aimed to identify areas of good practice and those where things worked less well. In order to do this, we undertook a census with a view to quantifying the number of inpatients likely to require palliative care, as well as conducting interviews with patients, their carers and staff in both palliative care and cardiology.

The process of undertaking the research has led to an increased understanding between the clinical leaders in both cardiology and palliative care with a joint determination to implement the data to provide an improved service for patients nearing the end of their lives. Results from the project have informed the local, national and
international debate, as well as leading to local service recommendations. The results from the project are currently being disseminated within the hospital trust but have already led to:

- Agreed specific referral criteria to palliative care (see table 4.1);
- A pilot parallel heart failure/palliative care outpatient service;
- Discussions between ward staff and palliative care staff regarding available resources;
- Review of psychological support to patients.
- Review of information available to patients

**All cardiac patients being referred to the palliative care team must have:**

- been reviewed by the Heart Failure team (x81012);
- know they have a diagnosis of heart failure;
- both patient and medical team must agree to the referral.

IN ADDITION one or more of the following merit referral:

- Symptomatic (e.g. breathless at rest or on minimal exertion) despite optimal treatment;
- Three or more admissions for heart failure within the past year;
- Heart failure when hospital admission may not be the best/only/preferred option;
- Stage IV patients (i.e. daily activities limited by dyspnoea) for whom hospice inpatient treatment may be of benefit, either immediately or in the future;
- On optimal therapy but with marked or deteriorating physical or psychological symptoms*;
- Those who may benefit from palliative day care or counselling*.

* Where only psychological issues are present consider referral to psychology

These guidelines have been compiled from a one year study undertaken at Guy’s and St. Thomas’ Hospital in collaboration with the Department of Palliative Care, Policy and Rehabilitation, Kings College London and St. Christopher’s Hospice. The study was supported by the Guy’s and St. Thomas’ Charity.

Table 4.1: Referral criteria to Palliative Care at GSTT for patients with Heart Failure*
5

Education and Outreach

5.1 General Education: Seminars, Masterclasses and Targeted Programmes

The department is active in providing a programme of seminars and masterclasses as part of the COMPASS collaborative (see section 7 for details). We have undertaken a programme of masterclasses and open seminars (see table 5.1).

Table 5.1 Open Seminars and COMPASS Collaborative Masterclasses 2004/5-2006/7

<table>
<thead>
<tr>
<th>Year</th>
<th>Speaker(s)</th>
<th>Title</th>
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<tbody>
<tr>
<td>2004</td>
<td>Dr Sunny Kaul, UK</td>
<td>Non-invasive Ventilation in MND</td>
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<td></td>
<td>Teresa Young, UK</td>
<td>The European Organisation for Research and Treatment of Cancer - Approach to Quality of Life Measures: Past, Present and Future</td>
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<tr>
<td></td>
<td>Dr Dan Munday, UK</td>
<td>Palliative Care Research at the Edge of Chaos – looking through a complexity lens</td>
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<td>Dr Peter Fayers, UK</td>
<td>Response Shift in Patients' Reports of Quality of Life: What is it, why it matters, and how to assess it</td>
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<tr>
<td>2005</td>
<td>Prof Derick Wade, UK</td>
<td>Do Biomedical Models of Illness Make for Good Healthcare Systems?</td>
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<tr>
<td></td>
<td>Dr Bee Wee, UK</td>
<td>Investigating Death Rattle: lessons learnt about research near the end of life</td>
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<tr>
<td></td>
<td>Prof Harvey Chochinov, Canada</td>
<td>Dying with Dignity: A contemporary challenge for end of life care</td>
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<td></td>
<td>Alicia O’Cathain, UK</td>
<td>Communicating Purpose and Practice in Mixed Methods Studies</td>
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<td></td>
<td>Dr Stephen Barclay, UK</td>
<td>Palliative Care in Primary Care: identifying and tracking deaths at home – development of a national study</td>
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<tr>
<td>2006</td>
<td>Prof Derick Wade, UK</td>
<td>Getting Papers Published – how to avoid certain failure</td>
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<td></td>
<td>Dr Sandra Decker, USA</td>
<td>Assessing Causality using Quasi-experiments</td>
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<td></td>
<td>Dr Magi Sque, UK</td>
<td>Mixed Methods Research on Organ Donation</td>
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<tr>
<td></td>
<td>Prof Derick Wade, UK</td>
<td>Data, Data Everywhere but No Result in Sight</td>
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<td></td>
<td>Dr Lewis Cohen, USA</td>
<td>Accusations of Euthanasia and Murder in End of Life</td>
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<td></td>
<td>Prof Alan Tennant, UK</td>
<td>The role of Rasch Analysis in Medical Outcome Studies</td>
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<td>Prof Peter Disler, Australia</td>
<td>Dimensions of Rehabilitation in Rural Australia</td>
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<td></td>
<td>Dr Richard Harding, UK</td>
<td>Palliative Care in Sub-Saharan Africa – current evidence and activity</td>
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<td></td>
<td>Dr Stephen Barclay, UK</td>
<td>Perspectives on Place of Death in Primary Care</td>
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<tr>
<td>2007</td>
<td>Mandy Stratford, UK</td>
<td>Dying to be at Home: relatives’ perceptions of caring for a loved one with advanced cancer</td>
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<td></td>
<td>Prof Allan Kellehear, Australia</td>
<td>What is Health Promoting Palliative Care?</td>
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<td></td>
<td>Dr Patrick White, UK</td>
<td>COPD and Palliative Care: does prognosis matter?</td>
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<td></td>
<td>Prof Jennifer Abbey, Australia</td>
<td>The use of Photographs in Research with People with Late-stage Dementia</td>
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<tr>
<td></td>
<td>Dr Wendy Magee</td>
<td>Music Therapy in Neuropalliative Rehabilitation</td>
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<tr>
<td></td>
<td>Prof Amanda Ramirez</td>
<td>Delivery Cancer Care in Multidisciplinary Teams: is it working?</td>
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</table>
A specific ‘Palliative care for people with MS’ (PwMS) education programme was undertaken and evaluated, delivering a programme accessible to health and social care professionals working with PwMS across Southeast London. Nine study half days were undertaken and the education programme was formally evaluated, with 182 out of 234 (77%) participants describing each topic as quite or very useful.

5.2 MSc, Postgraduate Diploma and Postgraduate Certificate in Palliative Care

The philosophy underpinning the MSc in Palliative Care (and the new qualifications – the Postgraduate Diploma and Postgraduate Certificate) is to enable participating students to develop the skills required to appraise research and evidence on palliative care-related issues to inform their clinical practice and to develop relevant services. The MSc in Palliative Care, run in collaboration with St. Christopher's Hospice and with the support of many talented external lecturers, who are experts in specific topics, is now very well established with a 10-year track record of providing a high class academic experience. It is distinctive from other national and international postgraduate palliative care degree courses in the following ways:

1. The MSc is focused strongly on evidence and on understanding research relevant to palliative care. This is because palliative care is a relatively new specialty. Knowledge about which interventions have the potential to enhance quality of life for patients and their families, be they pharmacological, psychological, social or service-based, are still poorly understood or do not exist.

2. The course is inter-professional. This allows students to explore similarities and differences in roles, skills, knowledge and their respective ideologies. It also provides scope for greater opportunity of open communication of all members within a group, consequently alleviating future hesitancy of single disciplines sharing knowledge with other professionals and non-professionals.

3. The MSc, Postgraduate Diploma and Postgraduate Certificate courses are truly international. We have always encouraged applicants from beyond the UK because the different working experiences and cultures students bring with them enhance the entirety of the course. All students therefore learn about each others' different funding arrangements for palliative care and related services, service configurations and their respective challenges, interventions to manage care, as well as the diversity.

Many students who have successfully completed the course have gone on to achieve promotion within their respective professions. Of these students a large number have attributed their progression directly to the course experience. For more detail about the perceived added-value of the MSc in Palliative Care please refer to the recent evaluation of the MSc published in the *Journal of Palliative Care*.155

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2004
The effectiveness of the respiratory nurse specialists’ role for people with chronic obstructive pulmonary disease: a systematic review
Judy Mulligan

An exploratory study of bereaved grandparents’ experience of losing a grandchild to a primary central nervous system tumour
Mandy Reynolds

The timing of the do-not-attempt-resuscitation decision for cancer patients in an acute oncology setting: how early is too early, how late is too late?
Ann Muls

The management of depression and irritability and aggression in people with Huntingdon’s disease - a systematic review of the literature
Rachel Taylor

The very old who die from cancer: epidemiology and place of death in England and Wales (1995 - 1999)
Anna Lock

The impact of weight loss on body image in advanced cancer
Ros Hinsley

What is the "pain" experienced by patients with heart failure and is there a role for specialist palliative care?
Katherine Thompson

Loss of appetite in advanced cancer patients: a retrospective study of the impact on the informal spouse-carer and their perception of intervention instigated by health professionals
Ginette Pilkington

Palliative care needs at a district general hospital: the view of patients, carers and health professionals. A descriptive epidemiological survey
Joan Hester

Continuing care provision for palliative care patients
Stella Whitehouse

A pilot study to assess the effectiveness of palliative care clinic in improving the quality of life for patients with severe heart failure
Paul Paes

2005
A qualitative study on attitudes of nursing staff to nursing patients with severe late Parkinson's disease
Phillip Jones

Attitudes of health care professionals to the palliative care needs of people with end-stage dementia.
A pilot study.
Juliet Hately

The thoughts and concerns of young people with advanced cancer; the barriers encountered in conducting palliative care research
Katharine Williamson

Dying to be at home: relatives’ perceptions of caring for a loved one or dependent with advanced cancer at home - meta-ethnographic review of qualitative papers
Mandy Stratford

Drug interactions in palliative care: how much harm do we do? The results from the palliative care unit in the county hospital of St Gallen, Switzerland
Daniel Buche

Physicians’ attitudes towards prognostication
Lotte Rogg

Palliative Care Outcome Scale (POS) - a pilot study in Dover Park Hospice: is it applicable in the Singapore setting?
Ee Wan Toh

A systematic review to assess the quality of the research evidence investigating the effectiveness of palliative radiotherapy in the control of ambulatory function in patients with metastatic spinal cord compression.
Louise Armstrong

A study to investigate the use and experiences of general practitioners of the palliative care services in the Bromley PCT
Sabrina Bajwah

A qualitative investigation into health care professionals' experiences of performing last offices and attitude towards carrying out this procedure with family members
Mary Macadie

Prospective randomised controlled trial: comparing winged vialon cannula with soft-set cannula for continuous subcutaneous infusion in palliative care
Rosemary Herbert

Is the Support Team Assessment Schedule (STAS) a good choice as a clinical audit tool in the specialist palliative care unit?
Liam O'Siorain

A systematic literature review to determine the effectiveness of administering megestrol acetate to cachexic-anorexic patients with advanced non-hormone sensitive cancer
Nicola Bland

Unmet needs in home palliative care: is there a role for communication technologies?
Penny Carleton

Evaluating the effectiveness of a palliative care link nurse system in an acute hospital
Annemieke Fox
2006
An exploration of palliative care nurses’ decision-making in the use of pro re nata (as needed) sedation
Pauline Ui Dhuibhir

Coping with loss. Do religious or spiritual beliefs influence bereavement? A systematic review
Gerhild Becker

Specialist palliative care in the adult intensive care unit: a multi-method project to investigate the need for integrating a specialist service into the ICU of a heart and lung hospital
Josephine Archer

Outcomes of palliative care in Sub-Saharan Africa - initial steps in the development of an outcome measure
Karen Frame

Multi-Disciplinary perspectives of music therapy in adult palliative care
Julian O’Kelly

Developing and testing a model of place of death in a macro-analysis of the trends in home death
Barbara Gomes da Silva

A research study to explore how bereaved families experience the use of cold bedrooms that enable their child to remain at a children’s hospice from the time of their death up to the funeral
Lynne Forrester

A description of the implementation of NICE guidelines on the palliative care of patients with chronic cardiac failure: an exploratory study in a community Setting
Nigel Konzon

Efficacy of intranasal ketamine for the treatment of breakthrough pain in patients with cancer pain: a randomised double-blind, placebo-controlled, crossover study
Birgit Haberland

Decision-making processes in adult Charedi Ashkenazi patients with cancer; an interpretative phenomenological analysis
Catharine Coleman

Complementary and alternative medicine (CAM) in metastatic colorectal cancer patients receiving chemotherapy
Tanja Trarbach

Supportive and palliative care for adults with Cystic Fibrosis - the perceptions of their bereaved parents
Kate Heaps

A pilot study to determine the effectiveness of electro-acupuncture as an adjunctive treatment to control neuropathic pain in patients with cancer and diabetes
Ollie Minton

2007
Interprofessional and inter-agency communication and cooperation in an ambulatory and hospital concept of palliative care provision for cancer patients in Germany - a qualitative study of health care professionals’ perception
Sabine Bader

The use of clinical supervision by palliative medicine consultants – a questionnaire survey
Chi-Chi Cheung

A survey of the attitudes and beliefs of patients regarding cancer associated weight loss and weight assessment
Simon Coulter

A systematic literature review to determine the analgesic effectiveness of topical administration of opioids in the palliative care setting – the role of case reports in evidence based medicine.
Beata LeBon

How is the meaning of life articulated in palliative care patients?
Natalia Lorenzo Garcia

Death and Dying in hospital – experiences of older people and their families
Annelise Matthews

A pilot study using a multiple case study design to evaluate the theory of dry wound management in palliative care using the product Youki
Jane McManus

Exploring the palliative care knowledge and symptom control skills of British Heart Foundation heart failure nurses
Deborah O’Hanlon

Does education of palliative care professionals improve confidence levels of health care assistants when caring for dying patients and their families?
Jackie Aaron

The management of death rattle in dying cancer patients
Eleni Karatzia-Chrysostomou
5.4 Undergraduate Education
The King’s College London School of Medicine, at Guy’s, King’s and St Thomas’ Hospitals is one of the largest medical providers of health care education in Europe, with over 400 medical students in each year. Dr Polly Edmonds and Dr Rachel Burman have led 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, special study modules (SSMs) and bedside clinical teaching to the hospice visits in year five. Using a variety of teaching techniques in all of the sessions, the course is always very well evaluated. It provides a comprehensive coverage of the undergraduate curriculum, which is unique for Palliative Medicine both in its range and time allocated.

The most innovative aspects of the undergraduate curriculum are the year five hospice visits and special study module (SSM) opportunities. The final year hospice visit, developed in partnership with St Christopher’s Hospice, Trinity Hospice and Pilgrim’s Hospice in Canterbury, 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 health care settings. During the visit students meet day centre patients as part of the highly rated goldfish bowl session. Other hospices involved in these visits over the past three years include St Michael’s Hospice in Hastings and The Martlet’s Hospice in Brighton.

Four SSMs are offered in year four of the curriculum: the management of pain in advanced cancer; the management of anorexia and cachexia in advanced cancer; the ethics of withdrawing and withholding treatment in advanced cancer and a generic palliative care SSM, delivered in conjunction with St Christopher’s and Trinity Hospices. This SSM has been designed to give interested students more detailed exposure to palliative care by attending palliative care ward rounds with the hospital palliative care team 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 SSM is in its second year and has been well evaluated by participating students.

In addition to the formal undergraduate curriculum, elective placements have been undertaken for GKT and overseas students at King’s (with the hospital palliative care team and academic department), Trinity Hospice and St Christopher’s Hospice.

Dr Edmonds is also deputy head of year 4 and the year 4 OSCE co-ordinator.
The Department is working with Cicely Saunders International, King’s College London and associated hospitals to establish the world’s first purpose built institute of palliative care, a centre of excellence housing research, education, information, support and clinical care. The Cicely Saunders Institute of Palliative Care will bring together academics, healthcare professionals, community organisations, patients and carers in one centre and will act as the hub for a network of international research. By providing a comprehensive approach to the physical, social and psychological needs of people with progressive illness, the Institute’s research will feed quickly and directly into practice and policy around the world – improving palliative care and enabling people to live better, with dignity and the least possible suffering.

The Institute will be a welcoming and peaceful environment, sensitively designed in line with the principles of palliative care and in consultation with potential groups, patient groups and Macmillan Cancer Relief.

The 1,600 m² of floor space will provide:

- Office space for over 90 staff, including researchers, clinical staff and several professors in palliative care, rehabilitation and related disciplines.
- Teaching space, including seminar, tutorial and workshop rooms and a lecture theatre.
- An information and support centre for patients, carers and healthcare professionals.
- Space for clinical palliative care and cancer staff, including offices, therapy rooms and clinical/consultation rooms.
- A video conferencing suite for international lectures and seminars.

It is essential that the planning of the Institute reflects and serves the interests of patients and their carers. To achieve this, and to ensure that patients and families continue to contribute to our activities, we have implemented a strategy for user involvement. We have held a number of meetings involving local patient groups such as Black Cancer Care, along with a user involvement workshop. We hope that these activities will ensure that patients and their carers can guide and participate in our vision for the Institute.

Building plans are now well advanced. The first brick will be laid in 2008, with completion of the building anticipated in 2009. On the ground floor we will be displaying some of the letters, photographs and books of Dame Cicely Saunders which are held in the King’s College London Specialist Archive at the Strand campus. We are very grateful to the private individuals, foundations and other donors who have contributed so far to the project, including: The Garfield Weston Foundation, The Wolfson Foundation, Macmillan Cancer Support, Atlantic Philanthropies, PF Charitable Trust and The Kirby Laing Foundation.

Cicely Saunders International is an international charity created in 2002 by Dame Cicely Saunders, the founder of the modern hospice movement. Cicely Saunders International supports high-quality research and education to improve the care and treatment of all people with progressive illness, helping them to reach the end of their lives with dignity and with the least possible suffering see www.cicelysaundersfoundation.org.
Research Collaborations, External Committee Work and International Keynote Lectures

7.1 Collaborations
The department benefits from, and is part of, extensive collaborations in research, teaching and clinical activity. These are too many to mention, but some new major collaborations are described.

COMPASS Collaboration
This collaborative was funded by the National Cancer Research Institute (NCRI) in May 2006 for five years, with the intention of developing collaborative research projects, to submit for grant funding.

The COMPASS (COMPLEX interventions: Assessment, trialS and implementation of Services) Collaborative seeks to:
• unite researchers from 12 UK universities, and more than 65 affiliated individuals or organisations, and
• create a strong research grouping that can effectively research the development, evaluation and implementation of supportive and palliative interventions.

COMPASS is led jointly from three Universities: King’s College London, University of Edinburgh and University of Leeds. The collaborative and its work on interventions span the whole trajectory of cancer care, from pre-diagnosis to longevity or terminal care and bereavement. The research has three main strands – assessment (led by Higginson at King’s), interventions and implementation (led by Ramirez, also at King’s). In addition there is a Masterclass programme of seminars and capacity building. The work on assessment links appropriately with the existing expertise in outcome measurement.

European Palliative Care Research Collaboration (EPCRc)
As part of a European collaborative, work is being taken forward to improve the management of three symptoms. Led by Professor Kaasa in Norway the group includes experts in 10 centres across Europe. The research plan of the EPCRc is based upon questions raised in the clinic, with focus on cancer palliative care patients, thus using a “true” translated approach. The research focuses both on diagnosis and classification of these symptoms and understanding of the underlying mechanisms. To achieve the aims of EPCRc a multidisciplinary approach was needed, bringing together basic scientists and clinicians that will translate human genome data into practical applications for these patients. Assessment and classification of pain, depression and cachexia (fatigue) are the basis for diagnosis and subsequent treatment. By use of modern methods of molecular biology the project seeks to increase the understanding of the role of genetic variability for pain and cachexia. European evidence based internet guidelines will be developed by members of the EPCRc supported by an international advisory board. By recruiting a pan European panel, cultural, social and language barriers will be taken into consideration in the early phase of the guideline development. At King’s, Higginson, with Professor Hotopf (Institute of Psychiatry) are leading the strand on the development of clinical guidelines for the management of depression, and providing input into the work on improving the assessment of depression. A first step is a Cochrane review into the effectiveness of antidepressants.

Breathlessness Collaborations
As part of the project supported by Cicely Saunders International we are establishing a Breathlessness Collaboration. We are developing a database of relevant work and extend collaborations with others working in this field. The breathlessness programme is working together productively with several other projects on breathlessness: (1) a study on palliative care needs of patients with COPD, led by Dr. White, and supported by the Charitable Foundation of King’s College London, to which Dr Gysels is a co-applicant and participant on the Advisory Committee of the project; (2) contact and support is provided to a project undertaken at Imperial College London on the development of a multidimensional measurement tool for dyspnoea.

As part of this we organised a joint meeting with the Medical Research Council in 2005+6, an international conference on Breathlessness in November 2006, and a think-tank/workshop in 2006 with additional support from the Novartis Foundation.

Partnerships, Research and Capacity Building in Africa
We have forged productive relationships with partner agencies across Africa, and international funders, to generate research activity and enhance research capacity in Africa.

In recent years the palliative care movement has made enormous strides in teaching, providing and advocating for palliative care in Africa. The HIV epidemic has greatly increased the requirement for palliative care and is the leading diagnosis for most services. However, cancer and other non-malignant diseases also contribute greatly to the required public health response to palliative care in Sub-Saharan Africa.

Our close partnership with two key organisations in Africa, the African Palliative Care Association (APCA) and the Hospice Palliative Care Association of South Africa, have been very rewarding and a great source of learning, for both sides.

We were very pleased to attend Archbishop Desmond Tutu’s birthday party at the British High Commission, hosted by KCL, to celebrate the life and work of our alumni member and to look forward to KCL’s support in digitising his archive.

We believe strongly that while our priority is to develop evidence and evaluation methods that are relevant and appropriate to Africa, this is best achieved through partnerships to enhance the capacity for the African palliative care community to conduct and report its own research activity.

We have had a number of successes in capacity building. Firstly, a Union Internationale Contre Cancer
This year we have the first students from Africa attending our postgraduate education and we hope that this will continue to be a route to enhance research methods and other specialist knowledge that can be shared by attendees in their home countries.

A particularly important development has been the appointments of the first palliative care research nurses in Africa, under a grant from the Big Lottery to Cicely Saunders International and King’s College London. We have been able to offer these specialist staff protected contracts to focus on research and quality improvement, and they have produced high quality research data in a number of areas. This very enjoyable and successful partnership is an innovative model we hope to expand, and the opportunity to attend locally-delivered research training from KCL staff has been particularly appreciated by the nurses.

**King’s Centre for Palliative Neurology**

The King’s Centre for Palliative Care in Neurology (KCPN) is an exciting development that builds on internationally recognised clinical and academic expertise in neurology and palliative care at King’s College London. Nowhere have these two activities been thoroughly integrated, despite evidence that many patients with long term and progressive conditions benefit from integrated approaches to care. The KCPN and the component departments have wide-ranging collaborations, with many hospitals, hospices, community services – too numerous to list. In addition there are collaborative projects with researchers and educators in many academic institutions and national and international organisations. The Centre is led by Professor Irene Higginson and Professor Nigel Leigh as Co-Directors, assisted by an executive team comprising key partners from the departments of Neurology, Palliative Care, Policy and Rehabilitation, and from King’s College Hospital NHS trust. The Management Advisory Group comprises representatives of relevant user groups and of the wider academic, clinical, community and national partnership. In addition the Directors and Management group are advised by a Scientific Board to foster collaboration between research programmes and organisations. Current members on the Scientific Board include representation from the Motor Neurone Disease Association, Parkinson’s Disease Society, Multiple Sclerosis Society, Royal Hospital of Neurodisability and clinicians and academics from a variety of settings.

**A Consortium for Neuro-palliative Rehabilitation (NPR)**

People often think of rehabilitation as a short-term intervention to restore someone to independence after an accident or injury. However, in the context of neuro-degenerative diseases, many people have profound and complex neurological disability (P&CND) and rehabilitation in this setting is focused on improving quality of life for patients and their carers, often against a backdrop of deteriorating physical, cognitive, communication and psychosocial function. It is a life-long process, which we have termed ‘neuropalliative rehabilitation’.

A UK Consortium for Neuropalliative Rehabilitation has recently been established which has its principal academic base within the Centre for Palliative Neurology within King’s College London. The consortium brings together the three leading UK clinical centres for P&CND, covering a large catchment population in the south east quarter of England, and is led by:

- Professor Lynne Turner-Stokes (NW London Regional Rehabilitation network),
- Professor Keith Andrews (RHN London Regional Rehabilitation network),
- Professor Derick Wade (Oxford Centre for Enablement).

The consortium already co-ordinates a London and SE England research group for collaborative and multi-centre research into complex neurological disorders, and in collaboration with the British Society of Rehabilitation Medicine (BSRM), setting up a national network of rehabilitation units involved in research in this area. In addition to its UK membership, the consortium has collaborative links internationally with key researchers in the USA, Australia, New Zealand and the Netherlands.

The purpose of the consortium is to undertake a co-ordinated health services research programme in Neuro-palliative Rehabilitation to address innovation and interventions to empower and support people with complex neurological disabilities following brain injury and other related long term neurological conditions.

The programme supports evidence-based services which improve the quality of long-term care offered to patients and their families, in line with user demand and with Government policy which emphasises patient choice, user-centred interventions and outcomes, integrated multi-agency care, and long-term evaluation.

### 7.2 Involvement in External Committees

**2004/5 – 2006/7**

**Professor Irene Higginson**

**Chair**

- MS Society Applied Research Panel

**Membership**

- Canadian Institutes for Health Research
- Multiple Sclerosis Society Grant Review Panel
- Dunhill Medical Trust Grants and Research Committee
- National Cancer Research Institute Palliative Care Study Development Group (and Primary Palliative Care and Breathlessness subgroups)
- Cancer Research UK Feasibility Committee
- Macmillan Cancer Support Observatory Group
- Motor Neurone Disease Association Clinical Advisory Group
- Guy’s and St Thomas’ Charitable Foundation Service Innovations and Development Group
- Association for Palliative Medicine Science Committee
- General Medical Council Guidance on Withholding and Withdrawing Treatment

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award enabled Richard Harding to attend Hospice Africa Uganda to teach nurses on the Distance Learning Diploma. The week-long module on research methods was very successful and attended by nurses from across East Africa.
• International Psycho Oncology Society National Scientific Committee for 2007 World Congress
• European Association for Palliative Care Scientific Committee for 5th Forum on Research
• HEFCE Research Assessment Exercise Panel – Sub-panel 2, Cancer Studies
• COMPASS Collaborative Management Board

Professor Lynne Turner-Stokes
Chair
• Research and Clinical Standards Subcommittee, British Society of Rehabilitation Medicine
• Multi-professional and Health Service Research Group, NWLHT
• London Neurosciences Modernisation Team: Neuro Rehab Executive Working Group
• Guideline Development Group for updating guidelines for use of botulinum toxin in spasticity management, BSRM / RCP guidelines
• Healthcare Resource Group (HRG) Expert Working Panel for rehabilitation, implementing Payment by Results
• Research and Evidence Subgroup for the National Service Framework in Long-Term Conditions
• London Neuro-rehabilitation Specialised Commissioning Consortium: Chair of Clinical and Audit Committee
• External Reference Group for the National Service Framework in Long-Term Conditions (Deputy Chair)
• Research Evidence Subgroup for the National Service Framework in Long Term Conditions

Membership
• Royal College of Physicians (RCP) Rehabilitation Medicine Committee
• Medical Defence Union Council and Cases Committee
• RCP Joint Specialist Society Clinical Effectiveness Forum
• Expert Working Group: Payment by Results. Chapter A (Nervous System)
• Northwick Park Institute of Medical Research Academic Board
• NWLHT Clinical Governance Committee
• NWLHT R&D Executive Committee
• NWLHT R&D Peer Review Committee
• NW London Sector Specialist Commissioning Group for Neurosciences
• Pan London Neuro-rehabilitation Specialist Commissioning Group
• Trust Board for the Institute of Complex Disability, Royal Hospital for Neuro-disability, Putney
• BSRM working party for report on Musculo-skeletal Rehabilitation
• RCP working party: Chronic Disease Management in the NHS
• Working party: Guidelines for referral for spasticity management
• Access to rehabilitation: a group convened by the Civil Justice Council
• National Institute for Palliative Care: Long Term Neurological Conditions Committee

Dr Polly Edmonds
Membership
• London/Kent Surrey Sussex Speciality Training Committee for Palliative Medicine (Director)
• Southeast London Cancer Research Network
• NCRI Breathlessness Subgroup
• King’s College Hospital Cancer Services Committee and Cancer Management Team
• Specialist Medicine Care Group
• King’s College Hospital Clinical Effectiveness and Audit Committee
• Southeast London Cancer Network Palliative Care Coordinating Group
• Southeast London Cancer Network Upper GI Cancer Subgroup
• Lambeth and Southwark Cancer Forum
• London Regional Group of the National Council for Hospice and Palliative Care Services

Dr Rachel Burman
Membership
• London/Kent Surry Sussex Speciality Training Committee for Palliative Medicine (Director)
• King’s College Hospital Resuscitation Committee
• St Christopher’s Hospice Ethics Committee
• University of London Senate Subject Panel in Medical Ethics

Dr Richard Harding
Membership
• International AIDS Society
• African Palliative Care Association
• International Association of Hospice Palliative Care
• Worldwide Forum for Hospice and Palliative Care

Jonathan Koffman
Membership
• Palliative Care Section, Royal Society of Medicine
• Research Ethics Committee, King’s College London/ St Christopher’s Hospice

Dr Sue Hall
Membership
• NCRI Brain Tumour Studies Group Palliative Care Sub-group

Dr Fliss Murtagh
Membership
• Working Party on use of the Liverpool Care Pathway for Renal Patients

Dr Morag Farquhar
Membership
• NCRI Palliative Care Breathlessness Sub-Group

Dr Claudia Bausewein
Membership
• Advisory Board for Palliative Medicine in Bavaria for the Bavarian Ministry for Work, Social Services, Family and Women (Board Member)
• German Association for Palliative Medicine (Vice-president)
7.3 International and Keynote Lectures

2004

**Professor Irene Higginson**


Latest progress with the Palliative Care Outcome Scale (POS). 12th Palliative Care Study Day, Norfolk and Norwich University Hospital, Norwich. Park Farm Hotel, Norwich. November 2004.


Advancing palliative care for the world’s aging population. Harold Hatch International Lecture in Geriatrics and Oncology, International Longevity Center, Mount Sinai, New York, USA. April 2004.


**Professor Lynne Turner-Stokes**

How to be an effective expert witness. Workshop: Doctors Update, Belle Plagne, France. Feb 2004.


2005

**Professor Irene Higginson**


Palliative Care, Ageing and Research at King’s: ARK. Wolfson Centre for Age-Related Disease, King’s College London. October 2005.


Hospice Education Institute Hospice and Palliative Care Study Seminar. King’s Fund, London. March 2005


**Jonathan Koffman**


2005

**Professor Lynne Turner-Stokes**


Dr Richard Harding


We were delighted that the International AIDS Society held a special session on palliative care at its conference in Toronto in August 2006, where Dr Richard Harding was an invited panel speaker.

Dr Fliss Murtagh


Jonathan Koffman


2006

Professor Irene Higginson

Being at home at the end of life: is it better? Lecture for receiving the Mendelssohn Award for outstanding contribution to palliative care. 10th Annual Interdisciplinary Approach to Symptom Control, Palliative and Hospice Care Conference. MD Anderson Cancer Centre, Texas, USA. October 2006.

Extending palliative care beyond cancer: past, present and future (Plenary lecture) plus 3 workshop sessions - Non-Cancer end of life care – Discussion; Overview of measurement tools for quality improvement and care in palliative care; Dying at home – making it an achievable goal; Cicely Saunders International – Future Plans. 16th International Congress on Care of the Terminally Ill. Palais des Congress, Montreal, Quebec, Canada. September 2006.


Professor Lynne Turner-Stokes


Dr Richard Harding


Jonathan Koffman

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16. HIGGINSON IJ, DONALDSON N. Relationship between three palliative care outcome scales. *Health and Quality of Life Outcomes* 2004;2:68-75


26. Lowton K. Only when I cough? Adults’ disclosure of cystic fibrosis. *Qualitative Health Research* 2004;14:167-186


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PUBLICATIONS IN OTHER JOURNALS


MEETING ABSTRACTS


353. Beccaro M, COSTANTINI M, Merlo F. Inequity in the provision of and access to palliative care services for cancer patients in Italy. Results from the Italian survey of the dying of cancer (ISDOC). European Journal of Palliative Care 2007: EAPC


357. FARQUHAR MC, BOOTH S, Fagan P, HIGGINSON IJ. Developing a breathlessness intervention service using the MRC framework for the development and evaluation of complex interventions. European Journal of Palliative Care 2007: EAPC


360. GOMES B, HIGGINSON IJ. How and where will we die by 2030: an analysis of future needs in an ageing population. European Journal of Palliative Care 2007: EAPC


362. GYSELS M, HIGGINSON IJ. Coping with breathlessness through self-management by COPD patients. European Journal of Palliative Care 2007: EAPC

364. HARDING R, SELMAN L, Beynon T, Hodson F, Coady E, Hazeldene C, HIGGINSON IJ. Improving end of life care for chronic heart failure patients: let’s hope it’ll get better, when I know in my heart of hearts it won’t? European Journal of Palliative Care 2007:EAPC

365. HIGGINSON IJ. Guidelines for depression in palliative care: current challenges and research agenda. Representing the EPCRC research group. European Journal of Palliative Care 2007:EAPC

366. HIGGINSON IJ. Developing a common language towards consensus based quality palliative care – Why are definitions important? European Journal of Palliative Care 2007:EAPC


370. MURTAGH FEM, ADDINGTON-HALL JM, EDMONDS PM, Donohoe P, Jenkins K, HIGGINSON IJ. Renal patients have symptoms too – a cross-sectional survey of symptoms in stage 5 chronic kidney disease managed without dialysis. European Journal of Palliative Care 2007:EAPC


375. SALEEM T, Leigh N, HIGGINSON IJ. Symptom prevalence against people affected by advanced and progressive neurological conditions – a systematic review. European Journal of Palliative Care 2007: EAPC


379. SPECK PW. Team working – fulfilling or frustrating. European Journal of Palliative Care 2007:EAPC

PUBLICATIONS IN PRESS


381. GYSELS M, BAUSEWIEN C, HIGGINSON IJ. Experiences of breathlessness: a systematic review of the qualitative literature. Palliative and Supportive Care

382. HALL S, Marteau TM. Practice nurses’ reports of giving opportunistic smoking cessation advice in three contexts. Nicotine and Tobacco Research


385. LONGHURST S, KOFFMAN J, SHIPMAN C, Taylor E, Dewar S. Helping people access information at the end of life: evaluating a helpline. King’s Fund Publications

386. MAGEE WL. Music as a diagnostic tool in low awareness states: Considering limbic responses. Brain Injury

387. MAGEE WL. A comparison between the use of songs and improvisation in music therapy with adults living with acquired and chronic illness. Australian Journal of Music Therapy

388. MURTAGH FEM, Chai MO, Donohoe P, EDMONDS PM, HIGGINSON IJ. The use of opioid analgesia in end-stage renal disease patients managed without dialysis: recommendation for practice. Journal of Pain and Palliative Care Pharmacotherapy

389. SELMAN L, HARDING R, Beynon T, Hodson F, Coady E, Hazeldine C, Walton M, Gibbs L, HIGGINSON IJ. Improving end of life care for chronic heart failure patients. "Let’s hope it’ll get better, when I know in my heart of hearts it won’t". Heart BMJ
390. SELMAN L, HARDING R, Hodson F, Coady E, Beynon T. Modelling services to meet the palliative care needs of chronic heart failure patients and their families: current practice in the UK. *Palliative Medicine*

391. TURNER-STOKES L, Disler R, WILLIAMS H. The Rehabilitation Complexity Scale: a simple, practical tool to identify ‘complex specialised’ services in neurological rehabilitation. *Clinical Medicine*

392. WILLIAMS H, Harris R, TURNER-STOKES L. Can the Northwick Park Care Needs Assessment be used to estimate nursing staff requirements in an in-patient rehabilitation setting? *Clinical Rehabilitation*


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The Weston Foundation
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Macmillan Cancer Support
PF Charitable Trust
Atlantic Philanthropies
Developments in Staffing

During this period we welcomed many new staff, or ones returning into more senior roles. Academic Rehabilitation, led by Professor Lynne Turner-Stokes, joined forces with Palliative Care in 2003, but over the last three years the department has expanded to include a further part-time chair (Professor Derick Wade), a Senior Lecturer, Senior Clinical Research Fellow and four honorary Research Fellows. Through their respective clinical services in Northwick Park and Oxford Professors Turner-Stokes and Wade provide a broad clinical base for the research programme. A consortium formed in collaboration with Professor Keith Andrews in the Institute for Neuro-palliative Rehabilitation, Putney, provides the largest research group for complex neurological disability in the UK (see section 7). In addition, two Visiting Chairs (Professor Peter Disler (Australia) and Professor Kath McPherson (New Zealand)) support the active research programme.

In Palliative Care, Dr Richard Harding was appointed as a new Lecturer in Palliative Care, and was promoted to Senior Lecturer in September 2007. Dr Sue Hall, a health psychologist, was appointed as a new Lecturer in Palliative Care to work on a new programme on palliative care for older people supported by the Dunhill Medical Trust and Cicely Saunders International. Dr Gao Wei is a new Statistician in Palliative Care, part funded by King’s College London and part by the new five year collaborative in Supportive and Palliative Care from the UK National Cancer Research Institute, which we co-leading with colleagues across King’s, Leeds and Edinburgh Universities. In 2007 Professor Massimo Costantini and Professor Peter Fayers were both appointed as Visiting Professors for a period of five years. We also benefited from working with individuals who spent several months with us on sabbaticals, including Dr David Gruenewald from the United States, Dr Joao Paulo Solano from Brazil, and medical students Troy Cartwright and Michael Walton.

We have also said farewell to some significant members of our group. Often they have moved on to new, more senior posts. However, we continue to collaborate with many individuals, because of continuing and sometimes new projects, through honorary contracts and because happily for us some have remained close by with King’s College London. There are too many to mention, but they include Professor Julia Addington-Hall, who moved to take up a chair in End of Life Care in the School of Nursing at the University of Southampton. Within King’s College London, Dr Nora Donaldson was awarded a Readership in Statistics in the School of Dentistry and Dr Elizabeth Davies a Senior Lectureship in the Thames Cancer Registry. We congratulated three successful PhD graduates, Dr Jean Potter, supported for three years from Mrs Coco Marcus, who has now taken up a new post as consultant in palliative medicine, Dr Christine McPherson, who is now following a career in palliative care research in Canada, and Dr Jo Armes, who took up a post in the School of Nursing, King’s College London.
Staff Biographies

Professor Irene Higginson  BMedSci BMBS FFPHM  PhD FRCP  
Professor of Palliative Care and Policy,  
Head of Department of Palliative Care,  
Policy & Rehabilitation, Honorary Consultant  
King’s College Hospital

Irene qualified in medicine from the University of Nottingham and won her PhD from University College London. She has extensive experience in leading national and international multidisciplinary collaboration in palliative care. She has dual training in palliative medicine and epidemiology/public health having worked in a wide range of medical settings, hospices and in public health and health services research. For the past ten years she has been Head of Department and Professor of Palliative Care and Policy at King’s College London and prior to that was Director of Research and Development in a London health authority, as well as Senior Lecturer at the London School of Hygiene and Tropical Medicine. She is currently leading the assessment strand of one of the two collaboratives in supportive and palliative care, leading the strand on assessment and measurement. This collaborative (COMPASS – Complex Interventions: Assessment, Trials and Implementation of Services) brings together over 61 Universities and associated hospitals, hospices and other services in the UK, and seeks to foster collaboration of research in supportive and palliative, including end of life, cancer care. In addition, Irene co-ordinated the production of the WHO guidance on palliative care (Palliative Care – The Solid Facts, Better Palliative Care for Older People). This project, undertaken for the WHO in Europe, in collaboration with the European Association of Palliative Care, and the European Institute of Oncology, brought together evidence from over 15 countries and wide ranging literature to provide guidance on ways to improve palliative care for the future. Irene is a member of the European Palliative Care Research Collaborative (EPCRC). She has over 180 scientific papers published in peer review journals, has published 14 books on palliative and end of life care. She is an advisor to many governments in research and policy in palliative care, including recently reviewing for the Italian Ministry of Health, as well as being an advisor on the end of life care proposals in the United Kingdom and led the development of the National Institute of Clinical Excellence (NICE) Guidance for Supportive and Palliative Care for those affected by cancer. She is currently leading the scoping exercise for the NHS Service Delivery and Organisation programme on identifying the research needs on the delivery and organisation of generalist services for end of life care.

Sarah Baber  
Executive Assistant to Professor Higginson /  
Department Manager

Sarah is Professor Higginson’s Executive Assistant and is usually the first point of contact for Professor Higginson. She is also Department Manager and manages the administrative staff.

Sarah has a BA English from Sussex University. After graduating she worked briefly at Kingston University in the Faculty of Health, in the Curriculum and Quality Office. She then went onto work at London South Bank University as a Faculty Quality Assurance Administrator in the Faculty of Arts and Human Sciences. Sarah began working at King’s College in July 2007.
Professor Lynne Turner-Stokes DM, FRCP
Herbert Dunhill Chair of Academic Rehabilitation, Head of Department 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 accredit 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 co-ordinated network of specialist rehabilitation services across North-West Thames. Within this network, the RRU act 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 KCL in 2001, with a view to developing a two-site academic department of rehabilitation between KCL and Northwick Park. Academic Rehabilitation joined forces with the Department of Palliative Care and Policy in 2003. Her 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. She is on the editorial board of Clinical Rehabilitation and is guest editor of the series ‘Concise Clinical Guidelines’ for Clinical Medicine. Lynne has a major interest in the development of NHS policy to improve rehabilitation services in the NHS. 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 research towards implementation of the NSF. She 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.

Stephen Ashford MSc MCSP
Clinical Specialist in Physiotherapy

Steve qualified in Physiotherapy at Salford University 1993 and undertook a part-time MSc in Neurorehabilitation at Brunel University between 1996 and 1998. He was a sessional lecturer at Brunel University, while working clinically, and undertaking a Post Graduate Certificate in Education between 1998 and 2001. He became course co-ordinator for the MSc in Neurorehabilitation at Brunel University from 2001 until 2003, while working clinically on the Regional Rehabilitation Unit, Northwick Park Hospital. In October 2003, he moved full time to the Regional Rehabilitation Unit, Northwick Park Hospital to conduct research on the functional evaluation of outcome following spasticity management intervention. Steve is currently registered for a PhD at King’s College London, Department of Palliative Care, Policy and Rehabilitation. Research interests include the evaluation and measurement of functional outcome in the upper limb following focal interventions and this is the focus of his PhD thesis. Other research interests include evaluation of the effectiveness of botulinum toxin intervention in the hemiparetic upper limb and management of complex disability.

Stephen’s current clinical role involves co-ordinating the outreach service from the Regional Rehabilitation Unit at Northwick Park Hospital Harrow and the related spasticity management service. The service provides consulting input to professionals, patients and families in the management of complex neurodisability including spasticity.
Dr Stephen Barclay  MA MB BCh MSc FRCGP MD
Honorary Senior Lecturer

Stephen joined the Department as an Honorary Senior Research Associate in 2002, becoming Honorary Senior Lecturer in Primary Palliative Care in the Department in 2006. He works as a General Practitioner in Cambridge, where he is also Honorary Consultant Physician in Palliative Medicine at the Cambridge Hospice, Specialty Director for Palliative Care teaching in the Clinical School and Macmillan Post-Doctoral Research Fellow in the University General Practice and Primary Care Research Unit. His research focuses on Palliative Care in the Primary Care setting, and he has collaborated with Cathy Shipman and Julia Addington-Hall over several years.

He was awarded the University of Cambridge Ralph Noble prize for his MD thesis entitled “General Practitioner provision of Palliative Care in the United Kingdom” in 2005 and in 2006 was granted a Department of Health / Macmillan Post-Doctoral Fellowship, which is to be at the Kings Department part of the time.

Dr Claudia Bausewein  MD MSc
Cicely Saunders International Research Training Fellow

Claudia went to Medical School at the University of Munich. She completed her MD on the situation of terminally ill cancer patients on admission to hospital. Although her background is internal medicine, she has been involved in Palliative Care in Germany for 15 years. She is now working as a consultant in palliative medicine at the Interdisciplinary Centre for Palliative Medicine at the University of Munich. Claudia is Vice-President of the German Association for Palliative Medicine and co-editor of the German Journal for Palliative Medicine. Claudia completed the MSc in Palliative Care at KCL in 2003. Her research project focussed on the validation of the German version of the Palliative Care Outcome Scale. Through the MSc Claudia developed her interest in research and undertook more training in research methods. She is currently undertaking a PhD funded by Cicely Saunders International focusing on breathlessness, looking particularly into the course of breathlessness in patients with COPD or cancer and their relatives. Within her PhD Claudia conducted a systematic review on measurement of breathlessness and is currently undertaking a Cochrane Review on non-pharmacological interventions in breathlessness in advanced disease. Besides breathlessness her main research and clinical interests are palliative medicine for non-oncological patients, pharmacotherapy and subcutaneous application of drugs.
**Sian Best**  
BA  
Department Administrator

Sian has a BA Hons from the University of Warwick. After spending a year in postgraduate teacher training, she decided that she would prefer a career in publishing. She has worked mainly in publishing, initially in marketing and public relations, and then as a picture researcher and picture editor for national newspapers and magazines. She was also a company secretary. She joined King’s College London part time in 2005, helping to organise a series of conferences for the Social Care Workforce Research Unit, and moved to the Department of Palliative Care, Policy & Rehabilitation in July 2005. She is responsible for the administration of the MSc, PG Diploma and PG Certificate in Palliative Care. There are currently 49 students enrolled on the course. Sian is also responsible for the administration of research grants, financial transactions including purchasing, and for the general administration of the department.

**Dr Sara Booth**  
FFARCSI and FRCP  
Honorary Senior Lecturer

Sara joined the Department in 2003 as an Honorary Senior Research Fellow, becoming an Honorary Senior Lecturer in Palliative Care in 2006. She is a Lead Clinician at Cambridge University NHS Hospitals Foundation Trust where she was appointed to set up a multi-disciplinary palliative care service. Sara has had an interest in breathlessness since her first post in palliative care at St Christopher’s Hospice in 1991 and has researched the topic of clinical management of breathlessness since then. This work led to the development of a Breathlessness Intervention Service at Addenbrooke’s which started seeing patients in 2003 and led to the collaboration with Professor Irene Higginson at King’s College London to research its effectiveness. During 2006/7 she has been the holder of a SuPaC Award to help develop her skills in clinical trials and research.

**Toki Allison**  
Secretary / Transcriber

After working in both the care and service industries, Toki gained a Foundation Degree in Media Practice at the London College of Communication, University of the Arts. She joined the department in August 2007 to assist as transcriber and secretary, specifically assigned to aid those researching the effects of the Gold Standards Framework for Care Homes.
Dr Rachel Burman  FRCP MA
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 multi-professional 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.

Emma Camplejohn  BSc
Project Assistant

Emma has a BSc Geography degree from Queen Mary’s, University of London. She joined King’s after completing her degree in July 2005 and is currently working as the Project Assistant for Dr Richard Harding and Dr Marjolein Gysels who have a number of research interests in palliative care.
Jo Clark  
Research PA to Professor Lynne Turner-Stokes  

Jo is the PA to Professor Lynne Turner-Stokes, working between sites of Northwick Park Hospital and the Weston Education Centre. She has qualifications at HNC level in Business and Computer Management. Previous to working for King’s College London Jo was the Clerical Assistant for the Therapy Teams on the Regional Rehabilitation Unit based at Northwick Park Hospital. She has also worked in varying positions in other multi-professional organisations.

Professor Massimo Costantini MD  
Visiting Professor  

Massimo qualified in medicine in 1985 at the University of Genoa (Italy). He spent the next five years specialising in oncology and training in clinical epidemiology at the National Cancer Institute (IST) of Genoa.

Since 1990 his main interests have focused on palliative care. He worked as a 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 of the National Cancer Institute, his research interests have increasingly focused on the areas of palliative care, quality of life, and psycho-oncology. He has published over 80 papers in peer-reviewed journals, and a number of book chapters on methodological aspects of palliative care research. His recent research activities have focused on studying multidimensional problems of terminal cancer patients and on investigating the effect of palliative care services on quality of care. He co-ordinated 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 provided care. As first step of a project funded by the Ministry of Health, he is co-ordinating the first Italian implementation of the Liverpool Care Pathway (LCP) for the dying in an Italian hospital. The programme involves a cluster-randomised trial aimed at assessing the effectiveness of LCP in improving the quality of end-of-life care in hospital.

Massimo is involved in Health Service development and assessment. He was a member of the study group of the Italian Ministry of Health that developed the national guidelines and standards for palliative care organisation. At present, he is co-ordinator of the regional group for development of the Palliative Care Network, with the mission to implement for each of the five Local Health Districts of Liguria a network of specialised palliative care services, quality assurance and total quality management programmes and, according to different
needs, educational programmes in palliative care. Massimo is a member of the Scientific Committee of the Maruzza Lefebvre d’Ovidio Foundation (Rome) leading the development of a qualified programme of research and teaching in palliative care. From 2002 to 2004 he was 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.

**Dr Polly Edmonds MBBS FRCP**
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.

**Dr Alison Evans PhD MSc**
Research Fellow

Alison completed her first degree in Psychology at University College London (1983 - 1986). She taught English in Spain and Japan and worked as a university administrator before returning to study to complete the MSc in Social Research Methods at City University (2000 - 2001). She went on to pursue her interest in research methods over the course of her PhD at City University (2003 - 2006) where she undertook a methodological investigation into use of the Internet as a social research tool for collecting data on sexual behaviour among gay and bisexual men. The PhD was supervised by Professors Dick Wiggins and Jonathan Elford and funded by the Economic and Social Research Council. Following this, she took up a one-year post-doctoral research fellowship at City University which provided the opportunity to develop her methodological research and publish work from her PhD thesis. She joined the department in 2007 and is currently working with Professors Irene Higginson and Matthew Hotopf on the development of evidence-based clinical guidelines for the management of depression in palliative care.
Dr Morag Farquhar BSc MSc PhD (Hons) RGN
Research Associate

Morag has worked in health services research for nearly 20 years, with the past 12 focusing on palliative care. During this time she has worked for health authorities in London, and within the universities of London, Manchester and Cambridge. A graduate nurse by background (King’s College London), she went on to obtain a Masters in Medical Sociology (Royal Holloway & Bedford New College) and PhD (QMUL) on the definition and measurement of quality of life in older people living at home. Research interests include palliative care, quality of life, older people, chronic disease, informal carers, service evaluation, breathlessness and the use of mixed methods (qualitative and quantitative). Morag is currently conducting an evaluation of the Breathlessness Intervention Service at Addenbrooke’s NHS Trust in Cambridge, modelled on the MRC Framework for the Evaluation of Complex Interventions. She is also collaborating on another Cambridge-based study of ‘Living and dying in extreme old age’ with colleagues in the Department of Public Health & Primary Care, University of Cambridge.

Professor Peter Fayers BSc PhD CSTAT
Visiting Professor

Peter joined the Department of Public Health at Aberdeen University as Professor of Medical Statistics in 2000. After graduating in statistics at University College London he worked in various branches of the Medical Research Council (Statistical Research and Services Unit, Tuberculosis and Chest Diseases Unit, Cancer Trials Office and the Clinical Trials Unit) before coming to Aberdeen.

Peter’s PhD in quality of life research (Open University) was completed whilst on sabbatical at Trondheim University (NTNU) in Norway, 1997, and he continues to work part time at NTNU as Professor of medical statistics. His main research interest remains in the area of patient reported outcomes and subjective indicators, particularly in quality of life research, he has written four books on the subject (see below). Peter was president of the International Society for Quality of Life Research (ISOQOL) 2005-2006. He was associate editor of Quality of Life Research, from 1998, and is currently a member of the editorial board. Oncology and palliative care have been two of his particular interests, and he chaired the Quality of Life Group of the European Organisation for Research and Treatment of Cancer (EORTC) for the four years until 2003.

Currently, Peter is working on HRQL assessment in diverse clinical areas: oncology, palliative care, children with asthma, Alzheimer’s patients, home parenteral nutrition, Paget’s disease, and orthopaedics. Peter’s other interests include clinical trials in oncology and other fields, data monitoring and stopping rules, and sample size estimation. He was advisor to the World Health Organisation’s Human Reproduction Programme, and has taught extensively in China and Outer Mongolia. In 2007 he was appointed Visiting Professor to the Department of Palliative Care, Policy and Rehabilitation.
Dr Wei Gao PhD MMed BMed
Medical Statistician

Wei Gao has a medical background and a PhD in epidemiology and health statistics. Before joining the Department as a medical statistician in April 2007, she worked at Imperial College London in the Infectious Disease Epidemiology department. She gained considerable experience in analyzing data from various disease registries, population-based epidemiology surveys and gene-environmental interaction studies through her working with the National University of Singapore from 2002 to 2005. She is a statistical reviewer for the Lancet and three Lancet series journals. She has expertise in generating statistical and epidemiologic hypothesis, describing large observational data and assessing population disease burdens, survival analysis, advanced modelling with traditional statistical models and artificial neural networks, ROC analysis, research design, computerised record linkage and data management. Her research interests are extending from previous statistical epidemiology and experimental medicine to palliative care and psychosocial medicine. She is contributing to Strand I of COMPASS (COMplex interventions: Assessment, trialS and implementation of Services) to develop assessment and outcome measures. She also provides statistical support for the researchers in the department and teaches MSc students.

Cassie Goddard BSc MSc
Research Assistant

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. Following her undergraduate degree, Cassie worked as Clinical Trials Support Officer on the AspECT Trail - A Phase III, randomised, study of aspirin and esomerazole chemoprevention in Barrett’s Metaplasia. In May 2007 Cassie joined the Department of Palliative Care, Policy and Rehabilitation at King’s College London School of Medicine as a Research Assistant, her main focus of work concerns the study “Facilitating Implementation of Gold Standards Framework for Care Homes”, researching into issues surrounding the provision of end of life care in care homes. The project is funded by Guy’s and St Thomas’ Charity.
Barbara Gomes  BSc MSc
Cicely Saunders International PhD Research Training Fellow

Barbara completed her first degree in Psychology and Health at the University of Porto, Portugal and an MSc in Palliative Care at King’s College London. Having gained experience in research (in topics such as healthcare staff training, the integration of vocational guidance in the school curriculum and family influence on life expectations), she spent one year as a psychologist in a Portuguese palliative care unit. Together with Professor Irene Higginson she has been leading a long-term project supported by Cicely Saunders International aiming to understand where people die and to discover ways of empowering patients who wish to die at home. Barbara’s PhD is looking at ways of improving the quality of palliative care at home and to discover more cost-effective models of home care. Barbara’s interests and projects include: decision-making at the end of life regarding place of care and death, quality of care and patient-centred care, cost-effectiveness, the role of the media on public education about palliative care, symptom prevalence in advanced disease, understanding risk, trends analysis and the evaluation of palliative care services.

Dr Marjolein Gysels  MA PhD
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. She worked for the TANESA project on AIDS in Tanzania on female infertility and for the MRC (UK) Programme on AIDS in Uganda on commercial sex work. At King’s College London, she collaborated on the PROMOTE Project, and she worked on the Research Evidence Manual which is part of the NICE Guidance for Supportive and Palliative Care for those affected by cancer. Since September 2004 she has been co-managing a programme on breathlessness in advanced and progressive disease, which is primarily supported by Cicely Saunders International. She is currently also involved in the literature scoping on the delivery and organisation of generalist services for adults at the end of life for a project funded by NHS Service Delivery and Organisation (SDO).
Dr Sue Hall  BSc PhD CPsychol
The Dunhill Lecturer in Palliative Care

Sue studied Psychology at the Polytechnic of East London 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 brain tumours. For most of the next 11 years, she worked with the Psychology & Genetics Research Group, King’s College London, running national and international studies focusing on adjustment to serious negative life events, behaviour change, and facilitating informed choice. During this time she spent a year at the Centre for Health Care Research, at the University of Brighton as Research Fellow and NHS R&D Consultant. In March 2006, she joined the Department of Palliative Care, Policy and Rehabilitation as 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 Solid Facts Series on better palliative care for older people, understanding the barriers and facilitators of implementing the Gold Standards Framework for Care Homes, exploring views of dignity of older people in care homes, and evaluating dignity therapy for older people in care homes.

Dr Richard Harding  BSc MSc DipSW PhD
Senior Lecturer in Palliative Care

Richard originally read Social Anthropology and conducted field work in the Netherlands before taking a Masters and Diploma in Social Work at the London School of Economics. He undertook his Doctoral studies in the Department of Palliative Care, Policy & Rehabilitation at King’s College London, developing and testing an intervention for informal carers. He has worked in diverse care settings as care provider, care manager, and social worker and in voluntary sector settings in group work and training. His interests are primarily in non-cancer (HIV, heart failure) and in developing an evidence base for palliative care in Sub-Saharan Africa where he collaborates in a number of exciting, productive and enjoyable partnerships with palliative care and academic settings.
Dr Diana Jackson  PhD MSc MCSP  
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. After taking an MSc in rehabilitation studies at Southampton University, she joined the Regional Rehabilitation Unit at Northwick Park Hospital in 1996. There she has carried out a series of research studies into aspects of the rehabilitation and after care of people with complex problems after acquired brain injury. A particular focus has been the design and evaluation of pain assessment tools accessible to patients with communication and cognitive deficits. This on-going work formed the basis of her PhD. Another main research interest concerns carers. In collaboration with researchers from the Institute of Psychiatry, she has recently completed a Department of Health funded national study into the needs and experiences of carers of adults with acquired brain injury. Findings are being widely disseminated and will inform service development for carers as part of the National Service Framework for Long-Term Conditions. Extension of this work to compare and contrast the experiences of carers according to their differential family circumstances, and the condition-specific problems they have to cope with, in a range of other long-term neurological conditions is now underway.

Jonathan Koffman  BSc MSc  
Lecturer in Palliative Care, MSc Course Co-ordinator

Jonathan has a BSc in Social Administration and an MSc in Sociology with Special Reference to Medicine from Royal Holloway and Bedford New College. Jonathan's previous work experience involved health services research and health services commissioning for a number of health authorities. He is now Lecturer in Palliative Care and Course Co-ordinator for the inter-professional Postgraduate Certificate, Diploma and MSc in Palliative Care run in collaboration with St. Christopher's Hospice. His research interests include the end-of-life experiences of black and minority ethnic groups, social exclusion, and palliative care education. He has published in the following areas: culture and ethnicity, older people, needs assessment, social exclusion and palliative care, palliative care education, HIV and AIDS, as well as mental health and homelessness. He is currently completing his PhD that has explored the experience of living with, and dying from, advanced cancer among black Caribbean and white patients living in south east London.
Anna Kolliakou BA MSc
Maruzza Foundation Research Assistant

Anna has a BA in Psychology from the University of Essex and was awarded an MSc in Clinical and Public Health Aspects of Addiction from the Institute of Psychiatry, King’s College London. Following her studies she worked at the Institute of Psychiatry for The Cochrane Collaboration Depression, Anxiety and Neurosis Group on an online European mental health library and went on to become a Research Assistant at the MRC Social Genetic and Developmental Psychiatry Centre, on a genetic study investigating issues in unipolar and bipolar depression. During this time she also held a post at Imperial College as a fieldwork interviewer on a co-morbidity study on mental health and substance use. Most of her work has been completed at the National Addiction Centre focusing on motivational interviewing in reducing drug use and drug related harm in young adults. She rejoined King’s College, after a year-long break, as a Research Associate for the Department of Palliative Care, Policy and Rehabilitation on producing a WHO booklet in Better Practice in Palliative Care for Older People. The project is funded by the Maruzza Lefebvre D’Ovidio Foundation.

Janet Law OT MSc
Honorary Research Associate

Janet trained in occupational therapy in South Africa. In addition to her work in South Africa, she has worked in America, and more recently in London. Through the years, she developed a clinical interest in neurological rehabilitation, which led to the completion of her MSc in Neuro-rehabilitation at Brunel University. Her MSc dissertation focused on Further Evaluation of the United Kingdom Functional Assessment Measure and Functional Independence Measure (UK FIM+FAM) extended activities of daily living items. Janet now combines her work as a senior occupational therapist on the Regional Rehabilitation Unit at Northwick Park Hospital, with a part-time role in research within the Department of Palliative Care, Policy and Rehabilitation at King’s College Hospital. Her interests lie within evaluation and development of outcome measures for neurological rehabilitation, of which her current projects include the Northwick Park Therapy Dependency Assessment Scale and Rehabilitation Complexity Scale with the rehabilitation research team.
Susan Longhurst  BSc
Research Associate

Susan has a BSc in Law and Social Science from Brunel University. Previously based in the Department of General Practice at King’s College London, Susan conducted research investigating the recruitment and retention of GP registrars and was also involved with the formation of the GP co-operative, SELDOC. Susan joined the Department in 2005 to work on a needs review for a local hospice. She was also involved in the evaluation of Compass, a pilot telephone helpline, funded by the King’s Fund, targeting people in South East London who are living with a life-limiting illness and their carers. She is currently working on a study to describe the perceptions of dignity of older people living in care homes, along with a Cochrane systematic review focusing specifically on palliative care interventions for this target population group.

Jennifer Lunan  EN AAMS
PA to Professor Irene Higginson and Dr Susan Hall

Jenny qualified as an Enrolled Nurse and went on to qualify as a Medical Secretary following her nursing training, gaining an AMPSAR Certificate. Prior to joining the College Jenny worked as PA/Secretary in the Health Centre at University College London for three years before joining the Imperial Cancer Research Fund (now CRUK), firstly based in the Clinical Oncology Unit at Guy’s Hospital as PA to a Consultant Histopathologist and a Biochemist, and then at the ICRF Laboratories at Lincoln’s Inn Fields as PA/Floor secretary to Senior Scientists and researchers. She worked as Professor Irene Higginson’s PA since joining the College in 1999, firstly based at St Christopher’s Hospice, then moving into new offices on the second floor of the Weston Education Centre, then moving into newer offices on the third floor of the Weston Education Centre. Jenny, along with previous colleagues, was a founding member of the Administrative Team and, with the current members of the Administrative Team, supports the activity of the department.
Dr Wendy Magee  PhD NMT ARCM  Honorary Senior Research Fellow

Wendy trained as a music therapist at the University of Melbourne, Australia, before coming to study and work in the UK in 1989. She is a specialist in neuropalliative rehabilitation having worked since 1990 as a clinician, researcher and manager at the Royal Hospital for Neurodisability in Putney. Her doctorate was awarded by the University of Sheffield for researching the experience of music therapy for people living with chronic and complex Multiple Sclerosis. She has completed research projects using both quantitative and qualitative methodologies examining the effects of music therapy in collaborative practice to address communication and well-being after stroke, and exploring of the use of electronic music technologies in music therapy practice. She currently holds a postdoctoral fellowship at the Institute of Neuropalliative Rehabilitation, Putney, London. She has published widely on Multiple Sclerosis, low awareness states, Huntington’s Disease and neuro-rehabilitation. Current research activity focuses on music therapy in the treatment of neurological disorders and the development and validation of evaluation tools with this population.

Dr Farida Malik  BSc(Hons), MBBS, MRCP, MSc  Cicely Saunders International Research Training Fellow

Farida studied medicine at UMDS, University of London, qualifying in 1996. Following this she trained in hospital general medicine before joining the South Thames Specialist Registrar Training Scheme in Palliative Medicine. She has previously undertaken an intercalated BSc in Psychology (University of London) and an MSc in Palliative Care at King’s College London. Farida joined the department in 2005. She is currently undertaking a PhD funded by the Cicely Saunders International Programme for Research into Breathlessness looking at the experience of caregivers of breathless patients with advanced disease. Farida’s research interests include breathlessness and sleep disturbance, steroids in brain tumours, symptom and quality of life assessment.
Professor Kathryn McPherson PhD
Visiting Professor

Kathryn has a clinical background in nursing training in Australia before moving to the United Kingdom to study midwifery and then Health Visiting, both in Edinburgh. Whilst working as a health visitor, Kath undertook a psychology degree then took up a research position at the Astley Ainslie Hospital in Edinburgh and then went on to complete her 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. She continues to co-supervise PhD students at both the University of Otago 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. She is also on the editorial board of Disability and Rehabilitation, Clinical Rehabilitation and the International Journal of Nursing Studies. In her role as Visiting Professor at the Department of Palliative Care, Policy & Rehabilitation Palliative Care and Rehabilitation, 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.

Dr Fliss Murtagh MBBS MRCGP MSc
Clinical Research Training Fellow

Fliss is a graduate of the Royal Free Hospital Medical School, London. She worked as a general practitioner with a special interest in palliative care for 10 years before specialising in palliative care from 2000. She completed the MSc in Palliative Care within the department in 2003, and has published work from her MSc dissertation on facilitating patient preferences in decision-making in the Journal of Medical Ethics. She has now completed consultant training in palliative medicine, and is currently undertaking a PhD researching the palliative care needs of patients with advanced chronic kidney disease who are managed conservatively, without dialysis. Together with Professors Irene Higginson and Julia Addington-Hall, she has completed a systematic review of symptoms in end stage renal disease, as well as a review of the use of opioids in conservatively-managed end stage renal disease. She is also part of the working group developing a renal version of the Liverpool Care Pathway for national implementation in the UK. Other interests include ethics, palliative care for other non-cancer conditions, and teaching palliative care.
Suzanne originally studied pharmacology at Southampton University but later changed to a career in public health research. Her appointments thus far have taken her to Bristol, Edinburgh and Aberdeen Universities. During these appointments Suzanne gained experience of conducting research evaluations in several aspects of reproductive health, including Scottish male reproductive health, Scottish teenage sexual health (PhD research project) and maternal health in developing countries. In this department she is working with Richard Harding to undertake an evaluation of PEPFAR-funded services in Kenya and Uganda offering palliative care for people living with HIV/AIDS. This longitudinal study explores links between components of care and health outcomes. Suzanne’s research interests include reproductive health research, evaluating complex interventions, health research in developing countries and infectious disease epidemiology.

Wendy 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 / honorary clinical senior lecturer 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 Kings 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. She is also interested in the development and delivery of education, as well as the various factors influencing end of life decision making. In 2002 she completed an MA in the Ethics of Cancer and Palliative Care, her dissertation within this focused on the issues of justice and resource allocation.

Diana and her family then moved to Uganda where she was appointed as a lecturer at Uganda Martyrs University, following which she worked for 3 years as consultant education advisor at Hospice Africa Uganda in Kampala developing clinical and distance learning courses in palliative care. She then moved to The Mildmay Centre also in Kampala, where she worked for a further 3 years running the BSc programme ‘A health systems approach to HIV/AIDS’ with students from Uganda, Kenya and Tanzania validated by The University of Manchester. In Uganda her special area of interest was developing effective palliative home based care services. During her time in Uganda she also gained a diploma in health services management run as a distance learning programme with the RCN.

On returning to the UK, Diana joined in the Department of Palliative Care, Policy and Rehabilitation in September 2007, and is currently working on a research project looking at the palliative care needs of the elderly.
Tariq Saleem  BSc MSc
Research Fellow

Tariq has a degree in Psychology from the University of London and an MSc in Health Psychology. Currently he has a leading role as Research Fellow and centre coordinator for the King’s Centre in Palliative Care in Neurology. The centre’s mission is to improve the treatment, rehabilitation and care of people affected by long term and progressive neurological conditions through research and development. He has published in the following areas: stroke, multiple sclerosis, Parkinson’s disease, progressive neurological conditions, cancer screening, sickle cell & thalassaemia, health psychology, anxiety and worrying, culture and ethnicity, bilingual health advocacy and palliative care. He is currently conducting a three year longitudinal study funded by the Department of Health looking at the symptoms and care needs in advanced Parkinson’s disease, multiple symptoms atrophy and progressive supranuclear palsy.

Lucy Selman  BA MPhil Cert Pall Care
Research Associate

Lucy read Philosophy at Nottingham University, and received an MPhil in Philosophy from Birkbeck College, specialising in Philosophy of Science. In 2006 she completed the Certificate in Palliative Care at King’s. After working for Help the Hospices, she travelled in India, undertaking fieldwork for the International Observatory on End of Life Care at Lancaster University. In June 2005 she joined the department to work on a project modelling a palliative care service for heart failure patients at St Thomas’ NHS Foundation Trust. She is currently working for Cicely Saunders International on the ENCOMPASS project, validating a version of the Palliative Care Outcome Scale for use in the African context. ENCOMPASS is a collaboration between King’s and palliative care centres in South Africa and Uganda, with preliminary development and validation of the POS through the African Palliative Care Association. Her academic interests include qualitative research, palliative care in the developing world, psycho-spiritual interventions and complementary therapies. A qualified yoga teacher and Thai massage practitioner, in 2006 Lucy was awarded a Churchill Travelling Fellowship to conduct research in India into the use of yoga and meditation in end of life care.
Cathy Shipman  BA  MSc
Senior Research Fellow

Cathy’s background is in medical sociology and her previous work has included research on out of hours care, transition to community settings for people with learning disabilities, health needs assessment, mental health promotion, local history and the impact of unemployment on the work of health and social service professionals. Currently, her main area of interest is palliative care in primary care. She is working on a scoping exercise on generalist end of life care commissioned by the SDO and is supporting the evaluation of a palliative care helpline for NHS Direct and the evaluation of the Policy Unit for the National Council of Palliative Care. She has conducted a needs review for a hospice and a pilot study developing methods for a longitudinal study of cancer patients over time. She has worked on the national evaluation of the Department of Health funded palliative care education and support programmes for district and community nurses, and on work with PCTs concerning palliative care service development and commissioning. Cathy also works in the Department of General Practice & Primary Care at KCL, on a study investigating the palliative care needs of COPD patients.

Victoria Simms  BSc  MSc
Research Associate

Vicky has a BSc in Natural Sciences from Durham University and an MSc in Public Health in Developing Countries from the London School of Hygiene and Tropical Medicine. She has previously worked on trials of environmental and sanitary improvements to reduce trachoma in The Gambia, community-based surveys in Sudan, and a national survey of physical disability in Rwanda, which included a case-control study of the relationship between disability and poverty. She is now working with Dr Richard Harding on an evaluation of palliative care provision for people with HIV in Kenya and Uganda, funded by PEPFAR. Vicky’s research interests include sanitation, communicable disease epidemiology, statistics and study design, and healthcare provision in Africa.
Reverend Peter Speck  BSc MA  
Researcher & Former Health Care Chaplain, Honorary Senior Lecturer

Peter 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 then hospital chaplain in Sheffield, Peter became 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 & Rehabilitation), Peter is author of several books on pastoral care, chapters on aspects of palliative care, and spiritual care and bereavement. He was a member of the Editorial Board of Palliative Medicine and served on the Editorial Board of NICE producing “Supportive Care in Palliative Care” Guidance. He is a Fellow and Member of the Council of Palliative Care section of the Royal Society of Medicine. His research interests include belief systems and whether they influence outcomes in illness or ageing, with several peer reviewed papers published.

Frances Stewart  BSc  
Research Assistant

Frances graduated from Sheffield University in 2004 with a 2:1 in Psychology. She then worked as a Research Assistant for the University of Sheffield where her main role was developing a disease-specific ‘Quality of Life’ questionnaire for use in young adults with Growth Hormone Deficiency. Her other research areas have included studying the impact of Cancer on childhood and adolescence Quality of Life. Following the completion of this study Frances joined King’s College London as a research assistant in 2007.

Laura Skingle  Research Assistant

Laura studied for her BSc in Psychology & Human Biology at University College Northampton and was later awarded an MSc in Health Psychology from the University of Bath in 2005. Whilst there Laura undertook a placement at the Royal Marsden Hospital in Sutton to study the impact of maternal breast cancer on children’s social and adaptive functioning. The research was undertaken in the context of an international multicentre research project entitled “Children of Somatically Ill Parents (COSIP)”.

Laura joined the Department of Palliative Care, Policy & Rehabilitation at King’s College London School of Medicine as a Research Assistant in July 2007. Her main focus of research is “Improving End of Life Care for the Elderly at the Hospital Community Interface: An A&E Audit”. This research will involve understanding the patterns of emergency department admission for the elderly with palliative care needs including if admissions to emergency departments are preventable for this population. The project is funded by Guy’s & St Thomas’ Charity & King’s College Hospital Charity.

Frances Stewart
Professor Derick Wade MA MB BChi, MD FRCP
Honorary part-time Chair of Rehabilitation

In addition to his general medical training, Derick trained in several specialities related to his current posts including neurology, neurosurgery, psychiatry and neurophysiology. He has expertise in many clinical areas, including: stroke, head injury rehabilitation, management of multiple sclerosis and motor neurone disease, assessment of patients in the Permanent Vegetative State, and the management of patients who have disability without any underlying disease. His research activities cover a wide area and he has published over 180 papers in peer reviewed journals on many different studies. He is starting studies on mental practice as a rehabilitation technique. He writes books and book chapters on many aspects of disabling neurological disease and has edited Clinical Rehabilitation, since 1994. He is involved in training doctors and other professions who are specialising in rehabilitation and supervises and examines higher degrees.

Derick is closely involved in health service management and development. He has been an advisor to Oxfordshire Health Authority and been involved in local working parties on many aspects of neurological rehabilitation. He has been involved in many national groups and committees. He has also been involved in WHO groups and advised national groups in the USA and New Zealand. In 2001, he was appointed Visiting Professor in Community Rehabilitation at the University of Maastricht, the Netherlands. In June 2002, he was made an honorary fellow of the College of Occupational Therapists; and in October 2005, he became a part-time professor in neurological rehabilitation at King’s College Hospital London.

Heather Williams MSc RN ONC
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 2004)

<table>
<thead>
<tr>
<th>NAME</th>
<th>POSITION</th>
<th>YEAR OF DEPARTURE</th>
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<tbody>
<tr>
<td>Professor Julia Addington-Hall</td>
<td>Professor of Palliative Care Research and Policy/Deputy Head of Department</td>
<td>2004</td>
</tr>
<tr>
<td>Bimpe Akinwunmi</td>
<td>PA to Professor Addington-Hall</td>
<td>2004</td>
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<tr>
<td>Dr Lara Alloway</td>
<td>Specialist Registrar</td>
<td>2004</td>
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<tr>
<td>Jo Armes</td>
<td>CRUK Research Fellow</td>
<td>2004</td>
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<tr>
<td>Jenni Burt</td>
<td>Research Associate</td>
<td>2004</td>
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<tr>
<td>Floss Chittenden</td>
<td>Data Entry Clerk</td>
<td>2004</td>
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<tr>
<td>Dr Elizabeth Davies</td>
<td>Clinical Senior Research Fellow</td>
<td>2004</td>
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<tr>
<td>Darryl De Prez</td>
<td>Head of Fundraising, Cicely Saunders International</td>
<td>2007</td>
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<tr>
<td>Sam Hart</td>
<td>Research Associate</td>
<td>2006</td>
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<tr>
<td>Dr Rhidian Hughes</td>
<td>Senior Research Fellow</td>
<td>2004</td>
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<tr>
<td>Maggie Johnson</td>
<td>Departmental Administrator</td>
<td>2005</td>
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<tr>
<td>Julie Payne</td>
<td>Student</td>
<td>2004</td>
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<tr>
<td>Sally Plumb</td>
<td>Honorary Research Associate</td>
<td>2005</td>
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<tr>
<td>Dr Jean Potter</td>
<td>Mrs Coco Marcus Clinical PhD Research Training Fellow</td>
<td>2004</td>
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<tr>
<td>Carolin Seitz</td>
<td>Project Support Officer</td>
<td>2006</td>
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<tr>
<td>Joel Sheridan</td>
<td>Research Assistant Psychologist</td>
<td>2004</td>
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<tr>
<td>Amanda Tadrous</td>
<td>Research Assistant Psychologist</td>
<td>2004</td>
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<tr>
<td>Bella Vivat</td>
<td>Research Fellow</td>
<td>2004</td>
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